



Circle of Life Hospice

Hospice Wisdom

(a collection of parables and pearls)



by Deb Girard RN, Administrator
Circle of Life Hospice

Introduction

What is death? The answer to this question is best left answered by those who have experienced the death of a loved one. It is the dying who teach us how to live. The parables and pearls of wisdom found inside this book are their messages and wisdom. Some of what I've been taught in my thirty years of being with the dying is that;

Death is part of the unending cycle of nature, part of the immensity of creation, rather than a mere abyss at the end of life.

Death is to be understood as an integral part of existence, rather than shunned as a dreaded enemy.

Death is a great teacher, offering striking insights into life, rather than a merciless threat to all we hold dear.

Death is to be faced consciously, even embraced, rather than avoided at all costs.

Death is to be discussed and prepared for openly with those we love, rather than a social taboo to be hushed up or hidden away.

Death, and all that surrounds it, is a precious interval for both the dying and the living. It is a mystery that deserves, and rewards, profound respect.

People who have lived fully are not usually afraid to die. Death is, after all, the natural end of life. We must all die. Perhaps the most important task for each of us is to help each other accept death when it can, or should, no longer be avoided, and to help ease the suffering of those who still live.



A Rose by any other Name

I received an email last week from my aunt regarding a message from her close friend whose mother had entered a hospice program and here are her initial comments; “I can't say I'm enchanted with hospice right now. So far I've had failure to return calls, multiple switched appointments, no follow through until I make waves or do things myself, and I haven't called on them for comfort, just the nuts and bolts stuff.” During the same time period I spoke with my step-mother who said that hospice was wonderful helping the family with her own mother's death. It saddens me to know that there can be such a difference in the provision of hospice care. During the next series of articles I hope to help you understand what you can expect and should receive from a hospice provider to make sure that your experience will be a positive one.

Hospice: A Non-Medical Model

Shortly before the founder of the modern day hospice movement, Dame Cicely Saunders died, she stated her disappointment in the direction the hospice movement had taken. She expressed her sense of failure that the sacred aspects of death and dying had been replaced by a medical model of “death care.” At a recent conference I shared the model that we have in place at Circle of Life Hospice. The most common response was “amazement” at the reality that the vision of hospice as it was intended by our founders survived right here in Reno Nevada. I am proud of the work our team does and for our vision that creates a holistic model of caring for the dying. Our commitment to our community will never vary from a model that honors that which is sacred in each of us.



Breaking Through

More and more people are coming to the conclusion that we have gone seriously astray in our approach to dying. For many people this break through begins with the shock of finding themselves almost completely unprepared when they are faced either with their own or with the death of someone they love. Even before hospice is a consideration, the professionals at Circle of Life Hospice are there to answer questions related to discussions with doctors, friends and family. They can help you cope with the storm of turbulent and powerful emotions that rise up within. If you find yourself standing at an ever widening abyss between you and those closest to you, call hospice. We can help.

Living with Gratitude

Joni Mitchell's lyrics "You don't know what you've got till it's gone," came into my thoughts today as I was driving to work. The majority of my life has involved working with the dying and their families. Through this work, I learned the lesson of appreciation and gratitude for the people and experiences in my life. My greatest hope when it's my dying time is to know with certainty that I lived with gratitude and expressed this frequently to my family, my friends, my co-workers and even the "strangers" that come into our lives each day. June Carter Cash said, "There are no strangers, they are just friends you haven't met yet!" It has been my experience that some of the most grateful people, the most life affirming, are those who are aware of their dying. Hospice can help the dying and their families with this place of gratitude when it seems out of reach.



Accepting the Unexpected

Recently during one of my less graceful moments I fell while attempting to get up and into my husband's new truck. This resulted in a wrist that fractured in several places. In an instant all the inconveniences this moment would cause flashed before me. When my husband asked if there was anything he could do I answered, "Yes, turn back time." I think this is a fairly common feeling when presented with a life altering condition. For those whose life altering event involves a situation that involves the initiation of hospice care and services, we can't turn back time, but we can help you set goals that assist you in living in the moment. At times patients feel guilty that a life style choice or decision may have precipitated the end of life event. What's important however is to reconcile to our present circumstances to enjoy each moment of every day.

Spring's promise

Watching the winter move into spring is always such a joyous time for me. Watching the trees budding, flowers bursting forth and the chill of winter leaving us, I am reminded of the circle of life in a very special way. I recall an elderly lady who faced her death believing that the only life she would ever experience was the one that was reaching an end on this earth. One day she told her hospice nurse that she had changed her mind. She said that she had been watching the same tree from the bed that she was no longer able to leave for the past several years and felt confident that "if a tree can die and come to life again so can I!" For all that have lost a loved one in the past year, hold the promise of nature's renewal close to your heart. Let yourself touch the place inside that holds the memories of springtime's that have passed and the new life that springs forth from within.



What happens when a patient decides to stop eating and drinking

Helen Nearing and her husband Scott lived into their late 90's. Scott died two weeks shy of his 100th birthday. A month or so before he died he said, "I think I won't eat anymore." At this point Scott took only juices. As he got weaker he said, "I think I'll go on water, nothing more." For ten days he had only water. Although bedridden and low on strength, he spoke with his wife daily. One night Helen told him "It's alright Scott, go right along, you've lived a good life and are finished with things here." In a soft voice with no quiver or pain Scott said, "All right". His breathing became slower and slower until there was no movement and he was gone out of his body as easily as a leaf drops from the tree in autumn. This is one of the finest descriptions of the process that I've come across and is consistent with my own observations.

What are some of the benefits of NOT using artificial hydration or feeding tubes in a dying patient?

The benefits are as follows: less fluid in the lungs and therefore, less congestion, making breathing easier; less pressure around tumors and therefore less pain; less urination and, therefore, less need to move the patients for changing the bed and less risk of bedsores; a natural release of pain-relieving chemicals as the body dehydrates. Some have even described it as "mild euphoria." This state that comes with no food intake also suppresses appetite and causes a sense of well-being. Lastly, less fluid retained in the patient's hands, feet, and the whole body in general. Forcing liquids into a person whose body is shutting down can create an uncomfortable buildup of fluid.



Overcoming our fears

Last week I had the opportunity to sleep under the stars with my five year old granddaughter visiting from the Midwest. Living in the city as she does, her familiarity with nature is limited. It took her three nights to work up the courage to crawl into my “mummy” sleeping bag where she proudly pronounced herself a cocoon that upon waking would be a butterfly. It was when she looked up at the sky fading to twilight that she said, “Look Grandma!” “Night butterflies!” These butterflies were of course, bats. Representing one of my fears as they did, my first inclination was to run. Had I gone inside with my granddaughter I would have helped her create a fear of not only bats, but of nature itself. Instead, the nighttime butterflies became BATS-Butterflies at Twilight Soaring transforming my fear. Whatever fears you may have about death and the dying process, hospice is there to help you transform them.

Hopelessness Pain: Death as Healer

R.M. Rilke said, “There is only this mystery that one can contain death, the whole of it and hold it to one's heart gently and not refuse to still go on living.” How is it that one set of circumstances in life can turn one person to hope and another to hopelessness? If forgiveness pain is the common cold of spiritual pains, than hopelessness pain is a terminal illness for the human spirit. Hopelessness pain means that one has lost all reason for living when, in fact, there is life left to be lived! Through the assistance of the hospice team both patients and those who care for them can discover what is “life-giving.” Words at times are inadequate when addressing hopelessness pain. Hospice recognizes simple gestures such as gentle touch, soothing environments and soft music can soothe and help us feel guidance from outside ourselves that remains unconditionally present.



Meaning Pain

Meaningfulness makes us well; meaninglessness makes us sick. There is ultimately only one spiritual question and that is, who am I? The answer to this question is rarely found except in the dark night of the soul. Terminal illness has power to silence us and create a crisis of meaning. Our search for meaning is what gives us life and can be a powerful agent of transformation into something better. The questions that often arise and can be discussed with the members of the hospice team are; how do I make sense of the illness and death? Is there something beyond the familiar world that I know and love? There is always a way into and out of spiritual pain and hospice can assist you in making your search for meaning a gentler journey.

Forgiveness Pain:

Many spiritual teachers say that we are forgiven to the extent that we are able to forgive. For many years I have taught team members that I have worked with that using a “find it, fix it, forget it and move on” approach allows us to lead a simple life, heal our hearts and allows us to continue to create healing spaces for others. I have since added “forgive it” to this formula as I have found that unless I am able to forgive I am seldom able to forget. Hospice team members are always open to the unburdening of the soul that is necessary to achieve a peaceful death. The dying teach us that at the end of each day, search your hearts to find what past events are living there that you can forgive.

Carl Jung said” to cherish such secrets is a spiritual misdemeanor for which nature will visit us with sickness”.



Whither shall I go From Thy Spirit

When it comes to dying, I'm an amateur. I haven't done it. My life has been about caring for they dying and I've learned so much from them. Yet, I think when it is my time to die I will still be an amateur. I will need comfort and reassurance, someone to help me with my fears and to listen as I unburden my soul as all that has happened in my life comes up before me. I know that I will be thinking about my family and my friends, and the love I have given and received. I will think about all the beauty I have tasted knowing that no matter how old I will lament leaving this world. My comfort and my consolation are in knowing that hospice will be there to guide me through just as I have guided so many others. Call hospice..

In the Blink of an Eye

Henry Van Dyke said, "Are you willing to own, that probably the only good reason for your existence is not what you are going to get out of life, but what you are going to give to life." When faced with the challenge of a life limiting illness sowing seeds of happiness, giving to life becomes a daily decision. How will I live this day? How do I manage to get out of bed each morning and keep going? Hospice philosophy talks about living each day. Those of us who walk the path with those who are dying understand that in the blink of an eye we can be gone. Healthy people die tragically and have their lives interrupted sooner than their time would suggest. Hospice can help you find what may seem unattainable...joy and a reason to be.



The Gifts of Caregiving

As we look around us in the world today we are filled with images of natural disaster, greed, increased burdens on families trying to find their way through life. If we look into the private rooms of care giving families, we will find the true nature of things as they are, beneath the veneer of the world around us. There you will find great kindness and devotion, a trust of life that surpasses doubt or pain. There you will find the highest expression of who we are. If we close our hearts to suffering we cannot open them to love. Humanity can evolve from it's recklessness into an age of caring exemplified by the modern heroes who fulfill the age-old mandate: to give.

Being Remembered

Long after we have left our physical bodies the memories we have helped create live on. Today I looked at a picture of my father-in-law holding his 18 month old granddaughter who, during his last visit looked up at the six foot four, elderly man and said "Poppy." Why she decided to call him this without any prompting is anyone's guess but from this point forward he will be "Poppy" to this little girl. Hospice helps preserve these special memories and creates memory tools that will live on long after the last chapter of the story of your life is complete. Long before the need for hospice arises have you thought about how you want to be remembered? Have you started the process of a life review? It is never too early to begin your legacy of remembrance.



For everything, there is a season

This morning I noticed how the leaves on the maple tree had turned to gold. I watched as the small creatures that feed on the cracked corn in my yard were preparing for the long winter ahead. This reminded me that many people I meet live each day getting ready for that time when all of their dreams of retirement begin to come true. The saddest of these moments is when I hear “We worked all of our lives for and now all of that has changed. Instead of a long life together it will be just a few months.” It is important that we pay attention to the practicality that nature teaches us, but it is just as important that we don't postpone living our lives. Hospice teaches me that life is meant to be lived so enjoy yourself on the way to your dreams. My motto has always been “plan as though you will live forever, but live as though you will die tomorrow.”

Regarding new relationships

Mother Teresa wrote, “I have found the paradox that if I love until it hurts, then there is no hurt, only more love.” After the loss of your life partner the thought of entering a new relationship can create a mixture of emotions. Fear of loss or guilt that you have opened yourself to loving again may be part of this experience. This phrase by Mother Teresa, captures the essence of love and loss. What better statement can be made regarding the relationship that existed in physical reality that lives on in your heart? What greater complement can be paid then in entering new relationships when your grief has lessened and you are ready to risk again. That is what makes life so amazing, that we can live, face loss, love and love again.



How are you within ?

One of the domains that we measure in our patient satisfaction survey relates to spiritual issues. The question that we pose to our patients and families is , “How are you within yourself?” This question allows us to ponder on our relationships with our friends, families, and a power greater than ourselves. We can gain a new perspective on how we are using our energy and time. If the answer we get from this simple question is not in alignment with our values and personal goals we can make the needed changes and at the end of our life we can say “Well done.” Hospice teaches that it is never too late to make sure that our inner life is in balance with our outer experience. Hospice is an inward journey of the human spirit and our staff is always present to support patients and families in this process.

The Blessing Box

With the year coming to a close it seems somehow fitting to thank all of you in our community who have supported our efforts to improve the care of the dying through a heart centered holistic approach. We also want to say to all of you who entrusted us with the care of your loved ones that our lives have been touched and changed forever in ways that carry tremendous blessings. Each team member at the Circle received a “blessing box” as a gift from my husband and me to thank them for the work they do each day and as a reminder of the blessings life holds. Mother Theresa said “I have found that if I love until it hurts, then there is no hurt, only more love.” This is one of the great truths of hospice work. May they bring you comfort and peace at this time of the year.



Addressing Spiritual Pain

Sometimes the question asked is “What is the difference between pain and suffering?” At times the questions are stated with a sense of innocence and child like curiosity when posed as “What do you think happens when we die?” or “How do I find that peace that exists beyond human understanding?” I think the best answer to the first questions is “suffering is what remains when you take away the physical pain.” Richard Groves in his wonderful book, *“The American Book of the Dying, Lessons in Healing Spiritual Pain,”* addresses these questions and more. The next four articles will address the four spiritual pain categories and discuss how hospice can help you and your family transform this pain and discover your own spirit within.

Carl Jung once said, “The American people are the only members of civilization that have managed to create the illusion that death is optional.” I was reminded of this when reading comments in a local paper that posed a “man on the street question” that asked “if you could, would you want to know how you were going to die or when?” For those who responded “how” their plan would be to avoid that activity! When we fear the inevitability of death we limit our possibilities, take fewer risks and live lives that are not quite as full as they could be. My advice to all is to move toward what you fear about the dying process. Take classes, read books and talk to your local hospice community as this will truly set you free and allow you to live fully human and fully alive.



Just Around the Corner

Henry Scott Holland (1847-1918) Professor of Divinity at Oxford University wrote, "Death is nothing at all. It does not count. Why should I be out of mind because I am out of sight? I am waiting for you, for an interval, somewhere very near, just around the corner. All is well. Nothing is hurt; nothing is lost. One brief moment and all will be as it was before. How we shall laugh at the trouble of parting when we meet again!" Whether newly bereaved or longing for the companionship of a loved one long gone, these words can open our hearts to the possibilities that whatever we were to each other we are still. Hospice provides continuity by offering bereavement support for a year following the loss of a loved one, to hold a hand, wipe away a tear, reminisce and think of their loved one as "just around the corner."

The Christmas Cactus

Every year at this time the plant in my office window bursts into bloom. The regularity of it's schedule reminds me that every living thing on earth has a natural rhythm and pattern associated with it. This is true when it comes to the dying process as well. Though every illness has different symptoms associated with it, the actual dying process has a rhythm and pattern that hospice workers teach to patients and their loved ones. Many people say its not death that bothers me but the process that will take me there. The dying process is as natural as the birthing process and can be as beautiful as the blossoming of the Christmas cactus that sits in my window. To everything there is a season. May the journey of the holiday season that is just around the corner be a peaceful loving time for you and those you love.



The Legend of the Dragon Fly

The sense that our loved ones are with us always gives us comfort and peace. Presenting the idea of continuance to children can be difficult but consider the following story. Dragon fly eggs are laid underwater-when they hatch, they emerge from the water to dry their wings and begin life. Two dragonflies made a pact that when one of them hatched, she would come back and tell the other what the world was like. When the day came for her to hatch and after experiencing the beauties of the world the pact was remembered. Upon returning to the surface of the water, she realized she could see everything below but couldn't re-enter the water. This story is about believing that our loved ones too, are in another place and watching over us from above.

To Die Well....

The term “good death” is often used to describe what hospice can do to help you achieve this end. But what exactly does that mean? Marcus Aurelius said, “Spend your brief moment according to nature's laws, and serenely greet the journey's end as an olive falls when it is ripe, blessing the branch that bore it, and giving thanks to the tree that gave it life.” This was said by a man living in a time when death was looked steadfastly in the face and embraced. Now more that ever to achieve a “good death” we need to listen to the wisdom of that remarkable tradition and its priceless legacy.



What do you grow in your garden?

I can't think of any other place than a garden to better symbolize the circle of life. The process of seed to flower to seed again is displayed daily this time of year. As I pondered how like gardens we are, the question of what grows in each of us formed in my mind. How bright are our blossoms? How many weeds are growing there? What needs thinning from our lives or pruning? People who come into hospice are sometimes surprised at what our Spiritual Care Team does. Their role is to help you tend your garden. Sometimes it's through gathering a harvest of memories to soothe the souls and calm the hearts of those who will remain tending their own garden long after you've gone. It is never too early to begin the process of weeding, thinning and harvesting your garden and hospice can provide the fertile soil for you to begin.

Knowing what to do.....

One day a mother watched her four year old son who was sitting on the lap of the elderly gentleman next door. The man's wife had died recently and she noticed her little boy sitting quietly stroking the old man's hand. Suddenly the elderly neighbor smiled at the small boy. Later the boy's mother asked what he had done that made the old man smile. He responded, "Nothing, I just helped him cry." Often people feel hesitant to call or interact with someone who has experienced a loss. The little boy reminds us that often all we need to do is "stay close and do nothing." Offering to do errands, make phone calls and assist with the care of small children if needed are all helpful but never forget that those acts of kindness that seem the least significant are the greatest gifts of all



To Ease Our Burdens

Recently while walking in the wilderness areas around our home my husband came upon a wild horse. What amazed him about the experience is that the horse approached him and for a brief moment allowed my husband to touch him. As he described the event to me I couldn't help but reflect on a story I heard once about an Indian Medicine man who was walking across the plains to visit the Arapaho Nation. He was approached by a Black Stallion who said, "I am from the Void where Answer lives. Ride on my back and know the power of entering the Darkness and finding the Light." Anyone who has experienced the heavy burden of loss of someone loved understands this experience. If you are entering the Darkness or moving through it know that the light is there waiting for you.

Give Sorrow Words"

It was Shakespeare who wrote the above encouraging us to express what we are honestly feeling in the moment. The holidays are a time when all types of emotions regarding our loved ones who have died will surface, no matter how distant or fresh the experience. Perhaps you already have found a way to deal with these feelings, such as calling family members or friends. Maybe you have prepared a ritual that includes your loved one such as a special ornament that is placed on the tree in their memory. I know of one family who writes letters that are placed in "Daddy's" stocking and read the first thing each Christmas morning. Our loved one's may be gone but never forgotten. If you would like support with managing your grief this holiday season, don't hesitate to Call Circle of Life Hospice Bereavement Department at 824-3883..



“Home” for the Holidays

The meaning of home and holidays of years past can create echoes of loneliness whether the grief experienced is new or a distant memory. In either case the holiday season can reopen old wounds and deepen the losses that are more recent. In the next series of articles I will offer suggestions for moving through the dilemma of feeling pressure to get into the holiday spirit or taking the time to grieve. Whatever the season it is important for the bereaved to find ways to take care of themselves. A very important element is to plan ahead. Know where you would want to scale back and know that it is perfectly appropriate to do so. Redefining your holiday expectations can help you transition into a new year where you can begin new traditions and let others go. The direct line for our Bereavement department is 824-3887. Our program is open to the community so don't hesitate to call if you need some extra support.

Women as Caregivers

Women are the traditional handmaidens to birth and death: it is most often a female face that a dying person will see, and a needy loved one. More than 80% of unpaid caregivers are women. Two-thirds of all caregivers are married and one half of them work. If you identify yourself as a caregiver make sure that you have accessed all community programs available to you, including hospice if the point in the illness has been reached when aggressive measures would no longer be desirable. Also access caregiver support groups in your area. You need to know that you are not alone.



How can I be sure that my Advanced Directives will be honored?

In addition to preparing your advanced directives, you need to share the information contained within with loved ones, health care providers and friends. Copies of the directive should be provided to each physician who is currently providing care as well as to family members and the designated power of attorney for health care. The need for such directives has been made very clear in the past with the case of Terry Shaivo. How much easier would her life and death been for her family if clear directives would have been in place.





Deb Girard, RN, Administrator
Circle of Life Hospice