Solution Focused Practice in End-of-Life and Grief Counseling

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When I was in my first job as a young doctor, an old colleague taught me two phrases that he said had been his guidelines for a lifetime of work. The first phrase was: “Most diseases heal despite the treatment” and the second one was: “The primary purpose of the health care industry is to produce a need for health care.” Since I have spent most of my professional life in the mental health business, I have changed the latter into “The primary purpose of the mental health industry is to produce a need for mental health care.”

In 1969, Elizabeth Kübler-Ross wrote about death and described five stages in the process of dying (denial, anger, bargaining, depression, and acceptance). These stages then eventually became stages of grief and since then many psychologists, psychiatrists, and psychotherapists have used them as a frame for listening to clients. “In what stage is he?” “Is he progressing normally?” “Is he stuck in a stage? If so, which one?” The stages quickly became yet another very useful tool for pathologizing the different ways people react and respond in situations of grief and loss, thus producing a need for mental health care.

I share Friedman and James’s experience:

Many grievers tell us that a mental or medical health professional “strongly suggested” they were in the denial stage, when all they’d said was that they were having some difficulty since Mom died. Even after reiterating they were clear that Mom had died, the therapist insisted they were in denial.

At first glance, this is a book about the hospice movement and about how solution focused work can be applied in that context. But it is much more than that. It’s a book about hope and growth in the face of death and loss. It is a book about possibilities – not finalities. Perhaps most

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important, it is a book about all the different ways that people deal with loss and bereavement – no way being the right or the wrong way – and how solution focused brief therapy can be helpful in making sense of the experience that people go through when facing death or accompanying a family member or friend who is facing death.

So here is the power of solution focused practice. Solution focused practitioners ask their clients: “How do you want to act, feel, think, and interact?” “What of this are you already doing?” “What is useful for you to do, think, and feel at this point?” They trust their clients’ answers and build dialogues with their clients around these questions. They know that clients have their own unique way of doing what they need to do and knowing when they are doing what is right for them. Solution focused practice de-pathologizes the person who, because he or she is treated as capable and competent, therefore becomes just that. Joel Simon’s book is evidence of this.

Harry Korman, MD
True hope is swift, and flies with swallow’s wings;
Kings it makes gods, and meaner creatures kings.
—William Shakespeare,
Richard III, Act V, Scene 2

No matter where I worked, my assumption has always been (at least for the past 16 years) that solution focus will be applicable, and that it is my job to apply it to the context. Hospice of Orange and Sullivan Counties in Newburgh, New York employed me in May, 2005. I immediately set out to discover the applicability of solution focus in this new context.

The application to bereavement counseling seemed to be a natural for me, but I have to admit I was not sure of how it was going to be applied to individuals facing end-of-life circumstances and their significant others. Having the opportunity to discover the applicability of solution focus to this population was an exciting prospect for me. Once again, I approached it with the assumption that it would work, and I was to discover how.

The staff had been briefed prior to my arrival that I was interested in and practiced solution focus. It was not my intention to immediately advocate for a solution focused approach; I had learned very early that solution focus was a very different paradigm from those in which most professionals had been trained. My own experience, and the experiences of others who have been more or less successful in developing a solution focused approach in various systems, suggested that it was best to go slowly. This was reflected in a chapter I wrote with Thorana Nelson (2007) entitled “Meta-Systemic Considerations of the Solution focused Brief Approach”:

The essence of the SFBP approach is a deep respect for the resources, abilities, and worldview of those with whom we work. This not only includes
our clients, but also extends to our colleagues and the intra- and intersystems with which we communicate. It does little good to insist on shining the “light of truth” on those who hold a different view. (p. 153)

When I first met with the social work staff as their new supervisor, they expressed a curiosity about solution focus. In fact, one of the social workers had recalled that I had presented a solution focused lecture to a psychology club at a local university. As an undergraduate student, she had been in the club at the time. I agreed to provide a series of presentations on solution focus to the hospice social workers. This included not only didactic material, but actual video case examples as well.

As would be expected, not everyone was interested in solution focus as his or her modality. Several of the social workers, however, began to incorporate solution focused interventions into their practices. There were a few who were interested about the prospects and began to use solution focus in their practice with individuals facing end-of-life situations.

There was one particular social worker who was very skeptical in the beginning. Some time later, she was faced with a family where the husband/father was terminal, and this served only to exacerbate an already conflicted family system (see Chapter 6). The man asked the therapist to meet with the family to deal with issues of “communication” within the family.

The social worker approached me asking what she should do. I suggested that she meet with the family and simply follow a solution focused format: how they will know that the sessions were being helpful, what differences they would notice, how would those differences make a difference, the Miracle Question, scaling, taking a break, and returning with compliments and a between session suggestion.

The social worker returned after the family meeting and announced that the session had exceeded her expectations. She went on to marvel at how the family was able to go beyond the conflict and begin to entertain the idea that, even in the face of a limited time frame for the husband/father, change was possible. The social worker’s story is not unique. Other staff that had entertained the idea of using solution focus principles were reporting similar results.

When I initially entered the hospice system, the social workers were unclear about their roles. During the first staff meeting, I had asked them what is it that they do that is different from the volunteers who also meet with patients and their families. There was much hesitation in answering that question, and I realized that my direction was clear – to help them
rediscover what made them unique as social workers. I believe, to a large extent, that solution focus provided them with tools and principles that were congruent with traditional social work values.

I wrote this book because I believe that solution focus provides an approach and valuable tools to naturally help those who face life-limiting conditions co-construct possibilities rather than limitations, and provides hope and comfort in a time of despair. When I broached the subject of the book to Yvonne Dolan – an author, presenter, and solution focused practitioner in her own right – her immediate response was that this is a book that needs to be published.

Chapter 1 explores the history and philosophy of the hospice movement beginning with Ancient Greece, moving through the Middle Ages, the Renaissance, the twentieth century first in the United Kingdom, and finally the United States. It includes an interview with a CEO of a local hospice, his involvement and thoughts about the current state of the movement including the issues that now face hospices on the local level (and, no doubt, will continue to face them in perpetuity). The chapter also includes an interview with a woman who was involved both on the state and national levels in the early introduction of solution focus to the United States.

Chapter 2 details the history of solution focused brief practice (SFBP), its influences, and its prime movers: Steve de Shazer and Insoo Kim Berg. It traces the history from Dr. Milton Erickson and the Mental Research Institute in Palo Alto, California in the 1950s to the pioneering work of de Shazer beginning in the early 1070s, and his eventual collaboration with Berg that culminated in the establishment of the Brief Family Therapy Center (BFTC) in Milwaukee, Wisconsin. The chapter takes us up to the present day and the establishment of the Solution Focused Brief Therapy Association (www.sfbta.org), and its role in furthering the work of BFTC both before and after de Shazer and Berg’s death.

Chapter 3 lays the foundation of solution focus philosophy through post-structural thought. Chapters 4 and 5 describe the basic concepts and tools of solution building. Chapter 6 is about the application of solution focus to clients with life-limiting conditions and their families. Chapters 7 through 9 put it all together with three case examples including actual verbatim taken directly from video recordings. The first case example is of a man with a very surprising story and outcome. The second is of a family that came for one session only. The final case is of a woman whose mother died a year prior, and who saw me for two sessions.
The ultimate goal of the book is to challenge the reader’s assumptions about work with clients with life-limiting diseases and their families, and bereavement work. Further, the book serves to show that solution focused brief practice can be a useful approach in end-of-life and bereavement work.

J.K.S.
My thanks to Yvonne Dolan and Terry Trepper who encouraged me to write this book. To the staff of Hospice of Orange and Sullivan Counties who teach about life and hope. To the clients and families of Hospice who paid me the honor of letting me into their lives and allowing me to learn from them. To my friends and colleagues of the Solution Focused Brief Therapy Association who constantly provide me with a source of support, knowledge, and inspiration.

Special thanks to Gale Miller for reviewing and making suggestions on Chapter 4. Also special appreciation to my daughter, Alicia (the artiste and art teacher), who provided the illustrations in Chapter 4.
Introduction
Hospice: History and Philosophy

There is a tide in the affairs of men
Which taken at the flood, leads on to fortune;
Omitted, all the voyage of their life
Is bound in shallows and in miseries.

—William Shakespeare,
Julius Caesar, Act IV, Scene 3

HISTORICAL ANTECEDENTS

According to Kohut and Kohut (1984), the word “hospice” is derived from the Latin hospitalis translated to “of a guest.” According to Siebold (1992), there are earlier antecedents to the modern day hospice movement that date back to 1134 B.C. and ancient Greece. Temples were created for weary travelers and “custom dictated that they be clothed, fed, and entertained with no questions asked” (p. 13). There is evidence that a special facility specific to the dying was in operation in India around 225 B.C.

The Christian era brought with it an emphasis on the care of the sick and dying: “Christian tradition, particularly Catholicism, held preparation for death and the afterlife in high regard” (Siebold, p. 14). The 100 years of The Crusades served to spread the concept of hospice throughout the known world. By the thirteenth century, the number of
hospices numbered about 750 in England, 40 in Paris, and 30 in Florence (McNulty & Holderby, 1983). At that time, hospices were established as facilities for weary travelers and crusaders.

The Renaissance brought with it an emphasis on the scientific method as it especially applied to medical treatment and cure. It is not surprising that as a result, “Research-minded physicians working in hospitals believed that their function was to cure diseases, not to provide supportive services for the dying poor or respite for the weary travelers” (Siebold, p. 20). During this period, there were few new hospices and many of the established hospices were converted to hospitals where the focus was on research, treatment, and cure. The dying and poor were relegated to almshouses and workhouses created for that purpose – no doubt, more a matter of out-of-sight and out-of-mind rather than treatment and cure. This is reminiscent of Scrooge’s statement in A Christmas Carol. When asked for a donation for the poor, he responded:

Are there no prisons? And the Union workhouses, are they still in operation? I help to support the establishments that I have mentioned – they cost enough, and those who are badly off must go there.

When the reply is, “Many can’t go there, and many would die.” Scrooge responded, “If they would rather die, they had better do it, and reduce the surplus population.” The irony here is that the poor and dying were given care during the Middle Ages. Given that medical treatment did not exist, death was commonplace and, therefore, accepted as the natural course of life.

With the advent and growth of medical science, death became the taboo subject that it is today. This is not to suggest that we would have been better off if the Renaissance never happened and if society had remained stagnant in the Middle Ages. Had medical science never evolved, life would have been short marked by the struggle for survival and governed by plague, disease, and superstition. Certainly, advances in treatment and care have resulted in greater longevity and a higher quality of life. However, with the prospect of treatment and cure, the subject of death is to be avoided even though the treatment of terminal conditions results in an improved quality of life.

The interest in hospice was renewed in the 18th century for two probable reasons: 1) the Irish potato famine and 2) the recognition by the clergy that those with terminal illnesses were being warehoused in institutions with less-than-humane conditions (Siebold, op. cit.). Our
Lady’s Hospice, which opened its doors in Dublin in 1879, was the first facility to provide palliative care for the dying. The establishment of the hospice was a result of the work of Sister Mary Aikenhead of the Irish Sisters of Charity.

**HOSPICE HISTORY IN THE 20TH CENTURY**

**The Hospice Movement in the United Kingdom**

According to Kohut and Kohut (op. cit.), Sister Mary Aikenhead also was the prime mover for the establishment of St. Joseph’s Hospice in 1905 in London: “She considered death to be the beginning of the final pilgrimage. She called her nursing home after the medieval respite – hospice” (p. 6).

The hospice concept took hold in the United Kingdom throughout the first half of the 20th century, sparked especially by Dame Cicely Saunders. Dame Saunders was originally trained as a nurse but a back injury prevented her from further pursuing that career. She returned to school and retrained as a social worker.

In 1946, Dame Saunders was working at St. Thomas’ Hospital when she came in contact with David Toma, a Polish Jew. In an interview with *The New York Times* (Stolberg, 1999), she reflected back on this meeting:

> I met a Polish Jew from Warsaw, who got out before the Resistance. He was 40, and had inoperable cancer, and because he had no family, I knew he had run into trouble. And so I kept in touch with him, and when he collapsed and was admitted to another hospital, I followed him there and was virtually his only visitor for the 2 months that he was dying. We talked together about somewhere that would be more suitable for him than the very busy surgical ward where he was. We wanted a place not just for better symptom control, but for trying to find out, in a way, who he was. (p. 1)

Toma bequeathed Saunders 50 pounds toward establishing a facility dedicated to end-of-life care. It was this experience that motivated Saunders to enter medical school to train as a physician. Upon graduation, she was hired as a medical officer with St. Joseph’s Hospice.

In 1963, with a grant from St. Thomas’ Hospice in London, Saunders visited 18 facilities in the United States. As part of this lecture series, Saunders showed slides of patients before and after hospice treatment. The “before” slides showed the patients physically affected by their
respective illnesses. The “after” slides depicted patients who were clearly able to maximize whatever time was left for them (Siebold, op. cit.).

Saunders’ lectures had a profound effect on those who came to hear her speak and, if not the main impetus, certainly her lectures were a major reason for the growth of the hospice movement in the United States.

The Hospice Movement in the United States

Separate from Saunders’ work was that of a psychiatrist, Elisabeth Kübler-Ross, who was truly a pioneer in the study of death and dying. With much resistance from the medical establishment, which viewed her interest as ghoulish, Kübler-Ross would interview those with terminal diagnoses to learn of their experiences, thoughts, and feelings. The culmination of those studies was her first book, published in 1969, *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families*.

In 1966, both Kübler-Ross and Saunders were invited to lecture at Yale University Hospital by Florence Wald, Dean of the Yale School of Nursing. Saunders addressed the spiritual and physical aspects of care; Kübler-Ross presented the results of her end-of-life conversations (Siebold, op. cit.). According to Siebold, “Had Kübler-Ross not become involved in the movement, it might not have become as popular as it did…. Kübler-Ross made the public sit up and take notice of death and dying” (p. 73).

Based on the work of the Yale Study Group, the Connecticut Hospice in Branford, the first established hospice in the United States, began serving the terminally ill in their homes in 1974. The Connecticut Hospice was funded through a grant from the National Cancer Institute with the goal of creating a national demonstration center for home care of the terminally ill and their families.

William Lamers, a psychiatrist, who had a personal experience with grief, sought to use his training to help others through their bereavement. According to Siebold (op. cit.), Lamers met Kübler-Ross and based upon her suggestion, founded the Hospice of Marin in California, the first Medicare-certified hospice in the United States.

In 1972, Kübler-Ross testified before the U.S. Senate Special Committee on Aging. She spoke of the isolation of those with terminal illnesses and, in general, the manner in which society denies death. Two years later, Senators Church and Moss introduced legislation to
provide funding for hospice programs; unfortunately the legislation was not enacted.

In 1978, a U.S. Department of Health, Education, and Welfare task force reported:

The hospice movement as a concept for the care of the terminally ill and their families is a viable concept and one which holds out a means of providing more humane care for Americans dying of terminal illness while possibly reducing costs. As such, it is the proper subject of federal support. (2003, www.nahc.org, p. 2)

The Centers for Medicare and Medicaid Services (CMS) initiated a demonstration project in 1979 of 26 hospices across the country to assess the cost effectiveness of hospice care. The secondary goal was to determine specifically what services hospices should provide to patients and their families. In 1980, through a grant from the W.K. Kellogg Foundation, the Joint Commission on Accreditation of Hospitals (later changed to Joint Commission on Accreditation of Health Care Organizations – JACHO) set out to develop standards for hospice accreditation.

Congress finally approved a provision to create a Medicare hospice benefit in the Tax Equity and Fiscal Responsibility Act of 1982. Because of its concern for cost containment, the Act included a cap on both annual per-patient expenses and inpatient hospitalizations. The CMS established a daily reimbursement rate under the hospice benefit program.

In 1989, the Government Accounting Office (GAO) released a study showing that only 35 percent of eligible hospices were Medicare certified. They listed several reasons why hospices chose not to seek certification, including the major reason: the low reimbursement rates. At this time, there were an estimated 701 Medicare-certified hospices that provided end-of-life services to approximately 61,000 patients with an average stay of 44 days (Hospice Association of America, 2003, p. 2).

By 1993, there were 1,288 certified hospice programs. The major increase in certified programs was in home care, agency-based, and freestanding hospices. At this time, the average cost per patient was “still significantly less than the Medicare hospice cap” (ibid., p. 3). In 2000, the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services and the Urban Institute released a study entitled, “Medicare’s Hospice Benefit: Use and Expenditures.” The study confirmed that hospices provided cost-effective end-of-life care.
Case Study One: The Local Community Perspective

Dan Grady has been the CEO of the Hospice of Orange and Sullivan Counties since 1988. While he has been CEO, he was involved in the planning stages prior to the hospice’s certification. Mr. Grady’s story is an example of the process that many hospices went through just after the demonstration period and prior to certification. The interview with Mr. Grady took place on June 4 and June 18, 2008. Mr. Grady received his Bachelors of Social Work and Masters of Business Administration from Iona College.

Joel: When did you first hear of hospice?

Dan: It was during my orientation to the Hudson Valley Health Systems Agency (HVHSA), a health care planning agency I was working with. HVHSA was set up by the federal government across the country to add local input to health planning. They started in ’76 and ended about 1985 but the state continued it on for another 5 or 6 years. It was where you came if you wanted to add anything in the health care arena: drug beds, hospitals, nursing homes, and home care. We were responsible for the seven counties north of New York City. We were the first level of approval. It was a state/federal match. Essentially it was a quasi-governmental agency. We reviewed and approved all new health entities in Orange County. Hospice was one of the new ones, so I had in-services on hospices with the rest of the team. Soon after I started there in the mid-80s. I think we started doing reviews in ’85. In ’84 we had just heard about them.

In ’85, because of the CON (Certificate of Need), we really had to start researching them – getting the mission, scope, the cost, and the 3-year projections. It’s a competitive mix; you have to do a little more work because you want to make sure that what everyone is telling you is true. It was very competitive. For example, in one county’s case, there were two consultants who were instrumental in the establishment of the National Hospice Medicare Benefit, Don Gates and Lou Westbrook, who became the founders of the hospice known today as Vitas – which is the largest in the United States. On the other side was a consultant from New York who was one of the first and founding members of the state association. An HVHSA board member (a volunteer), our director, and I had to hold numerous discussions with both parties on a potential merger of the project – some of these meetings became very confrontational. Therefore, as
the lead staff person, I had to learn all about both projects to function effectively in this environment. There was a lot of homework involved; the board packets were literally 3 inches thick.

Joel: How long did you work there?

Dan: I started in '84 and left in '88 to work here.

Joel: So, basically, your contact with hospice was what you were doing at CON.

Dan: HVHSA was the first organization to recommend approval; from us, it went to the state health department.

Joel: How did you go from there to CEO of hospice?

Dan: It was about '86. I worked on hospices and then I worked on home care. I could see that the health systems agencies’ days were numbered. I started looking around. This hospice had gone through enough and they were ready to hire somebody. Being someone with some experience (at least I knew how to say the word), going through the hurdles of starting hospices, and someone who had the connections, they decided to give me a shot.

Joel: At the point you came in, what was hospice like?

Dan: At the beginning of this company?

Joel: Yes.

Dan: There was a pre-existing group which voted itself out of existence. So in January of 1988 through February there was a new incorporation of a new nonprofit. At that point in February, I was hired as the first CEO and staff person. The other four people worked separately although we combined as a group. Technically there were two CEOs for a period of time. So our job was to get the policies, procedures, and manual. So by July we could have a pre-opening survey. Then we had to hire a staff. At that point, we were 100 percent grant funded. We went fee-for-service in July 1988. That was a big transition. A good number of our existing volunteers refused to continue and get the required health screenings. When we went under the Department of Health, they needed physicals and they couldn’t quite understand how they were seeing Mrs. Smith for 2 years; now they needed a shot.

Joel: At the point you came into hospice, what was the staffing like?

Dan: There were five: The social worker was doing volunteer coordination (that’s all they really had), bereavement, and counseling. He ran volunteer support groups around the county, he ran the volunteer training. The spiritual care person did a lot of public speaking about hospice, and seeing patients. There was a nurse who did assessments
but we weren’t doing medical care. Finally a bookkeeper and a clerk. The whole budget was about 100 thousand [dollars]. The first year we doubled the budget. We went to the county and got some grants. The county helped out; United Way helped out.

Joel: How many patients did you serve that first year?

Dan: Oh, we were so proud! We started with five. We went to 10; 5 of those 10 were on hospice for 6 months. At the end of the year, from July to December, we served 39 people. One day last year we had 139 people on the program. There were three part-time nurses including a part-time nursing director. In 2 years, we were up to 40 or 50. We thought that’s where it would end. We had four people showing up for our first team meetings even though we gave no services. We met for 3 hours.

Joel: Doing what?

Dan: I don’t know, but we knew everything about everybody.

Joel: So when you started there was no direct patient care.

Dan: That’s what we added when we went from Department of Education to the Department of Health. This took a couple of years because it required developing a Certificate of Need (CON). Up to that point, they were doing nothing else but volunteer and bereavement. We couldn’t do the hands-on nursing care until we were certified. We would go in with public health nursing. They would do the medical end.

Joel: When did hospice finally become certified?

Dan: July 1988. By the time I was hired, we already had the CON. It took 2 years to finally get a pre-opening survey. That was done by the state on behalf of the federal government.

Joel: When you came did you have a particular orientation or model?

Dan: We already knew about the concept of an interdisciplinary team. That had already been established. We used the concept of interdisciplinary team and everything else was built around that.

Joel: Personally, where did you want to take hospice?

Dan: My orientation was business. We had to think of it as a business. I had to make sure we had the supports: for example, bookkeeping, office. Within 2 years, we had computer support, new accountants; we did a lot more work with fund raising and we developed corporate plans.

Joel: When you first came here, hospice basically served Orange County, is that right?

Dan: No, we were Orange County before we started. When we started, we found because of the merger of the two CON into one, the two
from Florida I talked about before had plans for one hospice for Dutchess, Orange, Ulster, and Sullivan Counties. Once a neighboring hospice started, we pulled back.

**Joel:** How did we end up becoming Orange and Sullivan Counties?

**Dan:** There was a separate hospice in Sullivan County that was started about a year after ours. It never achieved a sustainable census. Within a year, they were in major trouble financially and in terms of quality, in trouble with the Health Department – they were there 1 minute and gone the next. We were asked to go in and do something but I knew that there could be potential legal issues so we couldn’t merge our corporations; our board would not have approved it. At that point, we were not able financially – we were living from Medicare check to Medicare check. It worked out 2 years later.

**Joel:** What are the challenges that face this hospice?

**Dan:** We’ve done great in donations this year, but operationally – survival mode. That’s the biggest short-term thing; we have to get out of our own way. For example, when we decided to build a residence, I explained to the Board that we’re going to lose money, it’s a new business, you know [it’ll take] 3 to 5 years. But Boards and executives find it very hard to actually live through the projected lean years. Now they realize, “It’s really big money!”

**Joel:** Businesses go through periods of consolidation and expansion. I assume we’re in that consolidation phase.

**Dan:** I’ve never had to consolidate before. As bad as things were those 10 years, we staffed up appropriately because we were up. Other hospices have increased their staff when they were up only to lose staff when they were down. How long will we continue to be successful [retaining staff]? I don’t know.¹

**Joel:** What do you see for the future? In general, where do you see hospice as a movement going?

**Dan:** If we don’t do more in this nation about the quality of hospice, we’re in trouble. Don Shoemaker (the president and CEO of the National Hospice and Palliative Care Organization) says you have a movement, you have a dream, you have an industry and then you have a gimmick. What does that mean? When we were losing money, we didn’t have any charlatans getting into the business. All of a sudden we did a good job of lobbying and we got to the point where some hospices were making money. At a state conference, a mother and

¹ In fact, my position was eliminated several months after this interview.
her son were overheard stating, “Mother and I are in concrete. But now we know that hospice is to go where you want to make money, so, we’re getting our own hospice.”

**Joel:** So that’s another challenge…

**Dan:** Quality.

**Joel:** We’re diluting the movement.

**Dan:** Some hospices give good service and some do not, but there are both for-profit and not-for-profit hospices in both camps. How can you have a state like Mississippi have an average stay of 111 when everyone else is at 50? How can states like Mississippi and Oklahoma have more hospices than the state of New York? You make the system work – that’s the gimmick part. I’m one of the few nonprofits that will say that there are some good for-profits. The challenges are money, governmental oversight. We have good quality indicators. In some rural areas of the country where the money is drying up, the quality indicators are going down. So where does that leave us? Well, whom can I merge with? The answer is probably to merge with someone stronger than you are, not as weak as you are. If we had one hospital system in the county, I’d probably be part of it. I would have had us put in years ago. But we have three systems and seven hospitals.

**Joel:** How much has managed care affected us?

**Dan:** Not at all. They love us. Why? Because we keep people out of hospitals – 160 dollars a day reimbursement versus a thousand [dollars]. And we do a better job of that than most hospices in this state very few hospital days.

**Joel:** Five or ten years from now, where would you want to see the movement?

**Dan:** We’re at a danger point now – it all depends where we cross the tracks. I actually think we would be better off if we had more oversight. I just wish that those that oversee us would remember that if you regulate an industry, you have to protect it because you take it out of the free market. There’s a difference between a planner and a regulator. Previously, the people who came from the state were trying to make you better. Now they’re just trying to make sure that the paper trail looks good. Where would I like us to be in 5 years? Well first, out of debt [laughs].

**Joel:** What about the movement in general – across the country?

**Dan:** I’d like to see less hospices with higher quality. I care less about ownership than about quality of service.

**Joel:** What about in terms of public acceptance?
Dan: I would like less fear. Hospice is the dead word. I’d like people to say, “Go there, you’ll have a great time!” “They came, they laughed with us, they paid for things, they made our lives easier.” We’re here to make their lives easier; we’re here to make you [sighs]. I would love it that people wouldn’t have less choice as it is now – “Come on hospice or give up other stuff.” Is that going to happen? No, but as long as you asked what I would like, that’s it. I would like to be able to say, “Well, we have a palliative care program that’s well funded.” We could get them on palliative care and then convert them to hospice. I would like for the government to be more consistent. You have to have equal enforcement of the law.

Joel: Why isn’t it consistent on the federal level?

Dan: Because the federal government subcontracts oversight with each state. Some states you only get surveyed upon opening and never again. Some hospices only do the minimal required by the states. Some states, for example, don’t mandate social work visits.

Joel: Is it possible to provide a quality program and still make enough money to break even?

Dan: Probably not in this county – we’re too close to New York City.² Maybe I should be more worried about money, but it’s the quality that bothers me. If quality indicators go down, we’d have to do something. The fact is if you give better care, more people will come to you. By the same token, one hospice giving poor care may taint the rest of us.

Case Study Two: The State and National Perspective

Carol Selinske had been an active community organizer working on the local, state, and national levels to help promote hospice, secure funding, and negotiate hospice regulatory policy. Ms. Selinske had worked with the New York State Hospice Association for 17 years. The interview took place on June 30, 2008.

Joel: What is your current position?

Carol: I’m retired since 1998.

Joel: Prior to your retirement, what were you doing?

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² Orange County, New York, is about 65 miles north of New York City. While the Medicare reimbursement rate for New York City hospices is higher than Orange County, the cost to Hospice of Orange and Sullivan Counties for providing services is equal.
Carol: Working backwards: I was the interim director of Hospice of Westchester. Preceding that, I was doing special projects for them.

Joel: Your own educational background?

Carol: I have a Bachelor’s from SUNY in human services administration and women’s literature. I went back to school in my mid-40s because I hadn’t finished. At that point, I was Executive Director of the New York State Hospice Association and needed to put some sort of degree in my resume. So I went back and finished.

Joel: Prior to your involvement with hospice, what were you doing?

Carol: A lot of volunteer community work. In 1977, I had gone to a national church conference and someone there was talking about community projects that worked. One group was talking about starting a hospice. That was the first time I had heard about hospice. When she described what that was, it was like the proverbial light bulb going off. I just had an aunt who died very, very badly. So I came home looking for people to start a hospice with – or help start a hospice. There were a few volunteers who were trying to get something going in New York State, but the state was resisting having hospices or any other new programs. I began by taking notes for the committee and one thing just led to another.

Joel: What was this resistance based upon?

Carol: Well, it’s a complicated case in New York because it’s one of the most heavily regulated states. The Health Department had just come off a huge nursing home scandal just prior to that in which they had failed to adequately monitor what nursing homes were doing. So they had no interest whatsoever in a whole new field to monitor and survey and they pointed out, somewhat fairly, that each time the legislature gave them new duties, it did not give them more money to do them with. They just viewed this as another way to look bad if a scandal occurred. In their view, terminally ill people were already getting adequate care. So the Health Department played games with the legislature off and on from the late seventies until ’84. In 1984, we got the federal bill passed as part of the National Hospice Association’s legislative taskforce. Once that was passed, then the state would be turning down federal money if they did not allow hospice.

Joel: So, basically, you started by getting a group of volunteers together.

Carol: In the late 1970s, there was already a small committee of doctors and nurses in Westchester County, New York. Unbeknownst to us, in upstate New York, there was a group in Buffalo around the same
time and a small group just outside of Albany. At that point, I started calling around the state to find out if anybody else was doing this. That became the coalition that became the New York State Hospice Association (NYSHA) and later the Hospice and Palliative Care Association of New York State (HPCANYS). I think we held our first meeting around 1979.

**Joel:** How many people showed up for that meeting?

**Carol:** Surprisingly, a lot. I would say at least 50 or 60, maybe more. People began to come out of the woodwork. We had just not been aware of each other’s efforts initially.

**Joel:** The U.S. taskforce came out about 1978, I believe.

**Carol:** That’s right.

**Joel:** They started the demo project in ’79.

**Carol:** That’s right. Things had already started under the table, but, yes.

**Joel:** You mean there were already funded programs?

**Carol:** No, not funded.

**Joel:** When you say “under the table,” what do you mean?

**Carol:** Groups had already started that were affiliated with nursing agencies; reaching out and sort of doing hospice. They were getting geared up so when it became legal they would be ready. Meanwhile, [they were] caring for patients in a hospice-like way.

**Joel:** I interviewed Dan Grady, the CEO of Hospice of Orange and Sullivan Counties; he recalled that it was basically a volunteer program in the early ’80s and the medical care was being done by outside nursing agencies.

**Carol:** Right. I recall up in Buffalo, it was led by Charlotte Shedd. She was at the heart of just going ahead and doing it. Other nurses were afraid to do that for fear of losing their licenses. But Charlotte said, “Fine, let them come and shut us down and take my license and we’ll see how much the newspapers like the idea of dying people being refused free care because the Department of Health (DOH) doesn’t want them to have it.” Of course the DOH backed off because that certainly would have been bad press. In some ways, it took skill, but it also took nerve. She was a very conservative person whose husband [was] a surgeon who went right ahead and did this with her. I believe the DOH initially gave Hospice Buffalo a home care license to get around the problem.

**Joel:** What was the original staffing like?

**Carol:** Well, I didn’t work for a hospice at that point. I worked for what was essentially a lobbying and educational group, even though we
didn’t call ourselves that. The group split. There were those who didn’t want to go ahead with organizing [a] political movement but just wanted to do patient care. There were those of us who thought the only way to change things was to go to Albany [the capital of New York State] and keep working the political end and the national end as well, since at the time the chair of the Senate Finance Committee in Washington was a New York senator, Daniel Patrick Monahan. So, New York pressure was key to moving things in Washington. As I said, once that happened, New York State couldn’t sit on it any longer. We played political games, getting it through one House but not the other until that happened. At that point, I was working for Hospice of Westchester, a largely educational group. We were going around, beating the drum for hospice, doing presentations, preparing printed materials, going to Albany and kept knocking on doors. We found some good supporters in Albany on both sides of the aisle. But that was [a] many-years-long process. We put together annual educational and caregiver conferences. I was also engaged in getting the program started from the Visiting Nurses end in White Plains. Ultimately the state and national organizing effort became too large and we needed a New York State Hospice Association. I took that on. We did all the educational and lobbying things. At that point, in every county in New York, there was somebody who wanted to start a program – somebody out of a nursing agency, hospital, or a community group. NYSHA took on fund raising and strong technical assistance so we could provide people with experts to consult where needed. The group became NYSHA formally in 1984, I think.

Joel: So, it sounds like this was pretty much on-the-job training.

Carol: Learning as I went, yes. I would go to D.C. and sit in with Health Care Financing Agency (HCFA), look at the draft regulations, and talk to people about what we thought we were going to do. Then I would come back to New York State, do workshops, and be introduced as an expert. In reality, I was only 2 weeks ahead. It was just a matter of being dogged.

Joel: Where was New York State in terms of the demonstration period?

Carol: Behind. I’m not sure when it started in New York. I do remember that, at first, most demonstrations were hospitals. The excuse was that hospitals could gear-up faster. That actually wasn’t true as it happened. In reality, the DOH felt that they could monitor hospitals more easily and DOH was nervous about what they didn’t know.
However, the first Medicare-certified hospice in New York State was Hospice of Schenectady, a community-based program.

**Joel:** The group you were working with, when did they become part of the demonstration?

**Carol:** I am not sure of the date. At that point, I had left the local group. Like a lot of institution-based programs, the local hospital-based program mistakenly thought a lot of money would come with this. When they found out there wasn’t going to be any money, they sat on their approvals until they knew where the funds were coming from. That was certainly understandable but at the same time demoralizing.

**Joel:** How did this get promoted to the public?

**Carol:** Well, we did everything we could to get in newspapers and to get on television and radio. At one point, I managed to interest Frank Fields, who was then on the CBS Morning Show. Donald Gaetz came as a representative of the national movement and did a rousing presentation. We were even able to get it into The New York Times sporadically.

**Joel:** What was the public’s response?

**Carol:** There was an immediate resistance from some groups that assumed that this was somehow related to euthanasia. For the most conservative Catholic and Jewish groups, the idea of giving up “life saving” care for comfort care was an anathema. We worked hard to keep ourselves out of the euthanasia debate – and the patient’s right to self-determination debate – which we had to enter in the end. I remember one fellow when we were doing Living Wills and Health Care Proxies in Albany. The phrase from his report was “this Pac Man of self-determination gobbling all before it.” I’ll never forget that phrase. We had been trying to work with him until I saw his report. I didn’t quite realize that what he really objected to was people having a right to determine their fate. That was our original problem – separating ourselves from euthanasia.

**Joel:** Yes, I suppose that was the big challenge along with the political and financial.

**Carol:** Yes, and they’re all intertwined.

**Joel:** Were there any other challenges that you recall?

**Carol:** Those were the three big ones. In way, we were probably one of the best, if not the best, organized state in the country simply because the DOH was so opposed to it. In a way, it served us very well. Because they were so totally unreasonable, people had to band together even if they didn’t agree on everything, and work with a
united front. So it was a double-edged sword. In response, we were organizing, adding new members, and getting great support. It was harder to come by in other states where health departments were not as aligned against them. That wasn’t the DOH’s intention, but that’s how it worked.

**Joel:** When it first started, what was the original model like?

**Carol:** The original goal of the people I worked with and a lot from around the state was that this would come out of independent, free-standing, home care type organizations. It quickly became mixed. People who worked in hospitals would have a very difficult time trying to turn around not only the financial questions, but ingrained physician practices where physicians ruled the roost. Some people from home care agencies thought that this would just be an extension of what they did for which they could do fund raising. They could get a feather in their cap and not change their services much. When the federal regulations came out it became clear that all programs would have to provide full hospice services or stop using the word “hospice.” The big challenges for community groups were not having an organizational base and money.

**Joel:** How much were you involved on the national level?

**Carol:** A lot. My good relationship with Daniel Patrick Monahan’s [senator from New York] staff and ultimately a good relationship with the New York-area Health Care Finance staff helped a lot. The founding mothers, Florence Wald in Connecticut and Dr. Jo Magno on the national level, were extremely well-educated and motivated health care professionals who really saw this from a spiritual end as well. They all knew Cicely Saunders. We invited Saunders here to inspire others. But many of the founding mothers didn’t understand and didn’t want to understand the political process. This was somehow dirty, tainted, and not pure hospice. What they would have liked to have done was to have (as was explained to me) a 10-year prolonged demonstration with a few hundred or thousand patients here and there to show its worth. When everyone would come to understand its worth, there would be funding. But the train was leaving the station – both New York State and the federal government were writing the regulations. This was going to happen and they could either get on the train or be left far behind. There wasn’t going to be any 10-year demonstration. Unless these founders took a part in this process, it was going to resemble something they didn’t like at all. At that point, there was a division. Some very savvy business, political types on the
nation scene, Don Gates and Hugh Westbrook, popped up. When the national group formed, it named Dr. Magno as its first CEO. Gates and others were actually able to get considerable funding to get this going on the national level. Dr. Magno went about doing inspirational speeches but not doing the work necessary to form a strong organization. So there was a prolonged period of infighting and disorganization. The National Hospice Organization, which was what it was called then, went through three or four CEOs and was deep in red ink. Each time they hired a CEO who did well what the last one didn’t, but this one didn’t do what the last one did well so one big piece of it would fall through the cracks. They finally got Jay Mahoney who was a financial person from a hospice in Colorado. He came in, took control, and got the organization back on financial footing. The business-type people – Don Gates and, to some degree, Hugh Westbrook – gained influence [and] got the organization into an effective lobbying and organizing group. So, some of the founding mothers at that point wandered away with hurt feelings. I sound unsympathetic, but I’m not. They put their hearts and souls into this and were the initial spark. But when one of these women tried to talk me out of lobbying, she sounded as if I had chosen to sell my body on the street. Her whole tone was, “How could you do this? You’re a nice person.” So, that was a big division. From my perspective, while it was very painful and some of the founding mothers dropped out, it had to happen.

**Joel:** I guess it never would have gone as far as it did without the political activism.

**Carol:** Right. How are you going to get Medicare funding? How are you going to get decent regulations so that you can have a balance between providing good care and being so heavily regulated that you can’t do good care?

**Joel:** Was part of the issue that the U.K. model was very different from the U.S. model?

**Carol:** Yes, the U.K. model was paid for – that was the big difference. In the United Kingdom, inpatient care didn’t have to be as strictly limited. It could be a place and not a program or it could be a place with a program. In this country, regulators wanted it to be a program that could use a place. It was a very different model. Cicely Saunders, much like Mother Theresa, is taken by followers to be this very

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3 Now called the National Hospice and Palliative Care Organization (NHPCO).
spiritual person—which she was. What they chose not to view was what a really canny political person she was. She worked her model and fed it into the British health care system. It took her decades to get where she was. Some people here just wanted to see just the feel good stories—the spiritual model—and not do all the grinding work that Saunders did.

Joel: What was the difference between your initial vision of hospice and what happened to that once you started realizing the reality?

Carol: I don’t know that I had a vision other than people not dying in needless pain and isolation. I thought the doctors, nurses, and social workers would figure that out. The more I sat with them and went to workshops with them I realized that they were on the right track. What we would have all liked to have seen was hospice centers with home-like settings that could take 8 or 12 patients and less restriction on inpatient care to augment a strong home care component. That would have been the ideal—and it still is in some ways. But most hospices have found absolutely no way to finance this. I have forgotten the exact figures but when we figured the initial Medicare rates, the assumption was about a 60-day stay. The rate worked out at that because all the intensive expense in the first 1 or 2 weeks was then mellowed out in a relatively calm period before the intense expense of the last weeks. The average stay at that point turned out to be something like 27 days and the median was worse—something like 19 or 21 days. So, the whole model was off. From the beginning, the federal government said “You all have come forth as volunteers, you sold this to us as having a very strong community volunteer aspect to it. Well, then, you have to prove that this is true. This can’t be just another fund-raising, expensive, hospital program.” That’s what the regulations limiting inpatient care and for the volunteer component were all about. Existing programs couldn’t just tack on one volunteer and say, “Look. We have volunteers, we are a hospice.” The federal government also assumed that you were going to do community fundraising—it was going to be cost effective for them. That’s the whole balance. Of course, the overhead in the hospital, especially if the step down is not in your favor, can be egregious. But they have the population base. Home care overhead is probably more reasonable but you don’t have the population base. You don’t have the hospital to draw on unless they’re really referring to you appropriately. Many were not, especially if they had their own home care programs to refer patients to.
Joel: From your perspective, what are the current challenges facing the hospice movement?

Carol: I haven’t been following it closely but I think that it is the same tug and pull. It’s not the spiritual-minded founding mothers anymore. It is more of a business-like approach. But I don’t think that’s an altogether bad thing – you’re more likely to stay afloat. Zelda Foster was the first president of NYSHA. Two years ago, HPCANYS was having an anniversary and she was invited to go, as was I. My impression was there was more of a division between the program leaders (the CEOs, the financial people) and the nurses, social workers, etc. The ideal in the beginning was this very close knit team all pulling in the same direction. While professionalizing the organizations was necessary, it sadly went back to a more traditional health care model in many cases, especially as the larger programs grew. The administration and the line people became very separate. Maybe that was inevitable, but it’s too bad.