

THE REVOLUTION OF HOSPICE: SAUNDERS AND KÜBLER-ROSS

Do not fear death so much, rather the inadequate life.

Bertold Brecht

The history of hospice goes back to the Middle Ages. In those times, hospices were places of rest and shelter for pilgrims and travelers. According to need, the sick were cured and terminal care was offered to the dying. The term hospice in relation to the dying was first used by the Irish Sisters of Charity, who opened Our Lady's Hospice in Dublin in 1879. Sixteen years later they founded St. Joseph's Hospice in London. The separate modern hospice unit was inaugurated with St. Christopher's in London in 1967. The home care aspect of hospice was begun in 1969. By 1985 there were about seventy such hospices throughout the United Kingdom.

In 1975 there were only three hospices in the US: the first was in New Haven, Connecticut; the second, in Marin, California; and the third, a hospice unit within St. Luke's Hospital in New York City. By 1977, there were about seventy initiatives covering the span of the entire country. By the early 1990s there were approximately 2,000 hospices in different degrees of development.

During World War II, as a nursing student, Cicely Saunders had seen much death and pain. She became concerned with giving dignity to the dying and attenuating their pain. She did this by taking on a degree in social work and then another degree in medicine. Subsequently she started working in religious hospices. She wanted to combine the ideas of caregiving with the comfort that modern medicine could offer. She rediscovered the Brompton Cocktail, a blend of heroin, morphine, cocaine, alcohol, and anti-nausea medication, and pioneered the idea of continuous pain control so that the dying could prepare themselves more readily for their transition. In 1967 she started her own hospice, St. Christopher's, in the suburbs of London. In it she integrated all the elements that she thought would add value to a stimulating environment for her patients: a feeling of family, religious support, art—all elements that offer a wider perspective of life.

In America, more than elsewhere, hospice has also received a considerable contribution from Elisabeth Kübler-Ross, through her work, her books, and her workshops on death and dying. Saunders and Kübler-Ross stand out as two of the most prominent figures in the development of the modern idea of hospice. In the United Kingdom, hospice was founded around the idea of a charismatic leader; in the US, more upon the idea itself. In the UK, hospice relied primarily on Christian ecumenical views, whereas in the US the multicultural factor, with the need for religious and moral pluralism, made hospice open to a new kind of spirituality of which Kübler-Ross is an apt representative. The two pioneers, who have just recently departed within a year of each other, form two complementary perspectives. Saunders led the way, and Kübler-Ross inaugurated future possibilities.

Accompanying the Dying: The Story of Cicely Saunders

Cicely Saunders's biography is truly astounding, primarily because of all the obstacles that personality and circumstance threw her way. However, these are the very same

adversities that made her uniquely suited to perform her task. Saunders was born on June 22, 1918 to an affluent English family, to a very unlikely and divided couple. The mother, Chrissie, rather charming and considerate, was out of touch with her own emotions and unable to deal with practical matters. Consequently, she left the children's upbringing to the family's domestics. Like Chrissie, Cicely inherited a congenital slight curvature of the spine that was to cause her ongoing hardships. She was unusually tall, so much so that she remembers, "I seemed to spend much of my time falling over myself because I am too big."¹ Added to this was a great shyness that caused her feelings to overwhelm her; she tended to accumulate inner tension until she could find an uneasy release for it. From her very extroverted father—with whom she felt very close—she absorbed a very lively and wide range of interests and great determination.

Saunders' personality is one of great dynamic tension and of marked contrasts. She was fearful and yet daring; very sensitive to people's needs and yet ruthless at times; concerned with overall vision and very keen on detail; knowledgeable of both the scientific and technological and interested in the spiritual; tending to the autocratic and yet acknowledging the need for the democratic and striving toward it; and especially, both practical and intellectual. More than any other quality, it was her extreme determination that could educate and propel her above her tensions and inner difficulties.

Armed with the experience of her own shyness and her physical pain, Saunders had a great ability to listen to her patients' pain, feel what they were going through, and tell them the truth without scaring or embarrassing them.

Nursing, religion, and intimate encounters formed the turning points that marked the path of the founder of modern hospice. Let us see how. It was the circumstance of the war that gave Saunders the courage to veer away from the path that upbringing and fatherly inclination had marked for her. At the outbreak of WWII, she took the Red Cross exams in home nursing and first aid. Later, at her initial training with the Nightingale Training School for Nursing, even with the stringent conditions of wartime London, she felt she had found home. However, her back problems did not allow her to finish her studies, nor to envision taking on the physical strain of the life of a nurse. In order to keep the precious contact with the patients she became an almoner, the rough equivalent of a medical social worker. Soon she found out that this new profession could not satisfy her as nursing had done, nor fulfill all her lively interests. It was through these interests that she came to volunteer for St. Luke's home for the dying, which, unique for its time, had both an ecumenical religious approach and a pioneering approach to pain control. Here, ever since 1935—little known to the public or the medical profession—a system of "regular giving" of pain control drugs allowed the patients to use the drugs they needed before the return of the pain. This important contribution to Saunders's quest formed the ground for the next step.

The surgeon Patsy Barrett, for whom Saunders started working, indicated to her that the problems of the dying stemmed primarily from the attitudes of the medical profession, and that, if she wanted to affect a change and have the credentials for it, she needed to "read medicine." Undaunted by the challenge, Saunders enrolled in medical school at age thirty-three, at a time when only 15% of the enrolled were women. She worked to prove that it was possible to prescribe pain control without causing addiction and without causing tolerance to the medicine. Most of all she felt it was important to

leave control of the matter in the hands of the patients. In the time that she worked at St. Joseph's she had managed to document more than a thousand cases of dying cancer patients. There she also started to emphasize the importance of seeing patients within the context of their families.

Saunders's medical career went hand in hand with key personal experiences that marked the genesis of the first hospice, Saint Christopher. Chief among them was a spiritual odyssey that she shared in great parts with key patients.

Saunders had not been raised in religion. A first interest was facilitated through the reading of such books as *Good God* by John Hadham, and C. S. Lewis's and William Temple's opuses, which appealed to her growing liberalism. The real turning point, however, occurred in the summer of 1945 when she joined a group of six evangelical friends who were heading to a holiday retreat with prayer, worship, and discussion. Still skeptical, after one of the services she decided to pray and ask to receive proof of "His presence." And she reported: "The Lord as it were said to me, 'It's not you who has to do anything. I have done it all.' At that moment I felt that God had turned me around and that it was all right."² After this episode, the friends could sense Saunders's transformation. She was quite fervent in her faith and shared it in the workplace despite disapproval.

In the genesis of the hospice idea, Saunders moved from realizing it could not be evangelical, to requiring a minimum level of commitment to Anglicanism, and finally to a full embrace of ecumenical principles. Saunders realized that hospice could not be a religious order, and that spiritual life had to be left to the individual. She accepted reluctantly that it would be a "community of the unlike."

In her ecumenical trajectory, Saunders had learned a lot from the pioneering Saint Luke's, but most of all from the patients themselves. After becoming an almoner, among the first patients with whom she worked was David Tasma. He was a forty-year-old Pole who had terminal cancer and felt quite desperate and empty, not to mention utterly alone. The relationship soon blossomed into love. It was with him that Saunders started discussions about how to care for the dying. Through this encounter she not only found love, but also confirmed her vocation for bringing relief and comfort to the dying. At his death, the loss left her to deal with personal grief that she could not publicly acknowledge. After three months, however, a spiritual experience helped her in the grieving process. At the time she was in Scotland, walking by a river. In the beauty of nature she felt as if she were slipping out of time and sensed David's presence at her side, giving her the feeling that everything was all right. She called the experience "very strong and comforting."

This constellation of events was to repeat itself, as if at a higher level, in her relationship with another dying patient, Antoni Michniewicz, a devout Catholic Pole, thirteen years later. This was in Saunders's words, "the hardest, the most peaceful, the most inhibited and the most liberating experience I have ever had." For a long time Michniewicz was just a friend. Then one day he expressed his love. Their relationship remained brief and public throughout, and Saunders recorded a diary of her conversations with him. She had never experienced such love in her life, and it provided her inner peace. Saunders was with him when he died. After that she was surprised by the depth of

her grief—after all, it had happened before. Once again, but more than with David Tasma, she was left to mourn in a position that was not socially recognized. This was the time leading to the founding of Saint Christopher's and Saunders's determination was sorely tested. She wrote, "It does feel like the end of the world. I had to do this work and though I wanted to do it, I could hardly bear to go on living. I often thought how nice it would be to die."³

Hospice: The Community of the Unlike

Hospices begin with two questions. What do dying patients need, and how can we accommodate their needs? Although it may seem obvious, this is an important prerequisite to underline. Putting the patient at the center concretely means that hospice has the ambition of accepting everyone. Although this is an ideal that is far from realized, it is already a major difference from a regular hospital, where the financial element plays anywhere from a very important role to an almost exclusive one at times. Thus business efficiency plays a role in hospice care that remains subordinate to the goal of individual care.

The goal of offering true care cannot be reached without real teamwork. Only people who have rededicated their lives through a common goal can achieve such high standards. Hospice standards of professional services have to match and surpass those of any regular hospital unit caring for the dying. Another major difference between hospices and corresponding hospital units is the ability of hospice to offer more constant attention to the dying patient. In medical terms this is expressed with a higher nurse-to-patient ratio. This, however, is looking only at a quantitative side of the picture. The nurse's work is assisted and facilitated by a host of other professionals, and also often by trained volunteers. In short, the patient is not only treated, but also surrounded by an entire community.

Let us look at the professional side of hospice. The hospice ideal is for the patient to be able to die in familiar surroundings. Whenever possible, this means dying at home. Only a marginal number of patients may need a hospice room for logistic, social, or medical reasons. Hospices look at the whole person, not just the medical case. It is body, soul, *and* spirit that need attention.

According to *Hospice: Current Principles and Practices*, an ideal hospice team is composed of the following specialists: nurses and doctors, social workers, psychologists, counselors, priests, art and music therapists, physical and occupational therapists, dieticians and nutritionists, pharmacists, and trained volunteers. While this wide variety is in many cases still a goal to attain, the integration of many specialists is a common practice in hospice work.

Starting with very practical aspects, expecting death means a disruption in the everyday needs of a patient, a couple, or a family. The patient may need help with transportation, with finances, executing a will, and other personal errands. If the person is hosted on the hospice's premises, the patient is made to feel as close to home as possible. The patient should be able to bring in houseplants or private objects, music, clothes, favorite foods, and even such "unsanitary" things as a favorite pet. Visitors continue to be part of everyday life and are accommodated as much as possible. Couples should be

given space for physical intimacy. Many of these tasks that ensure physical comfort can be facilitated by volunteers.

The other large component of physical care is the medical aspect, an essential point of it being pain control. Pain can be relieved with the aid of simple, logistic therapeutic interventions: a pillow placed in the right position, physical massage, or a change of diet can be the first important steps. A helping ear can help separate the different levels of pain and offer a degree of relief. Physical pain relief involves the delicate use of potent drugs such as morphine. In an anonymous setting, pain control can make addicts out of individuals afflicted with various levels of pain. It can kill the individual's will and turn patients into vegetables.

It has been found through clinical studies that fear of pain increases pain itself. Beyond a certain level, patients who are in pain and do not foresee an improvement of their situation in the near future experience horror and hopelessness. Pain control cannot accomplish its role without enhancement of the patient's responsibility. That is why in hospice settings it is important that patients are able to administer their own medications to find their individual level of comfort. This is a very practical way to reduce the amount of morphine and other addictive substances.

The doctor who views patients as more than medical problems has to develop a whole new perspective on the medical profession. Dr. Robert Twycross has written *The Ten Commandments for Physicians*, dealing with the pain of terminal cancer.⁴ Among his tasks he lists the need for a doctor to consider the patient's feelings and support the whole family. This means including the patient in their private life, at least to some degree.

Psychological needs are cared for in a variety of ways. The most urgent need of patients is to deal with the psychological turmoil of dying. Counseling helps them come to terms with their feelings. It should allow them to resolve family issues and prepare themselves for crossing to the other side. It may help them through single steps of their illness, or prepare them for a difficult chemotherapy, or for the will that it takes to face a different physical appearance after medical interventions.

Kübler-Ross contributed to the understanding of the emotional transition into dying with the now famous five emotional stages: denial, anger, bargaining, depression, and acceptance. At each stage the hospice patient discovers new challenges to personal growth. These stages should not, however, be understood as a mechanical sequence, but rather as a fluid continuum. Within this perspective, they blend into each other in a highly personal way, so much so that some stages may be barely present in some instances. In a later book, *Death: The Final Stage of Life*, Kübler-Ross adds to these five steps (which she dubbed "stages of resistance") another two: a stage-of-life review, facilitating the completion of "unfinished business," and a stage of transcendence, an active preview of what is to come in the life of the spirit. In 1963, Robert Butler wrote about his patients' urge to do the life review and proposed using this process as a therapeutic tool to facilitate life closure.⁵ This process offers patients a sense of an emerging self beyond the confines of the body and a whole new sense of wonder and ecstasy.

Emotional support does not end with patients. It is extended to their loved ones through bereavement or support groups, pastoral care, and the like, since it is clinically proven that the bereaved stand a much higher risk of contracting illnesses or having accidents.

Finally, it may be difficult to clearly separate what is psychological and what is purely spiritual when dying obliges us to question our core beliefs. Nevertheless, the presence of a pastor, priest, rabbi, or other religious professional is a necessity for those who want to turn to an understanding of the other world. It is not the role of the clergy to work at a conversion—rather to offer answers to the soul who earnestly seeks understanding that lies beyond the limits of physical existence. This last element is what holds together patients, professionals, and those people who are open to it. Spiritual support, although primarily given by the clergy, is given by the whole spectrum of people in hospice. It is most often given in a way that encourages patients' own religious convictions. Most of the patients appreciate the staff's desire to act toward them in a religiously or spiritually motivated manner. Under optimal conditions, this means a certain level of familiarity with people's beliefs and backgrounds.

Without the capacity to embark on a journey of self-knowledge, hospice work may be more than many could handle. When self-development is integrated, hospice work rewards professionals and volunteers more than any similar profession could. When self-development goes hand in hand with an intense interest in the other human being, death becomes a path of development for the dying and the living alike.

It is of great interest to the scope of this work that hospice work makes the reality of the soul a visible experience for those who work around it. It has been observed that two to four months before death, sleeping patterns change. Patients will start taking afternoon naps, then morning naps, and finally spend more time asleep than awake. They will be more at home in their dream world than in day consciousness. This is why their visions and communications with departed ones increase. Some visions may be drug induced, but these will tend to include the living as well as the dead. When the patient starts to see only departed ones, we can be sure the time of death is near. We can conclude from the wealth of observations that, for the dying, both worlds are true and present at the same time, and patients may have trouble discriminating between the two. This explains why their language becomes symbolic or imaginative in order to include the new level of reality.⁶

Dr. Karlis Osis and Dr. Erlunder Haraldsson found that 84% of patients have visions of dead relatives to whom they felt close. They also witnessed apparitions that ranged from angels to beings of light and spirit guides. These visions are culturally colored; for example, Christians will see angels, Jesus, or the Virgin Mary, and Hindus will see Yama (the god of death), Krishna or one of his messengers, or another of their deities. These visions occur regardless of whether or not medication was taken. Around the time of death, people start to transform; as their bodies die, the dying seem to awaken to the spirit.⁷

From actively living in the dimension of the spirit in practical ways, it naturally follows that hospice has fostered the understanding that artificial life preservation is not desirable. Death needs to be consecrated, not endlessly postponed, when it is becoming unavoidable. Euthanasia, too, becomes absurd when pain is controlled and patients are loved. No patient who could control the dread of pain and loneliness can still desire induced death, nor could hospice entertain the thought. Saunders, who was a vocal opponent of euthanasia, offers examples of patients in critical condition who entered

hospice with the desire to die, but not only came to feel at ease in the new settings, but also managed to die peacefully and reconciled to their fate.

Hospice not only promotes a better understanding of the spiritual element that surrounds us, but, by catering to the needs of the dying and their loved ones, also helps to restore the community network that conventional medicine has most often disrupted. Hospice—in practice, most often the home—is the place where dying patients can be in the company of children and family. This makes it possible for family members to incorporate death into their daily experience and witness the transformation that every human being undergoes through such an experience. Dying at home gives the bereaved a sense of completion that impersonal hospital care cannot offer. The death of a beloved one can be the beginning of a quest for meaning and the avenue to new discoveries of the spirit.

Caregivers see their relationships extending beyond their professional role. They may choose to share in recreational activities or rituals, particularly funerals, and offer support at the hour of a medical treatment or share in social or personal occasions on hospice premises. Contacts will continue after the death, in a first step with bereavement accompaniment. Bereaved families may decide to contact and support each other. People come together who would not do so in other circumstances. These links often go on among relatives after the death of the patient. Thus new, unexpected relationships develop that effectively replace traditional structures that have mostly died out in modern societies.

Death, as the most critical part of life, is the most “spiritually charged” event in life. Hardly any time is as important as dying; no place can cause so much pain as well as hard-wrought wisdom and joy. The two possible outcomes make a world of difference. Bereaved people can go on mourning and holding the deceased captive to this side of existence. Otherwise, our purpose for life on Earth can find harmonious resolution and culmination even in the act of dying. Hospice can effectively restore the sacredness of death and offer the fruits of such an experience to modern-day individuals. Many family members can describe the death of a loved one as both one of the most trying and most memorable times of their lives.

Such an experience may be, for some, the first window through which to view the sacred. The following is the experience of Virginia Hine at the death of her husband:

There are moments of closeness that can heal long years of scratchy and even hostile relationships. There is a strange “ethereal” quality to the way a dying person looks just before death. My husband died of a disease that had rendered his strong body quite misshapen by the end. Yet to those of us who were tending him, he began to look incredibly beautiful a few days before he died. . . . Death really does have its own majesty, if it is allowed, and it seems to affect the perceptions of those involved in it. Religious people have many ways of explaining this emergence of beauty at the very end of life, but you don’t have to be religious, in the conventional sense, to experience it.⁸

Through Death to the Spirit: Elisabeth Kübler-Ross

Elisabeth Kübler-Ross, whose work offers new glimpses at the direction that hospice work can take in the future, stands as the representative of the second phase of growth of hospice, its growth into a movement that is actively shaping its own spirituality and contribution to modern culture.

In Kübler-Ross's biography, a few elements seem to point toward her life mission: her upbringing, the influence of Switzerland and the United States, her personal experiences with death, and finally her scientific training.

Raised in Switzerland, where she lived until age thirty-two, she immigrated to America. Her upbringing gave her strength and assurance, coming from a life steeped in traditions, festivals, love of nature and art, within a tight-knit social fabric. Of those days she also recalled her love for animals and her care of the vegetable garden. Kübler-Ross acknowledged her debt to Switzerland thus: "I had . . . my family, memories of hiking and climbing in the Swiss mountains, strolling through moors and forests, collecting rocks. . . . Without them I would probably not have survived and achieved as I have."⁹

America provided her a completely new opportunity. Having come from the land of tradition, she now faced the opportunity to innovate. This is how she viewed the contrast: "My destiny had to be the United States, where I was free to pursue my own work, my own research and my own teaching, none of which could have been possible in any other part of the world."¹⁰

Death itself was a constant companion in Kübler-Ross's life, practically since the day of her birth. Born a very weak triplet, she survived only through her mother's devoted round-the-clock care. She weighed only two pounds and had to be nursed through a baby-doll bottle.

Another element prepared Kübler-Ross to be a trailblazer in her field. Although deeply steeped in tradition, her family wasn't religious. When she met with the scientific worldview, she naturally adopted it while at the same time retaining everything she had been taught during her upbringing. Thus, she was able to address the scientific world with the credentials of a medical doctor. However, her yearnings could not be blotted out by her scientific knowledge, and later she did actively pursue a spiritual understanding of the world.

At age twenty-one, Kübler-Ross met the woman she called Golda, in the concentration camp of Maidanek, Poland. Golda, a German Jew, was a miraculous survivor of the gas chambers. Although the rest of her family had died, she vowed to forgive all who caused her hurt. Because of the contrast between the horror of Maidanek and Golda's love, Kübler-Ross formulated an important question that would determine the later course of her life. How can evil hold sway in the world in such a way? How can individuals allow it to happen? As soon as she arrived in America, she experienced human callousness in a way reminiscent of Maidanek, although on a much lower scale—this time toward mentally ill patients in Manhattan's State Hospital. She pondered the image of the butterfly she had seen drawn on the walls of Maidanek by many children. Here was an image of innocence and hope amidst the horrors of inhuman death. This led her to important discoveries she would utilize later in her career.

Having realized early in life that the possibility of evil lives in each of us, Kübler-Ross started focusing on the issue of death. The challenge came to her from the American medical profession's attitude toward dying patients. Why was death ignored and

shunned? Why were dying people left with no support? These questions led her to first explore the experience of dying people by simply listening to them. Later on, she explored and discovered ways to alleviate their suffering.

In 1969, at age forty-three, two important events propelled her to the task that made her famous. The Macmillan publishing house asked her to write 50,000 words on death and dying; the book that resulted from it sold very well. In that same year, *Life* magazine wrote the famous article about Kübler-Ross's interview with Eva—a twenty-one-year-old woman dying of leukemia. The reaction to her book and the prompt readers' responses to the *Life* article propelled her into a new career—offering death and dying workshops all around the world.

Kübler-Ross felt that working with death was just the first part of her task. The success she encountered also taught her to handle fame. But her real task encompassed more. It wasn't just the attitude toward death that she challenged, but all the belief systems that surrounded it. Similarly to the Golda episode, it was again a simple woman, Mrs. Schwartz, who opened for Kübler-Ross the research on near-death experiences. At a point when Kübler-Ross was discouraged and contemplated abandoning her work, Mrs. Schwartz, recently dead, appeared in a disembodied form to the unbelieving doctor. She entreated the doctor to continue her work. Moreover, she assured her of the continuing help of departed souls.

In the years to follow, Kübler-Ross embarked on an often-tumultuous exploration of spiritual reality. It sometimes led her to extreme experiences due to her impatience and desire to obtain knowledge of the other side prematurely. The spiritual experiences are central to an understanding of Kübler-Ross's life and work, as we have already seen on the occasion of Ms. Schwartz's apparition. In a revealing statement in her autobiography, Kübler-Ross says that "if I had not been on the other side, I would not be able to be with dying children, with parents of murdered children."¹¹

Kübler-Ross had at least three important spiritual experiences. The first occurred in 1976, at the Monroe Farm in Virginia.¹² This was a laboratory environment designed to stimulate out-of-body experiences. She was in a soundproof booth, lying on a waterbed, eyes blindfolded. Relaxation was induced by artificial sound pulses. Against the advice of the scientists, she asked that they send the highest impulses possible. Of the resulting experience, she said that she did not know where she was, and she had the feeling of having gone too far. Upon going to sleep, she was besieged by nightmares. This was what she defined as "going through a thousand deaths." One after the other she experienced—bodily and psychologically—the deaths of all the patients she had assisted. The pain was so intense that she somehow got to the other side, rising above it. After a series of experiences connected with the perception of her body as an energetic field, she came in contact with the white light that she knew from the description of her dying patients, merging into a blissful state of warmth and love. On coming out of the experience, she could perceive, in a heightened state, the energetic field of all living beings. When that faded she had to struggle to reintegrate into everyday life and apparent humdrum reality.

A second experience, which occurred two years later, was a typical NDE caused by three bites of black widow spiders, which would normally cause death. Kübler-Ross felt she had a choice between living and dying. Walking into the living room, where a picture of Jesus hung on the wall, she made the vow to keep living. At that moment she felt

enveloped by a bright light and moved toward it, knowing that she would survive. A final NDE occurred when she visited her sister Eva in Switzerland in 1988. There she expressed to Eva that she was dying and ready to go. Once again, she experienced the white light and returned to this side of existence.

These short observations undoubtedly point to Kübler-Ross's special mission in connection to death and dying. In her, we find the desire of the modern soul to bring spirituality and science to a dialogue where neither is subjugated to the other.

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