

Being with Dying

Contemplative Approaches to Working with Dying
People

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Joan Halifax

Each week I sit with a group of people, some of whom are dying, some of whom are care givers. Others come because death is an issue they want to be with and explore. I have worked with dying people for 25 years. I sit and listen, sit in silence, do the most simple things for and with dying people and people concerned with the issues of suffering and death. Sometimes, I work with family members or care givers. I am defined in various ways: as a Buddhist priest doing pastoral work; a medical anthropologist; as a care giver; as a friend. I prefer the latter definition because I do not want to be distanced by roles and titles. I am simply a person in the community who brings a certain quality of presence to those who are suffering. I try to bring to these relationships the "presence" of mindfulness and compassion, in addition to years of experience of spending time with dying people and of practicing meditation. These relationships have had a profound effect on my own life. They have changed me in the most fundamental way. I have learned more helping others to face death than in doing any thing else in my life. It has been a great privilege and challenge to be a kind of midwife to dying people.

My background of working with dying people ranges from being a medical anthropologist in clinical and research settings to working independently with dying people and their families and friends as a teacher of Buddhism, a meditator, and a person committed to helping people who are suffering find a way to transform their suffering into compassion and ease. I believe that my experience in the clinical setting where I have been exposed to the physiological dimensions of suffering and dying has been of immense value in the work I currently do as a Buddhist priest. In addition, my background in cross-cultural anthropology has made it easier for me to be with people who have differing world and religious beliefs.

I also have spent time in cultures where death is a natural part of the fabric of life, and death is kept in the weave of the family and community. Although this combination of experience is perhaps a little unusual, my sense is that it can be translated into a form that is learnable through contemplative practices and teachings. In any case, it forms part of the basis of a view of suffering, dying and death that is based in accepting the inevitability of change as an undeniable condition of existence. It also confirms the existence of suffering in the world and the possibility that there can be freedom from the experience of suffering.

Until recently, I had not intended to widen the scope of my work with dying people. I liked the simplicity of doing this type of contemplative work in an informal way, outside of an institutional framework. I am a teacher of Buddhist meditation and my vocation expresses itself in quite diverse ways. But in the past several years, there has been a dramatic change in this pattern in response to a strong call in our community and other communities around the country to teach people how to bring a contemplative dimension to being with dying.

This paper reflects this inquiry into a practice of a contemplative and spiritual approach to dying, an approach that is based in a Buddhist perspective. In it, I use some terms that might not be familiar to you. You might ask what I mean by view, meditation, mindfulness, concentration practices, and contemplation. I hope the following definitions will be helpful.

View in Buddhism refers to understanding the nature of reality. It is a perspective on reality that includes some of the following elements: the impermanent nature of the phenomenal world; the existence of cause and effect; the interdependence of phenomena and the absence of a separate self identity; and the possibility of freedom from suffering. Although "view" can be

conceptually communicated, it is rooted in understanding that is realized through personal experience.

Meditation practice is a means for us to study the nature of the mind and to understand directly the nature of reality. It is a way for the mind to look at itself, and through this practice of observation to transform itself through understanding. This group of practices is called wisdom or insight practices in the Buddhist tradition.

Mindfulness is a practice of giving attention to what is happening at the present moment. This refers not only to what is happening in the mind and body of the observer, but it includes what is going on in the surround of the individual.

Practices of concentration are done to develop particular qualities, such as mental stability, compassion, peacefulness, generosity and love. This group of practices also includes prayer and practices of devotion.

I have chosen to use the word **contemplation** to refer to these three forms of mind practice. Contemplation usually occurs in relation to an object. In the case of meditation, the so-called "object" is the mind. In the case of the practice of mindfulness, the "object" is the

present moment and all that is occurring therein. In the case of practices of concentration, the "object" is the state or quality being cultivated. We discover in the course of these practices that in fact there is no fundamental separation between subject, the one who is practicing, and the object of contemplation.

These forms of contemplation have been developed and refined in the Buddhist tradition. Contemplative practices are also found in many other religious and spiritual traditions. The study of the nature of the mind and reality, the development of a fine awareness of the present moment, the cultivation of wholesome mental, emotional and physical qualities, and the understanding and compassion that can arise when mental stability is achieved is the basis for the work that we are proposing as important for being with dying people and going through the experience of death itself.

In my own work with dying people, from one point of view, there is nothing special about what I do. I do what any care giver does, what any friend or relative might do for one who is suffering, for one who is dying. These activities range from sitting in ease and silence for long periods with a dying person, giving a sponge bath or foot rub to alleviate discomfort, to entering the questions around dying that many people are fearful of asking or exploring. But there is a way of being with

ordinary and difficult activities around dying and death that has prompted dying people and their families, as well as professional and lay care givers, to ask for guidance on how to deepen their relationship to the experience of dying. This they ask not only for those whom they might be serving, but also many ask for themselves, for this is a question that all of us will face. People want a peaceful death, a gentle death. We, each of us, want to die well.

As you might imagine, this call has come mostly from friends who have AIDS. From this request for training in contemplative work in being with dying has come a small but burgeoning grassroots program that I believe can be easily implemented in other communities. What is clear to me now is the timeliness in this work. It is also clear that no matter what one does vocationally with people who are suffering or dying, a contemplative approach can be the basis for a more effective and compassionate approach to this very sensitive and inevitable process of living.

Years ago, I spent time with an extraordinary woman who had breast cancer. Just before she died, she told me that you can never really know what dying is about until it is happening to you in a way that you know it is happening to you. I was thirty years old at the time, and as I gazed into her eyes, they said even more than her words did. I believe Helene was basically right. But

I am now aware that familiarizing oneself with the physiology and psychology of the dying process, exploring the truth of impermanence in a deep and fundamental manner, and stabilizing the mind can well be the basis for a good death.

Interestingly enough, meditation practice in the Buddhist tradition is based in the direct observation of the principle of impermanence as it operates in our minds and in our lives. This is one of the discoveries that the Buddha made in the course of his meditations. This insight of the transient nature of the phenomenal world is a sword that cuts two ways. From one point of view, we can see the mystery and necessity of change: the seed grows into a tree, a baby becomes an adult. Dead flowers in the compost are transformed into living plants. But impermanence is difficult for many of us to accept, such as in the experience of loss and death.

The Buddhist teacher Thich Nhat Hanh has said that "Life is impermanent, but that does not mean that it is not worth living. It is precisely because of its impermanence that we value life so dearly. Therefore we must know how to live each moment deeply and use it in a responsible way. If we are able to live the present moment completely, we will not feel regret later. We will know how to care for those who are close to us and how to bring them happiness. When we

accept that all things are impermanent, we will not be incapacitated by suffering when things decay and die. We can remain peaceful and content in the face of change, prosperity and decline, success and failure." This perspective on the transient nature of things can have a profound effect on how we die, and how we live.

There are many stories of the "good deaths" of Buddhist teachers. In fact, death is looked at as a friend to practice, for it is our awareness of death that deepens our commitment to awakening and to living a life of value and meaning. It is said by the most adept of Buddhist teachers that understanding death is the bedrock of the entire spiritual path.

What is wrong with death in America?: In having been in the "field of dying" for many years, I have frequently encountered the tragic limitations of dying in America. Working with dying people in often difficult external situations and dealing with the challenges of denial, fear, and institutional resistance have made the experience of entering the "question" of dying extremely rich, if not challenging. As we all know, death in America is all too often looked on as a management problem and as a biological and moral evil.

There are a number of important factors that contribute to the difficulties that we have in facing suffering and dying. In thinking about death in America, it is important to take into consideration a complex of factors that are co-related, including world view, society, psyche, and biology. These elements, and others, make a web of interdependence that mutually influence one another.

Changing the context of dying in America means changing some fundamental aspects of Western culture. It also means looking into the rich cultural and spiritual traditions found in America for ways of being with dying that are compassionate and sane. It means addressing the problem of Cartesian dualism that has separated humans from nature, fostered the split between body and mind, created a context of good and evil, and separated life from death. It has emphasized the supremacy of the individual giving rise to a sense of ownership and possessiveness - including looking at life and others as possessions. In our concern with the material aspects of our lives, we have often neglected the spiritual, religious and philosophical dimensions of living and dying which give life depth, meaning and a moral basis. This is certainly the case for dying and death that is usually considered a problem to be solved or overcome, not a context for the sharing of meaning and value, and even an experience that may give rise to an experience of awakening.

In looking at important shifts in attitudes around dying, the AIDS crisis can be considered a context of important change. Since the mid 1980's, AIDS has precipitated an open, and even political approach to the experience of dying. yet in spite of more than two decades of so-called "conscious dying in America" since the hospice movement of the early 1970's, Kubler-Ross' popularization of the spiritual aspects of death and dying, and an increasing awareness of the dying process through the AIDS epidemic, many Americans die alone, in technological contexts in hospitals; they are often pharmaceutically diminished and apart from their families. Indeed, death in America still exemplifies a firm denial of the transient nature of life, and an aversion to and often morbid fear of pain and decay, and the conviction that it is not possible to be free of suffering.

Looking at death in America, exploring how we can help make the dying process be more compassionate, more gentle, more peaceful could have far-reaching consequences on how we live and our fundamental values and world view. Under the present circumstances, death is justifiably feared. It is an experience that is difficult to accept under the best of circumstances. But when aging, sickness and death are accompanied by psycho-social alienation, denial, and other conscious and unconscious strategies of

distancing, it would seem as if the only solution to the problem of dying is to avoid it at all costs! And this is too often what is attempted, illogical and tragic as this is.

What are some of the fundamental characteristics of dying in America? Death in America cannot be generalized into a few simple patterns. We are a nation of many cultures and sociologies. Dying in the urban North can be quite different from what happens in Black communities in the rural South. Native American communities in the Rio Grande area often care for their elders at home until death (for traditional and economic reasons), and many whites in neighboring communities in Taos, Santa Fe and Albuquerque put their elders and sick relatives in institutions or arrange for institutional home care.

The range of practices in relation to dying people is great in our country. When we examine the detail of practices around dying emerging from the cultures found in our country, we can learn a great deal about what is healthy and what is unwholesome about how suffering, dying and death are perceived and worked with. I suggest we need to look at the dying process from a cross-cultural and multi-cultural perspective.

Indeed, there are general trends influenced by Western dualism, pragmatism and materialism that have had

tragic consequences in relation to the dying process in the dominant culture of the West. These attitudes and practices that are based in the view of death as an enemy are strongly present in white communities, and this style of distancing around death has adversely influenced non-Anglo groups and communities based in more rural areas.

How can we help improve the experience of dying?

There has been a shift away from this alienation around dying and death in the past 25 years. This shift began in the 1960's and 1970's with the work that Elizabeth Kubler-Ross, Stanislav Grof, I, and others (like Cecily Saunders in England) were engaged in at that time, which included direct work with dying people and their families, the creation of hospice, as well as an increase in public awareness of death through books, teachings, and trainings. Much of this work emphasized a psychological and spiritual approach to the dying process.

Since this work with people dying of cancer, I and many others have helped people develop the skill of listening with compassion in order to open themselves and learn about this experience of dying which is all too often considered to be non ordinary. We have explored concepts of death in other cultures and used our experience of contemplative practice as a place to learn how to live and indeed how to die. Dying will

touch all of us. Death is, in no uncertain terms, intimate and inevitable. Being with dying means that we bear witness to one of the most natural events of living. Learning to hold to truth, compassion and openness in the face of dying is so very important to all of us, but most especially those whose lives are being wound into the immediate experience of death. A contemplative approach to listening is profoundly important when working with the dying. And a contemplative practice can help us liberate ourselves from suffering when we die.

Being with a dying person can be a very inspiring process. It can also be very complicated, very troubling. Dying calls for truth in a more fundamental way than any other experience we human beings go through. We in the West need to articulate a psychological and philosophical foundation, a point of view, and a practice for working with the dying process. We need to develop a view, a perspective that makes work with the dying process more fruitful, more authentic. This view or perspective emerges not as a conceptual understanding based in a mental philosophy but, I believe, needs to emerge out of the ground of authentic contemplative and spiritual experiences with oneself and one's community, including dying people.

We need to explore ways of being with dying that can serve both the caregiver and the dying person practically and spiritually. We need ways to work with ourselves and with the dying person that are basically helpful and pragmatic, often very ordinary and essentially practical. Dying is a completely natural event. But there are things that we can do, ways we can be that help the true nature of dying come forth. These "ways of being" are expressed in terms such as compassion, tolerance, ease, kindness, humor, warmth, wisdom, authenticity, mindfulness, stability, openness, concentration, and so on. These are some of the qualities of a psychologically and spiritually mature person. How are these qualities fostered in our culture? What can we do to open these sensibilities within professional and volunteer care givers (who generally enter their professions with the highest intentions), as well as in our communities in general, so family members and friends can have the internal means to work with suffering and dying in a compassionate and skillful manner? These are fundamental and important questions that direct us toward a thorough examination of our world view, attitudes toward death, and the spiritual value of a contemplative approach to living and dying. Today, some people realize that in a very fundamental way, they may have a choice in how they die. A dying person can dwell in justifiable suffering or use death to move him or her to a new level of psychological and spiritual realization. We need to

explore the elements of this process of conscious dying, including the actual difficulties of making this possibility a reality for a person who is suffering from depression, anxiety, fear, or anger.

Over the past decade, my work with dying people has concentrated on people with AIDS, although I continue to work with people suffering from cancer as well as those with other severe illnesses and injuries. But in working with people with AIDS, I have had the opportunity to be with individuals who are particularly motivated to learn how to die well. Indeed, we are all being called to die well. We all want this on some level. Dying well is not only for ourselves. It is also for others, those who survive us.

Indeed, death is not an individual act. The dying person is a performer in a drama that will be observed by others and participated in by others. Like the last will and testament we leave upon our deaths that materially benefits those who survive us, we also leave to others a legacy of how we have experienced our own death. It seems important to explore the way in which this legacy effects our perceptions of dying and death, and how these perceptions shape our experience of living and dying.

Often, we concentrate on our work with dying people. Yet, those who give care to dying people are actually

working with many of the same issues as those who are immediately dying. The knowledge of the inevitability of our own deaths has called many of us to do this work. We want to be familiar with this most profound experience of living. The issue of our own dying and death and how we have worked with it effects and shapes the work we do as care givers.

Over the past twenty years, I have trained many people in how to work with the dying process. In this work, it has become clear to me that the issue of one's own death stands at the center of the work. There is often a great need for support and processing around personal issues care givers have in relation to working with dying people and their feelings about death, suffering and loss. Setting up support networks that include care givers and dying people is an essential element in keeping alive the communication and learning process around death and dying for those who are in service to the dying and those who are aware that they are facing death in the future.

We need to develop ways to reach care givers and dying people how to have a more realistic and open approach to the experience of dying. As we have spoken about a contemplative baseline for making this possible, this work must be not simply a metaphysical guide for being with death and dying. It must be a guide on how to be with both the spiritual *and*

practical aspects of death and dying from a contemplative perspective.

In brief: **What are some other ways that we can improve the situation in America around the experience of dying?**

* Help develop and support programs for care givers, dying people and professionals that are based in a contemplative perspective and offer spiritual care. Training in contemplative approaches and practices is important at the professional level, where dying and death are encountered on a daily basis, and the pressure of work and "patient load" is great. This should be introduced into medical curriculum as a core element.

* It is important to identify already existing groups and institutions who are doing, have done or can do this type of contemplative work and infuse them with support to deepen and expand their efforts. This would include Christian and Jewish groups and congregations, elder community volunteers, hospice groups, and so on. Grassroots work can be very effective because this is not only where dying is happening, this is where low cost, effective support can be given.

* Training in contemplative work with the dying needs to be developed that is culturally and spiritually flexible. An inter-cultural and inter-religious group should be formed that approaches the challenge of creating culturally relevant, flexible, and effective training programs and care giving programs in spiritual care for the dying that are appropriate for different cultural contexts.

* Just as there is sex education in the school system, there should be education in the awareness of death and dying and how to work with it. I feel that this educational process should cover not only the physiology of dying but also the cultural, spiritual and psychological dimensions of dying. There should be a curriculum developed for young people and adults on training in the awareness of death.

* Programs in community building around the issue of death and dying should be created. Such programs can deepen relationships in the community. It can deepen inquiry, make genuine and effective support more available. It can help alleviate care giving families who are under stress and pressure around the situation of dying, take some of the work load off of the professional community, and put dying where it most often should be, i.e., in the home and community with loved ones.

- * Model projects using a contemplative and spiritual basis should be supported, created and evaluated as to their effectiveness for: the dying person, the family, the care givers and physicians.
- * There should be a computer network for dying people and caregivers where information and support can be given.
- * Small group meetings should be supported for the exchange of ideas among care giving and physician groups. Dying people should be included in such meetings.
- * It is important to support the development of pharmaceuticals to manage pain that do not diminish mental acuity. It is also important to *explore* contemplative techniques for dealing with severe pain.
- * There should be a wide range of audio, video and CD programs for care givers and dying people on the many aspects of the dying process, including contemplative work with dying people.

Project on Being With Dying

In 1994, the Buddhist organization, [Upaya](#), began the Project on Being with Dying in response to a call in the

community to bring spiritual care to dying people and care givers. We hope that this project will be replicated in other communities. For further information, you may contact:

Joan Halifax

Project on Being with Dying

Upaya

1404 Cerro Gordo Road

Santa Fe, New Mexico 87501

upaya@rt66.com

505 986-8518

Please send questions or comments to upaya@rt66.com

What is the process of dying? How can you prepare for it? And how should you be with someone who is nearing the end of their life? Illustration: Dionne Gain Credit: What are the earliest signs a person is going to die? The point of no return, when a person begins deteriorating towards their final breath, can start weeks or months before someone dies. Death and dying are a part of life, and being prepared to cope is part of healthy aging. Find resources to prepare you for the downside of longevity.Â Mark Stibich, PhD, FIDSA, is a behavior change expert with experience helping individuals make lasting lifestyle improvements. Learn about our editorial process. Mark Stibich, PhD. Working with dying people was inspired by my grandmother, who was from Savannah, Georgia. In her elder years, she took care of dying people. When I was a young girl, we would spend summers with her. She would talk about being with dying people. For her, dying was very much a natural part of life. My grandmother was intimate with both the challenges of dying and the truth of death. She was a "village woman," like many women of the South who took care of their own and their neighbors.