

## End of life issues

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Related: WebCafe's online support forum: Dealing with grief and loss

From the UK, online, "Advance Directives and Living Wills"

Interesting online article about spiritual beliefs and grief:

"In recent years research has moved from focusing on the psychological and medical consequences of grieving to examining what constitutes vulnerability and resilience in bereavement. Our main finding is that strength of spiritual belief is an important predictor of bereavement outcome. People with low strength of belief resolved their grief more slowly during the first nine months but by 14 months had caught up with people with strong beliefs. Participants with no spiritual beliefs had higher grief scores than the remainder at the one month and 14 month follow up points. The comparison fell short of statistical significance, but strength of spiritual belief remained an important predictor after the explanatory power of most other variables was controlled for. Although the degree of closeness to the person who died and the level of emotional distress before the death increased feelings of grief, neither affected the rate at which the grief was resolved. "

British Medical Journal

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Considerations: Pain Healing vs Curing Hope Spirituality Dying Well

So here I am in mad preparation to die. Now it's coming up on me like a freight train. I have come to terms with my own death. Once you face the fears and what's the worst that can happen.... oh dear, you're going to die, then there is nothing else to worry about. I am going to die, that sucks it's painful, but it's going to happen so I'm going to make the most of it.

Soulla

How precious and exquisite is the language of human life. How rich and deep the unfathomable ordinary mind. How remarkable that we speak to death, as if an old friend. How revealing that, at the end, it smiles and shakes your hand, and says: 'See, I'm not so bad after all, am I? Am I not just what the Doctor ordered?'

Johnny

## Introduction

The WebCafe site and e-mail list has focused on the necessary issues of diagnosis and treatment of bladder cancer, the issues of post treatment adjustment to living with cancer, the intricacies of life with all the new plumbing alterations, and all the anxieties of ongoing vigilance. We have not focused on the issues of helping people through what happens when the treatments were begun too late, have ceased to work, or when there has been an aggressive recurrence with metastases, and the threat to life is now imminent. Many people have chosen to sign off the list at that point of reorientation, to go their final journey without the help and support of the group.

This section is dedicated to our fellow warriors who are moving to a different phase of their life journey; from fighting cancer to fighting for quality of life in the time they have left.

The news often arrives or is delivered in the doctor's office, perhaps the same office where we first got the lightning bolt of our cancer diagnosis, and where we have discussed all the various treatment options, and progress, or recent lack thereof, over the preceding months or years. Hearing the news that death is imminent, that there is nothing else to be done, that there are no other treatment options, sometimes makes time seem to stand still for a bit. Things may suddenly feel cold or distant, colors and sounds may seem flat, different or far away. The very floor may not feel stable under our feet. There may be a sudden profound sense that something has changed about the safety and predictability of life. We may feel that we have not really heard right. How can this be? How can this have happened? It can be a disorganizing moment, with a lot of thoughts flooding in, or a moment of silence and clarity, or a time of numbness, where those initial thoughts and seemingly fragmented pieces of information will have to be sorted out later.

A physician on a recent episode of a popular TV show confronted his impending death. His brain cancer had advanced, and he realized he no longer wanted to go on with his treatments. He could not continue being an effective healer; he could no longer control his arms and legs and mind enough to do his job. At one point in the episode, having disconnected his own IV, he returned to his job in the emergency room. He tries to cope with every crisis as usual. But things are no longer "usual." He realizes that he can no longer keep giving to everyone around him, that he needs to let go of his life as he knew it, that he has no more to give, that he needs to let go of everything he has been doing every day, and acknowledge that he is going to die. He looked at all the activity and need around him, and realized that he needed to spend his remaining energies on his own dying journey. At what point do we let go and make that acknowledgment, and turn to our dying?

Those of us living with cancer have an idea of what may take us from this world eventually [and we are still doing everything we can to keep that eventuality in the far distant future]. Those who have moved into what LeShan calls the Dying Time, have the answer to the remaining mystery of life, they know for certain that they will die, and approximately when life will end. While this was not looked for or desired, it is nevertheless a gift. Unlike other life transitions, whether joyful [marriage, leaving for college, buying a house, etc.] or sad [divorce, other chosen separations, etc.], the exact date and time of dying is not usually up to us, however. We cannot pick the precise time or date when the end will come, but we know we now have to plan for this imminent life event.

How we die is at least as important as how we have lived. People die in the same manner or style as they have lived. Those with a spiritual style will comfortably turn to those beliefs to help them understand and make it through this final transition. Those with a more cognitive or informational style will use those tools to assist and comfort them. Those who characteristically reach out and plan and take charge will approach death with this same attitude. And those who are comforted, at peace and content to let others make significant life decisions will make this final part of their journeys the same way. There is no one right answer for everyone; many take what they need from a variety of resources and supports, and people must find their own paths on this final journey. Those who have received the news that their illness is now terminal have the unique opportunity to plan how they will leave this world.

Entering this new part of the journey, means making the major transition from the activities and regular schedule of cancer treatments, with all the hopes for a cure and healing, to the acceptance and realization that the treatments are no longer working. Another outcome is now likely. This is an intensely felt time, and also a time when how others [especially one's physicians] behave can really shape the process. This transition usually begins with a doctor's visit, where recent tests and symptoms are reviewed and the new outcome is discussed.

The relationship with one's regular medical caregiver needs to go through a transition as well, and many doctors are not comfortable continuing to work with someone they think they have failed. It is hard to look into someone's eyes and tell them you can no longer help them in the way you both had hoped. The transition to the idea of dying is necessary for both patient and physician; a new type of open and collaborative relationship needs to form, and both must trust each other to work toward the new goal of having the best life in the time remaining. If your regular doctor cannot make this transition with you, then, unfortunately, a new doctor or care team must be found. If you choose to die at home, the choice of home health care aides skilled in helping people die is at least as important as the physician and nurses you work with.

There have also been great social changes in how we experience death and dying. One hundred years ago, people were born and died at home. We moved into the era of modern medicine where doctors were part of every major physical transition or event from cradle to grave. Families were kept out of medical decisions and the treatment room. Today, patients and families want to be part of all medical decisions and have access to information to make informed decisions, at all stages of life. Some medical professionals are not comfortable with this collaborative shift, others share information and decision-making easily with patients and families.

The period of moving toward dying is a time of re-orientation of approach to daily life and plans. It is a time of many examinations: of self, one's life, one's usual priorities, and of one's relationships. It is a time for honest assessment of those tasks, experiences and achievements one has always wanted to do, balanced against what energies and possibilities remain to do them. It is a time of planning for the physical, medical, palliative, emotional, psychological, spiritual, and environmental aspects of the life remaining. It is a time of figuring out how to tell people of one's coming death, of determining what kinds of assistance may prove necessary, of finding out what to expect, and of making financial and funeral/memorial plans. Plans may also include bequests and arrangements for the rearing of children left behind. It can also be a time of possible writing and of poetry and of some burst of creativity (this sentence is awkward, but don't have the right spin just yet). It can be a time of silences, or intense communication with self and loved ones. It can be a time for intense involvement from family and caregivers, and a time of closeness and anticipated loss.

This is also the time when our specific fears of death and the process of dying must be confronted and processed. Those fears [perhaps of pain, or of dying alone] can shape or distort the journey, unless they are acknowledged and discussed. How we approach this time as either the patient or the family member/caregiver, is very much determined by both our prior experiences with death and the dying, and also by our fears of this unknown territory. Were those prior deaths sudden, as after an accident, so no goodbyes were possible? Were they lingering deaths with much rage, suffering and isolation? Were they planned, comfortable and transcendent deaths, with loved ones gathered around? When we think of prior deaths of loved ones, we may think of sadness and loss, of perhaps, the goodbyes not said; or of our memories of the lies or secrets we were told about impending family deaths, held back from us when we were children, perhaps to protect us; or the great silences which were not breached, or perhaps the helplessness of watching someone slip away, perhaps in great suffering, or in a distant comatose state. Our approach will also be tempered by the patient's stage of life, independent of exact age. Has the patient had a life of happiness, met challenges, achievements and satisfaction? Or is the patient approaching dying with the sense of having a life's load of unfinished business, unmet goals, and unhealed relationships?

People typically want and need information about the physical changes and needs of the patient. They need to know what to expect as someone is dying, need to find ways to work with doctors and other medical staff, find a hospice program and understand the role of hospice, emotional supports, psychological supports, spiritual supports, plans for the last days, find how to be with the dying person, need information about effective pain management, financial planning, how to say goodbye to a loved one, how to take care of oneself in the midst of caring for someone else, how to explain things to children, etc. The list may seem endless and overwhelming.

A recent study reported in the Journal of Clinical Oncology [2002;20: 2514-2519] , suggested that the terminal patient's own sense of his or her overall health was the best predictor of the length of time remaining. That those who reported that they were feeling well during this time lived longer than those who reported otherwise, regardless of actual clinical condition. The authors suggested that doctors respect the patient's sense of his or her own health when making treatment decisions.

The pathway each journey takes will be shaped by many things. Among these are the patient and family's psychological style and the degree of adjustment to the idea that the patient is now dying, by the spiritual beliefs, by the actual medical condition, by the palliative needs determined by that condition, by the timetable of the progression, by the level of pain, by the degree of physical supports needed, by the realities of available money and insurance, by geography, the physical environment, and available social supports.

## Considerations

## Cancer Pain

Pain is, naturally, one of the possibilities that people with cancer fear most. The most important points to remember about cancer pain are

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Cancer is usually considerably less painful than people fear it will be. An estimated 90% of cancer pain can be very adequately controlled.

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Most physicians are not well trained in pain control, which is a real art and science. Pain management specialists should be considered/consulted in cases of intractable pain.

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The probability of becoming addicted to opiate medications for pain is usually low, because the body metabolizes these drugs differently when it is in pain.

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There are important nonpharmacological approaches to pain control, including psychological approaches such as relaxation, hypnosis, imagery and acupuncture. See also WebCafe's Survival Guide: Relaxation and Visualization An excellent website on the subject of cancer related pain can be found here: [Cancer-Pain.org](http://Cancer-Pain.org)

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The people who know how to control cancer pain in most communities - doctors and nurses - work with hospice organizations, and you do not have to be dying to get their help.

### Healing vs. Curing

Michael Lerner, in his wonderful online book, "Choices in Healing" writes, "There is a fundamental distinction between healing and curing that lies at the heart of all genuinely patient-centered approaches to cancer treatment and care." 1

Although the capacity to heal physically is necessary to any successful cure, healing can also take place on deeper levels whether or not physical recovery occurs. Healing goes beyond curing and may take place when curing is not at issue or has proved impossible.

Shamans in traditional systems of medicine around the world found that if they sought first to safeguard the soul, rather than the body, the body tended to respond better. We can create the conditions of growth, or the conditions of healing, by nourishing, nurturing, and tending within us that which we value and wish to help grow.

As Michael Lerner wisely says,

There are many different kinds of conditions for healing: physical conditions such as diet, exercise, relaxation, clean air, good water, and time spent in nature; social conditions for healing, such as work that is meaningful, friends that you care about, and a loving family; and emotional, mental, and spiritual conditions.

It is useful to differentiate between universal, common, and unique conditions of healing. For example, inner peace is an almost universal condition of healing. A deep experience of love is also almost universally healing. By contrast, anger or hate is a less common condition of healing.

There are many common conditions of healing. Many of us are healed by attention and care from our friends and family, by finding work that we deeply enjoy, by laughter, by music that moves us, by great art. But some of the most important conditions of healing are the unique conditions of healing. William Blake said that any man who would help another must do so in "minute particulars." He was talking about helping another person by assisting him in the minute particulars--the

unique way--that is most meaningful to him.1

How can you participate in your own healing process?

If you could do (or be) absolutely anything in the world that you wanted during the rest of your life, what would you truly want to do (or be)?

This is the question that the pioneering psychotherapist Larry LeShan asks in *Cancer as a Turning Point*. "What is the unique purpose of your life, the unique song that you were put on earth to sing?," LeShan often asks. Some people know the answer instantly. Others discover it after a time of living with the question. Still others have to work long and hard for the answer. It is a great question, and a great guide on the path to healing, for if you discover the answer, LeShan's next question is: "Under the present circumstances, what would be the first steps you need to take to begin moving toward living this life?" Embarking on this path can bring great healing.

Questions to ask yourself

What do you find has become important to you, and what that previously seemed important do you discover you are ready to let go?

A cancer diagnosis can thus lead to a profound transformation of values.

What do I want to hold on to? What do I choose to let go of? and, more painfully, What that I care about am I able to hold onto? What that I care about do I need to let go of?

Within the circumstances of the cancer diagnosis, what would I optimally choose in every area of my current life:

What kind of mainstream and complementary therapies should I undertake?

What kind of relationships?

What kind of work?

What forms of relaxation or meditation?

What forms of exercise or recreation?

What kind of diet?

What rhythms of daily life?

What studies or activities?

What kinds of support and response do I want from family and friends?

What are some of the unique things--very personal to me--that would give me special delight and pleasure each day?

This is an exercise in making yourself aware of what feels authentic to you. It is surprising how many people with cancer

have never given much thought to what they would actually like. Discovering the little (and big) activities that give you special pleasure is both fulfilling and healing. One way of exploring this question is to divide your life into different areas of inquiry.

What are the specific physical, emotional, mental, and spiritual conditions that could support healing for you?<sup>1</sup>

See also, here at WebCafe: [Living With Cancer](#)

### On Retaining Hope

Some practicing oncologists consciously uses hope as a treatment tool. In ancient times, when medical technologies were more limited, the physician's appreciation of the therapeutic uses of hope was much more refined than it is today.

Even if one has no difficulty accepting the prospect of death, human beings need hope. To hope for a miracle is something we are capable of doing until the very end. There is no such thing as false hope.

We can certainly hope for a peaceful, pain-free death with dignity. Or the hope that death will reunite us with our loved ones who have passed. We can consciously aim and prepare for a death that doesn't impose too much on family members.

Michael Lerner wisely writes, "If a patient with a serious cancer hopes to be the one person in a hundred or in a thousand to overcome the cancer, it is not correct for the physician to propose that this is a false hope. It may be a slender hope, but that slender hope may still provide light as the cancer patient goes through the inner work of learning to live under new and difficult circumstances." <sup>1</sup>

### Healing and Spirituality

The healing process not only has a tendency to bring people closer to an appreciation of who they uniquely are and what their unique purpose is in this world. It also brings them closer to God, spirit, inner peace, connectedness, or whatever we choose to call that which is great and mysterious.

A real possibility exists that life in some form continues after death, and intriguing scientific literature supports the spiritual writings and the experience of many people who have had remarkable near-death experiences.

Many cancer patients cannot relate to the concept of a spiritual reality, but that they can relate deeply to nature, mankind, friends and family, art and music, or science and reason. At the heart of all great spiritual traditions is a clear recognition that all forms of dedication to what is worthy in human experience are ultimately spiritual. In this sense, the spiritual quest is the search for the life path on which we explore the highest potential each of us was given in this life. The spiritual quest can be undertaken as completely by an atheist or agnostic, or a worshiper of nature, family, mankind, art, music, or science, as by a believer in an explicitly religious or spiritual tradition.

For the cancer patient engaged in an intense search for healing and recovery, these considerations are not abstract theological issues. Like a soldier in a trench under bombardment who suddenly discovers prayer, or a prisoner in a forgotten cell awaiting execution, the person with cancer often has urgent reason to reflect on ultimate questions: the meaning of his life; what has true value for him; what happens when he dies; how he should live from now on. If he immerses himself in books about alternative cancer therapies, he will read about many spiritual approaches to cancer. But he may feel blocked and frustrated because he does not consider himself a religious or spiritual person, or because the kinds of spiritual experiences that the books describe seem foreign to him. For such a person, the fundamental distinctions between spirit, spirituality, and religion may never have been made clear. Without these distinctions, he may not see -- or give himself permission to explore -- the path to the realm of spirit that for him, as a unique human being, would be authentic, life-enhancing, and perhaps lifesaving.

We need to recognize that patience, grace, prayer, meditation, hope, forgiveness and fellowship are as important to many of our health initiatives as medication, hospitalization, incarceration or surgery. The spiritual elements of experience help us to rise above the matters at hand such that in the face of suffering we can find purpose, meaning and hope.<sup>1</sup>

## Dying Well

A good death might be described mentally and emotionally as one in which as much movement toward wisdom and healing as possible takes place for the one who is dying and for those who love him. A good death might be described physically as one in which pain and discomfort do not exceed what can be decently endured.

It is very useful to recognize the distinction between our fear of dying and our fear of death. This distinction then helps us focus first on specific fears we have about the dying process. Most people are [unnecessarily] more afraid of being caught in interminable suffering during the dying process than they are of death itself.

Some people are afraid that making practical estate arrangements or other arrangements for dying means that they have given up the fight for life, but taking care of the things you want to take care of actually releases energy for the fight for life.

A very important part of preparing for death is giving some thought to helping loved ones with the grieving process. This can be tremendously important, because incomplete grieving often injures the rest of the life of a mate, a parent, or a child. In the process of a good death, a great deal of the mutual grieving of patient and loved ones takes place while the patient is still alive and participating. If this process takes place as consciously and fully as possible, the death can sometimes become, strangely, a great healing for all involved.



Our culture's attitude--in which death is a highly toxic subject and seen as a failure, either of the doctor or of the patient--is not only new historically but at odds with that of other cultures. In many cultures, dying is surrounded by rituals in which everyone participates. For many centuries in the West, this was also so. Death was often seen as the culmination of a life, and people gave great thought to how they might die well.

In the face of sincere contemplation and prayer, the toxicity with which our culture has surrounded death often begins to dissolve.

All of this leads to exploration of what benefits we and those we love may receive from death and dying. We know all too well what the pain and losses will be. We know all too well that some people die with great difficulty and suffering, while others die peacefully. The question is whether or not we can find anything of value, in the midst of pain and loss, from death. The answer of some wise people over the centuries, and of many in our time, is that it is possible to find deeply meaningful and important experiences in the midst of facing death.<sup>1</sup>

## References

1. Choices in Healing, Michael Lerner. M.D.

Chapter One: On Never Giving Up Hope

Chapter Two: Healing and Curing: The Starting Point for Informed Choice Chapter Nine: Spiritual Approaches to Dying

Chapter Twentyfive: Controlling Pain

Chapter Twentysix: On Living and Dying

<http://www.commonweal.org/pubs/choices-healing.html>

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