From the Editor:
The first issue of HV News received great praise from the hospice volunteer community. Those of us who serve the dying through hospice know how important it is to have a forum like HV News to share our stories and perspectives.

The interview with volunteer Barb McClarty and insights from Volunteer Coordinator Susan Barber were very inspiring to our readers.

PLEASE REMEMBER:
HV News is designed to be read online. ALL of the bright blue underlined text represents hyper-links that you can click on to rapidly move around the document. If you wish to print the document, we recommend that you return to the HV News Archive and select the PDF version of this issue HV News.

In This Issue:
Volunteer Interview
Vanda Marlow, our featured volunteer this month, is an excellent example of how those who learn to serve others as hospice volunteers become important community assets. After Vanda completed her term of service with a hospice in San Francisco, she found herself using her skills of mindfulness and compassion to independently serve friends who were dying. I think you will find Vanda’s intimate stories of caring for the dying in and out of hospice very touching and informative.

When did you start as a hospice volunteer? I began volunteering at the Zen Hospice Project (ZHP) in San Francisco in 1997.

How many years have you been a hospice volunteer and what organizations have you volunteered with? I volunteered at ZHP for several years, spending time both at their wonderful Guest House on Page Street - an intimate 5 bed residential facility, and also the special unit they staff with volunteers at Laguna Honda Hospital - one of the largest public hospitals in the country.

What made you decide to become a hospice volunteer? It was an unusual departure for me, to be honest. I have had no direct experience of loved ones dying, which is what often brings people to hospice work. When I was 37 I took a traveling sabbatical from my business life in London to do some soul searching and gain perspective on my life which had hitherto been a very self-directed, externally focused one. In the course of those travels I did some intensive psycho-therapeutic work, during which, one day I had a distinct but quiet realization that death was not a frightening thing, and that I should go be with people who were dying. The very next stop on my travels was San Francisco, where I met someone who was a volunteer at Zen Hospice. I’ve learned to pay attention to these synchronicities, so I dropped in on the Guest House, and ended up moving to the Bay Area permanently! 'Be careful what you wish for' as they say!

Volunteer Interview Con’t

Hospice In The News
Advance Directives  Cultural  Home Funerals  Rituals in Dying
Alternative Therapies  Death & Dying  Nursing  Spirituality
Awards  EOL Care  Palliative Care  Training
Bereavement  Ethics  Pet Hospice  Volunteerism
Business  Euthanasia  Philosophy & Death
Children  Families  Prison Hospice
Communications  Healthcare  Psychology
Volunteer Coordinator's Perspective

Victoria Wild is Director of Volunteer Services at Hospice of the Valley, which has been serving the community in San Jose, CA for over 25 years. She guides over 60 volunteers in their care of the dying. In this issue Victoria reflects on the challenges and the rewards of managing a volunteer force.

[The Privilege of Serving]

I have been coordinating the volunteers at Hospice of the Valley for over ten years. Prior to becoming a volunteer coordinator I served as a hospice volunteer for 18 months. I feel extremely privileged to be working at a job I adore. I wake up each morning excited to go to work. The involvement I have with patients, families, our staff and the amazing volunteers feeds my soul and helps keep my world in perspective. While not the easiest of jobs, it renews me daily to observe the relationships that develop between our staff (paid and unpaid) and the families we serve, as well as to witness the results of the comfort and support that we provide.

[Meeting Hospice]

My introduction to hospice care was through the death of my father in 1992. He died in South Africa and was cared for by an amazing team of hospice workers who I witnessed not only supporting my father, but the rest of our family as well. I lived in Virginia at the time and the physical distance between me and my father was a source of distress. My mother is the type that when you call will state "everything's fine" even though at that time my father was in the final stages of pancreatic cancer and she was overwhelmed with his care. Being able to communicate with the hospice personnel enabled me to gain a more accurate perspective on the situation, and gauge the best time for me to make the journey there. Even though I was thousands of miles away, their support of me was incredible.

[Choosing a Career Path as a Coordinator of Volunteers]

When I reached a point in my life where I felt I had time to spare, hospice was my obvious choice as a place to volunteer. I was living in California by this time and attended the volunteer training at Hospice of the Valley. My role as a volunteer was extremely rewarding and at the time I could not think of anything else I would rather be doing. During my second year of service, the Coordinator of Volunteers resigned and I was asked if I would like to consider applying for the position. I loved the "freedom" my volunteer role provided and it took some serious thought to work out if I was ready to become employed with all the related constraints. Having worked in the market research field for ten years and then training as an Interior Designer, coordinating volunteers could not have been further off my career goal path! However, I am delighted that this opportunity presented itself and that I decided to follow this path. I could not imagine myself doing anything else or finding a more rewarding career.

[The Circle of Nurturing]

The challenges faced by the coordinator of volunteers are many, but from my perspective they pale in comparison to the wonderful work we accomplish as a team. Working closely with those willing to donate their time to the dying is an amazing and uplifting experience. I am constantly inspired by the number of volunteers willing to meet all the requirements of becoming a hospice volunteer. At Hospice of the Valley we ask for quite an commitment. Supporting the needs of our volunteers requires constant effort. It is heartening to observe that as we nurture the volunteers directly involved with our patients and families, they in turn, by the nature of their accomplishments, support us in our role.

On a daily basis I may receive a call from any one of our 70 hospice families or any one of our 30 Transitions clients requesting volunteer support. (Transitions is a volunteer-driven program offered to those facing a life limiting illness, with a prognosis of one year or less who do not yet meet the criteria to be admitted for hospice care.) I am continually in touch with our Direct Patient Care volunteers to fill these assignments. I also receive "check-in" calls from those volunteers currently on a regular assignment. Supporting our team of Direct Patient Care volunteers is a crucial and vital part of my role. This is done informally through one-on-one contact but also more formally at volunteer support meetings that take place twice a month.

[Volunteer Recognition]
Beyond the support provided I need to make sure these volunteers are appreciated and recognized. This can be a daunting task for the coordinator. The very nature of the kind of person who is involved in hospice volunteering isn’t generally someone who wants much of a fuss made of them. I find personal notes as well as an understanding and acknowledgement of who they are goes a long way in bolstering the relationship.

I regularly nominate one of our volunteers for an award. Even though only one volunteer is being recognized, the entire volunteer team perceives it as group acknowledgement. We organize several appreciation events throughout the year that do not identify one volunteer’s contribution over another but thanks them as a group. This is also a time when the rest of the hospice team can acknowledge the support they receive from the volunteers. We have our annual “birthday party” for all our volunteers at the end of the month. The volunteers love being together in a social setting as they spend so much of the other time they are together discussing their roles as hospice volunteers.

[Training New Volunteers]

I thoroughly enjoyed reading Susan Barber’s article in the first issue of Hospice Volunteer News, as I could directly relate to her love of training prospective volunteers. Accompanying new volunteers through their process allows us to create a strong bond. As the Coordinator of Volunteers my interactions with the new volunteers during recruitment and training permits me to get a reasonably clear picture of who they are and how they can best assist in the care of our patients and families as well as themselves. Post training we mentor our new volunteers with someone who has been volunteering for a time to help them not only out in the home for their first few visits, but also with all the documentation requirements.

While most volunteers come to us with an underlying motivation to serve as a hospice volunteer, I believe it is important to convey to them in the training the broad spectrum of potential benefits in donating their time in the service of others. This allows us to communicate what might not be obvious and increases the likelihood that they will have a meaningful experience and choose to serve beyond their initial commitment.

[Integrating New Volunteers into the Hospice Team]

Integrating new volunteers into the program is challenging. It is imperative that they feel connected with the agency through the Coordinator of Volunteers and that they gel with the rest of the direct patient care volunteers and with the rest of the hospice team. A team concept is vital in every aspect of hospice work. I never want a volunteer to feel they are out there alone, but have a clear understanding that the rest of the team is only a phone call a way. Volunteers at Hospice of the Valley are seen as unpaid staff. They are required to fulfill personnel file requirements that mirror those of our paid staff. They are privy to patient and other sensitive information necessary for them to fulfill their role successfully.

At Hospice of the Valley any member of the hospice team can make a volunteer referral, including another volunteer. I try to maintain very clear lines of communication between the families we serve, their needs and our ability to meet those needs. I encourage any team member in a patient’s home not to say no to an assignment, however inappropriate it may sound to them, but rather to say to the family that we will see what we can do. Until I have asked each and every one of our volunteers if they are willing to do whatever it is that the family is requesting, and when each one has said no, then it is time to say no to the family. I may not want to clean the windows of the patient’s bedroom, but I may have a volunteer more than willing to do so. Collaboration and communication within the team is crucial if we are to adequately meet the needs of the families we serve.

[The Many Roles of the Volunteer Coordinator]

The Coordinator of Volunteers has quite an undertaking, from recruiting and retaining volunteers, coordinating volunteer assignments, collaborating with the rest of the team and representing the volunteers within the agency while at all times making sure that policy and procedures are followed. In my role as Coordinator of Volunteers at Hospice of the Valley I am also responsible for our office volunteers, the training and personnel file requirements of our bereavement volunteers and interns, as well as coordinating the needs of our Transitions clients. I also assist with our community outreach and fund raising efforts. Time management is difficult, but prioritizing my assignments is not. It is always patient and family first.

In the San Francisco Bay Area the volunteer coordinators meet quarterly to support each other in any way they can. Having no one within your agency who is dealing with the same issues, this external support proves to be very beneficial.
HVA Officer Elections

Calling all candidates!!

Are you interested in being one of the candidates for elected office within HVA? HVA is a national organization and will be governed by officers elected by the HVA membership. If you are interested, please submit a photograph, brief biography and a statement as to why you are running for the office you wish to be elected to. Your info will be placed on the HVA website in the Members Only Area so all members can get to know you.

Elections will be held during the last quarter of 2006. The newly elected officers will take office on January 1, 2007. Please contact Greg Schneider toll-free at (866) 489-HEAL (4325) if you have questions.

Volunteer Interview Con’t

What are some of the ways you have served others as a hospice volunteer? At the Guest House and at Laguna Honda, I have simply been a companion - to those in the bed, and to their families and friends. I have learned to follow my instincts and do what feels most honest and naturally full of heart - from the mundane tasks of laundry through to the sacred task of washing a newly dead body. So many favorite and very human moments - learning to make malted milkshakes, just the way a resident likes them, reading favorite passages from his well worn bible to an elderly man, watching television with the sound turned down, sitting meditation with an atheist, sitting on the edge of the bed with a fishing rod, listening to one man’s stories of fishing in the Bay for his food. Cooking in the kitchen, working in the garden, deeply listening to the stories people tell, and the silences in-between. The stories are as numerous as the individuals we have served, and just as colorful.

Did you have any fears when you first started? Yes. Absolutely! At the beginning I was terrified of bodily fluids - pee and poop! Blood and spit! I was a very proper Englishwoman who had never had children and had lived a very tidy life! Hospital smells turned my stomach, and I was afraid I would not be able to handle myself in any ‘untidy’ situations.

Has your perspective on the fears and challenges that face you as a hospice volunteer changed over the years? I remember my first Christmas Eve at the Guest House, going to say goodnight to Robert, a resident whose condition was changing quite

[Sharing in the Gratitude, Feeding the Soul]

I would like to close by sharing just one of the many amazing stories that feed my soul about the selfless work our volunteers do on behalf of our agency and the families we serve. When one of our social workers had arrived for a lunch time visit with a young woman whose death was assessed as being imminent, she found the patient’s husband, parents, brother, sister and six year old daughter all at her bedside. Exhausted, distressed and feeling unable to remove themselves from her side, the social worker suggested that maybe a massage therapist to work on the family members one at a time might ease their stress and make them a little better able to cope with the difficult situation they were facing.

The family was receptive to this idea. The social worker called me early that afternoon to inquire about the availability of a massage therapist. Knowing we didn’t have too much time I immediately called two of our volunteer massage therapists. Both were available but not until about 8 PM that evening. This timing was fine with the family, who to be honest, did not know if it was day or night at this point.

The volunteer massage therapists arrived that evening and spent more than two hours gently massaging each family member, as well as spending time with the patient’s 6 year old daughter.

The patient died at about 3 AM the following morning. Although very distressed at the death of their loved one, the family was filled with gratitude for the care they had received from the hospice team, especially those two volunteers. They were stunned that these volunteers were willing to give up their evening to support and comfort them during this most critical time for their family. The effect of this intimate experience on both the family and the two volunteers involved was immense. I believe the coordinator of volunteers lives vicariously through the experiences of their volunteers. This experience made me feel extremely proud of all our volunteers as well as all those who make up the hospice team.

I thank all of you who volunteer time to hospice work. You have my utmost admiration and respect. You help make the job of the Coordinator of Volunteers rewarding and meaningful.

NOTE TO VOLUNTEER COORDINATORS AND MANAGERS: If you manage hospice volunteers and would like to submit an article to be considered for the VC’s Perspective column of a future issue of Hospice Volunteer News, send an e-mail to HVA.
swiftly. As I turned to leave he called out to me to help him to the bathroom, but as I returned, it was too late, he had urinated in his bed. Robert had AIDS, so I reached for the gloves kept by his bedside to follow correct protocol, struggling fruitlessly to get them over the cast I had on my newly broken thumb. Robert was embarrassed at his situation, I was embarrassed at not being able to get the wretched glove on and mop him up. Outside the window carol singers’ voices rang clear in the night air. ‘I’m so sorry Robert, this is my first time’ I said. ‘Me too’ he said. And we looked at each other in this most poignant of moments and laughed. ‘I’ll always be grateful to him for helping me get over that fear, for showing me in the most visceral way that we are the same - the one in the bed and the one struggling with the gloves - we are the same, no separation. When the heart is engaged, fear melts and we find something more solid in our common ground of humanity and imperfections.

What has been the most challenging aspect of being a hospice volunteer? Talking about it with people ‘outside’ the circle of those involved with hospice. Our culture has such an ingrained fear of death and the dying process. It was very hard for my family and friends in England to understand why I had chosen to give up a career to volunteer with the dying, thousands of miles from home! People either think you are mad, or they put you on a saintly pedestal. Either way is a hindrance to them seeing death as a normal part of everyday life that our culture has cut itself off from.

Another challenge was that it called me to face all my own denials, inauthenticities, glib responses and practiced answers. Every shift I worked was a five hour personal authenticity test - you can't bullshit the dying. It was the fiercest spiritual practice I have ever engaged in - constantly coming back to the present moment and being alive in that, without being self-conscious. Actually one of the greatest gifts of this work was to leave my 'self' at the door and come alive in service to others. I really learned the difference between helping and serving, that is the core of Frank Ostaseski’s teaching (Founder of ZHP).

How has your past experience as a volunteer helped you in caring for your friend who is dying? My friend Marta Butterfield, in this photo with me at her 83rd birthday party, died July 25th 2005. I came to know her when she rented her old houseboat to me upon entering a Nursing Home. It was hard for Marta to leave her home of 25 years and independent living to a lifestyle of being bed-bound with folk she had nothing in common with, apart from age. Because of my hospice training, I was comfortable listening to her fears of change - of the possibility of dying. These things were not topics of conversation she felt she could explore with family or others, who shied away from acknowledging the reality of her situation. My training at ZHP had taught me how to actively explore these with Marta. In the two years I knew her before she died, we laughed together a lot, and as each new change slowly dawned, together we noted them, explored how she felt and didn't pretend that she was getting better - except in those seemingly rare times when we forgot and did pretend! Always, I met Marta 'where she was'!

A few months before she died, Marta had a nasty brush with the Emergency Room. Right after that she phoned me to announce that she was coming home to live on the boat again. Initially I felt swept up in everyone else's common sense response that this was not practical. Thankfully my hospice experience, which taught me to listen deeply, stay still and try to understand what was really happening, kicked in swiftly and I worked hard as an advocate for her to come home. We held hands one day as I sat on her bed, tears in both our eyes, wordlessly acknowledging that she wanted to come home to die, and 'practical' had nothing to do with it anymore.

She came home on Mother's Day weekend to try it out. The thing she had been dreaming about for years in the Nursing Home - to sleep on her precious boat with its view of the Bay and seals and ducks swimming past the window. Except it didn't really turn out like that. Very quickly Marta faced the reality that she couldn't get about the way she could in her wheelchair at the Home, and she felt trapped and vulnerable. Once again the ZHP training was crucial - being in the now, working with what was real now, letting go of ideas and being with what is. Marta returned to the Nursing Home, finally grateful for
The Flower Hour

This unique video was just released and is intended for use in hospices, hospitals and nursing homes.

Bellfy/Sloan Productions, the producers, were insistent that it be released to the hospice community first. This DVD is currently not available anywhere else.

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Not long after she was taken to the Emergency Room again. I went to see her and was amazed at how perky she was. I apologized for not being there the week before, but I had been with another friend who was dying (this is what happens when the word gets out that you have Hospice experience!) After giving me her condolences, Marta paused, then said 'Vanda, I am wondering if I am dying now.' Again, my hospice training prompted me to help her by exploring her inquiry deeper. What made her wonder that? What was changing? How did she feel about that? Was there anything she wanted to do or say to anyone? And so on. Her last conscious words to me were 'I think I'll know when I am and I'll turn towards it.' And she thanked me for being her friend. In the days that followed Marta slipped into states of restlessness that were familiar to me from hospice. I sat with her, playing her music, holding her hand, doing relaxation visualizations with her when she panicked at her shortness of breath. All the while, it was rather frustrating to see the medical establishment poke and prod her and shout 'How are you doing Mrs Butterfield? - You're looking much better today!' as she slipped away. Ultimately I know that Marta embraced her death as clear eyed as she lived her life, and I am humbled to have been able to share some of it with her.

What type of training did you receive as a new volunteer? When I did the Zen Hospice training in 1997 it was still led by its founder Frank Ostaseski, who is an amazing and world-renowned teacher in the field of death and dying. The ZHP training program took the prospective volunteer on a very heartfelt and a fearless exploration into the spiritual dimensions of hospice work, as well as giving them solid training on the practical aspects of caregiving such as how to move people from the bed to the commode etc. The 40-hour training program transpired over about a two-week period with several evening sessions and an intensive weekend that brought the volunteers together to learn the core essentials of hospice volunteering in a very intimate and experiential setting.

It was wonderful to do this training with a group of 20 or so peers, from all walks of life. This aspect of doing hospice work in community with people who share a meditation practice, provided essential grounding and allowed me to experience the work in ways I could not have done on my own.

Have you continued to partake in continuing education relating to hospice? If so, what types of ongoing training are you receiving through your hospice or from other sources? When you asked me to participate in this interview, I was shy to, because as I said, I am not formally volunteering in any programs at the moment. My life has moved on, but I realized in talking with you how indelibly it has been touched by hospice work. Since leaving hospice and having the opportunity to care for friends like Marta, I have been involved in Frank Ostaseski’s teaching programs on death and dying such as his workshop series and End of Life Counselor training program.

I did spend a little time in India with Mother Theresa’s organization, because I wanted to experience what it would be like to do this work when I didn’t even speak the language - it takes you to such a place beyond language - but that was a hopelessly romantic notion I was soon home where I felt I could be of more use. I also spent time with The Center for Attitudinal Healing which has a great program working with children and their families. Recently, perhaps most profoundly, I have unwittingly brought my Hospice experience into my new career. As a Life Coach, I work with people in transitions of many kinds, but most unusually I find myself working with people, and their families, in the final transition of End of Life. I use poetry, meditation, deep listening and intuition to accompany people as they explore the issues that arise at this time. In the short time I have been practicing as a coach, I have been deeply touched and moved by the people who have found their way to me.

What would you like to see HVA bring to the hospice volunteer community? I think HVA’s great contribution is to build a sense of community, like we had at Zen Hospice. This work can be extremely taxing when you are doing it in isolation. Burnout is common. What HVA is doing brings together folks from many different programs and reinforces a feeling that this is community work, it's nothing special, it's always been done by ordinary folk for each other through the ages. It helps us reclaim death as a community event, not just a medical event, and lends power to the basic human qualities of kindness and presence.

To conclude, do you have any personal thoughts you would like to share with other volunteers regarding your experiences as a volunteer or perspectives on hospice? The following is my recollection of one night I had at the bedside with one of Zen Hospice’s residents about 8 years ago. This experience was very inspiring for me and HVA Founder, Greg Schneider, who was able to share it with me. I hope it conveys how accompanying the dying can be a most intimate experience. My mental thoughts at the time I was having this experience are shown in brackets [like this].
I had just attended one of the bi-weekly Tuesday evening volunteer meetings at the ZHP Guest House. We had most of our volunteer meetings at this exquisite Victorian house that could house up to 5 residents on the upper floor. Before departing for the evening I took the front stairs two at a time in my haste to see Helen. I paused at the door fearing what degeneration I might see since my shift just three days earlier. Inside, all was hustle and bustle with activities of the deathbed, medication, water sips, blanket folding. Several other volunteers who had the same idea were already present, lingering as they made affectionate conversation with the tiny frail woman in the bed.

[Good heavens, I thought, it's like Grand Central Station in here. Don't these other volunteers have homes to go to?]

I observed my resentment at their presence that seemed to keep profound intimacies at bay. I noticed it rise and fall away, as I saw under each pleasantry, an unspoken good-bye, shining in love from their eyes. It was clear to us all that her death was imminent. The hubbub soon faded leaving just Patrick, Greg and me gathered around her as we helped her to sit up. The conversation continued to flutter around her physical needs.

[Why are we fussing about her body when it's clear that she has no further use for it and is very focused on another world?]

I remembered what Nahid, our hospice nurse, had told us during the meeting about the dying person's need to talk about their reality of death as it approaches and how that can be difficult for others to hear. Emboldened, I asked Helen how she was feeling. She sensed the meaning and paused. Then she said in a soft voice that she kept hearing the word "agitas" and what did this mean? I explained it was the Latin root of the word agitated.

[Really, Vanda, do you think she needs a discourse on epistemology?]

And then out of the blue I found myself telling her that the word that sprang to mind as she talked was "agape." Her face beamed as she rolled "agape" around in her mouth like a good wine. Agape is the Greek notion of love. Not romantic love or sexual love of our gratification culture, but the noble love of a common humanity. The unconditional love that Nahid had spoken of in her stories earlier that evening.

"Yes, yes," Helen whispered, "that's how it is here." A pause and then, "I can hear voices." "Are they the voices of people you know?" I ventured. "Yes," she smiled. Time hung, stretched in the silence as twilight edged in closer round the three of us, gathered at the feet of the Bodhisattva. "Are you frightened?" I asked. "I'm afraid I might have to leave," she breathed. And almost inaudibly: "I'm afraid they won't have space for me." Then gazing directly into my eyes, she asked "What do you think?"

[Well that's done it. You can't say "Oh, I don't think heaven can hang out a no vacancy sign like Stinson Beach Motel" or "God always has room for one more angel." Remember what ZHP Founder, Frank Ostaseski says--You can't bullshit the dying.]

I took a deep breath. "I think that maybe space and time are concepts we create here, to make shape of our world, but maybe they don't apply in the same way there." Helen nodded in relief. But then another concern furrowed her brow. Her voice dropped. "I'm afraid I won't know how to do it." Her physical fear flowed like a current to me as she held my gaze. I heard myself ask her if Will was her first born. My voice sounded steady and calm and I sensed my responses were coming from some deep place of shared consciousness. I was completely present in the moment. She nodded and I went on. "Do you remember that night you gave birth to him? When the fear of the unknown and all that physical labor lay ahead of you?"

I felt her slip away to that night forty years ago. "Remember how your body took over and the whole process unfolded? Well, maybe this is just like that, that our bodies know how and will do it if we let them." The tension in her fingers melted and she murmured "Oh yes" as her body remembered its hours of triumph. Helen seemed to tire once more at the memory of such exhaustion and almost without words we three moved gently, adjusting her position to let her sleep. We sensed the room come back into focus. Lying back on her pillow she murmured knowingly, wistfully, "agape."
Heart Wide Open -- Self-Care for Caregivers

Drawing from their experience as hospice volunteers, Sandi Kimmel and Patrick Murphy created HEART WIDE OPEN - Self-Care for Caregivers™, an easy-to-use handbook of techniques intended for everyone who has ever cared for anyone else.

Unique, visually beautiful and practical, this handy 48-page pocket book, contains helpful suggestions for a variety of lifestyles dealing with depression and stress while guiding you back into balance with gentleness, humor and love.

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Hospice In The News Con't

NOTE: To read the full articles, click on the article title

[Advance Directives] return to News menu

Woman Gives Others Courage to Choose
Mary Matthiesen is on a mission: to catalyze the power of women to shift end-of-life care for their loved ones, one conversation at a time. "We haven't been told what we really need to know to ensure compassionate care for our loved ones in the realities of 21st-century medicine," says Matthiesen. "We don't know what’s possible, or what will happen if we don’t participate."

There's nothing worse than deathly silence
"I can't tell you the number of times that a patient who is suffering from a disease, like cancer or heart disease, comes into the intensive care ward, having slipped into a coma, and the family can't tell us what to do," Dr. Bill Silvester says. "It might be somebody who has known that death is coming, but they haven't talked to their family about what should happen when they are no longer in a position to make decisions for themselves." In the absence of any other instructions, emergency ward doctors often rush to save the dying patient by inserting a feeding tube or putting them on a respirator. The result, of course, in these modern times, is that technology and medicines are applied. The patient is saved and then must live for months or years, unable to move, speak or feed themselves.

Boomers Hesitant to Discuss End-of-Life Issues with Aging Parents
Baby Boomers have much more trouble discussing sensitive matters about financial planning, medical care and end-of-life issues with their senior citizen parents than do these parents now in their 70s. Hartford Financial Services Group, sponsor of the research, says there are ways to improve these communications.

[Alternative Therapies] return to News menu

Joy, love spread by instinct by canine volunteer
When Athena entered the Castle Shannon home of a terminally ill 5-year-old girl as part of Three Rivers Hospice's volunteer pet therapy program, the Rottweiler went straight to the girl's bedroom in the back of the house and jumped on her bed. From then on, the two were inseparable during the weekly visits that summer of 2004, with the girl even making him a "doggy cake" with dog biscuits around it.

Dignity Therapy Adds Meaning to End of Life
A dignity therapy intervention among cancer patients near the end of life was well accepted by patients and has the potential to improve both patient and family outcomes, according to a study published in the Journal of Clinical Oncology.

Harpist uses music as medicine
Dr. Diane Schneider is fully aware the chords of her harp will not cure the terminally ill, but Schneider is equally convinced the tranquil music she plays provides the type of comfort they cannot get from a prescription. Schneider, affiliated with Mayo Systems, has a Ph.D in the area of theology and spirituality. Pastoring as a hospital chaplain, Schneider began using her harp with patients while working for Franciscan Skemp-Mayo Health Care Services in La Crosse for three years.

[Awards] return to News menu

California Hospice Medical Director Receives Prestigious Award
The California Academy of Family Physicians in April presented Dr. Robert Werra with the 2005 "Family Physician of the Year award." In the 1970s Werra helped found Hospice of Ukiah and since 1982, has been its medical director. "Partly because his parents died at home and partly because of what he saw as a change in how families cared for the dying after World War II, Dr. Werra is an advocate and benefactor of Ukiah Hospice," CAFP states. Werra said the local hospice is all volunteer and accepts no reimbursement. Even though the services are donated to people, "you get more than you give," he said.
Grief doesn't spare the young
In a perfect world, high school is supposed to be the time of your life. Unfortunately, our world is far from perfect. The events of the day can change in an instant. Whether these life-changing events occur from natural causes, such as Hurricane Katrina, or other situations, such as car accidents, suicide, illness or divorce, teens are going to experience loss.

Together in the Dark
The death of a loved one can be a time of wounding or healing. This is an interview with Rachel Naomi Remen, clinical professor of family and community medicine at the UCSF School of Medicine and the author of two bestsellers, Kitchen Table Wisdom and My Grandfather's Blessings. A pioneering medical reformer, she is the founder and director of the Institute for the Study of Health and Illness at Commonweal and has been a physician to people with cancer for more than 30 years. She was interviewed by Reform Judaism editor Aron Hirt-Manheimer and managing editor Joy Weinberg.

Dallas snags hospice firm
The nation's seventh-largest provider of hospice services has moved from Oklahoma to Dallas. The relocation could jump-start an aggressive growth plan by Trinity Hospice, including acquisitions in an industry that's gaining momentum as the general population ages. Seven-year-old Trinity, previously based in Tulsa, provides a range of end-of-life health care, spiritual and social services for patients with six months or less left to live.

Report Outlines Unique Needs of Dying Children
Nearly 1,000 of the more than 40,000 people who die each year in Maryland are children under 18. With almost every one of those deaths, a pediatric palliative care program can offer support to the child and to the family through the dying process and beyond. A recently released comprehensive report, "Challenges and Opportunities to Improve Pediatric Palliative Care in Maryland," makes recommendations for improving the care of dying children in Maryland and summarizes the results of the Maryland Pediatric Care Summit held last fall. The summit findings focus around five central themes: denial of death, compassionate communication, continuity of care, public education, overcoming barriers, and current programs and services.

George Mark Children's House Receives Prestigious Honor From Children's Hospice International
George Mark Children's House (GMCH), the first freestanding respite and end-of-life care facility for children with life-threatening and terminal illnesses and their families in the US, is awarded for its innovative program development with the Children's Hospice International Sister Frances Dominica Award. The award recognizes a health care provider organization which has created a unique program benefiting children with life-threatening conditions and their families.

Palliative and Hospice Care for Dying Children
Our cover story this week concerns children at the end of life, in pain and, often, alone. A new report from the Institute of Medicine, which advises the government on health policy, calls on the U.S. to do far more than is now being done to relieve the suffering of dying children and their families.

Hospice for kids gets Medicaid waiver
The state of Florida is the first in the nation to receive a Medicaid waiver for the Program for All-inclusive Care for Children. The program takes an innovative approach for providing palliative care for children with life-limiting diseases. Many times hospice care was provided gratis because the family's insurance wouldn't cover the program or the family was uninsured. If the families did choose to have insurance or Medicaid pay for hospice care, they gave up their rights for additional medical treatment for the child. It was a no-win situation for many whose children could live for several years or to young adulthood and possibly beyond.

Open Conversation Keeps End of Life Care In Line With Personal Values
Patients and their families struggle with myriad choices concerning medical treatments that frequently precede death. While advance directives can be useful tools in some circumstances, experts say that open communication among families and physicians is most important for avoiding unnecessary conflict and ensuring that treatment decisions reflect the individual.
This is a collection of all of the HEAL Project InfoLetters from the first Community Outreach Program in Education (COPE) program, a public education series intended to educate the public about hospice and caring for dying loved ones.

The series was developed to help guide caregivers and families on their journey as they care for a dying loved one.

Each InfoLetter in the series covers a specific topic relating to death and dying in the context of caregiving.

This valuable collection addresses the following topics:
1) Series Overview
2) You and the Healthcare System
3) Legal Considerations - Advance Directives
4) What is Hospice?
5) Understanding the Dying Process
6) Comfort Management
7) Nearing Death Awareness
8) Belief Systems - Faith & Spirituality
9) Grief of the Dying Person
10) Rituals Around Death
11) Bereavement Support - Continuing Your Life After Their Death
12) Life After Caregiving

Spiral Bound, 14 pages

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Teaching deathbed manner
One cancer patient calls them "MIA doctors" - doctors who go missing in action when their patients are about to die. Doctors, even with patients they've known for years, often avoid saying goodbye, said Dr. Anthony Back, a cancer specialist who teaches young doctors communication skills. And their inability to say those little words often leaves patients feeling perplexed and abandoned at an especially vulnerable time.

Conversing brings comfort to terminally ill
While the adage "life is short" may seem true for everyone, no one understands this better than those facing a terminal illness. In the time they have left, serious, unsettling questions regarding spirituality, relationships and identity can weigh heavily on their minds. Experts who work with the dying say precious few resources are currently available to address these types of concerns. But a new program that allows groups of terminally ill individuals to meet and talk out their problems may offer comfort.

[Cultural] return to News menu
Views on End-of-Life Care Vary Widely, Differ by Ethnic Groups, Sex, Race
Researchers at the University of Michigan set out to explore how older Americans feel about their personal care as they near the end of their lives. They were surprised by the diversity of views and found some significant differences determined by race, ethnic group and sex.

End-of-Life Decision Making: A Cross-National Study
In End-of-Life Decision Making, editors Blank and Merrick bring together scholars from 12 countries on five continents to examine the past, present, and future of how the dying process interfaces with the medical world. The book describes cultural, religious, legal, political, and medical factors and their impact on the approach to hospice, euthanasia, pain control, health care costs, and other aspects of death and dying in each country.

[Death & Dying] return to News menu
The Unseen Realm - Science is making room for near-death experiences
Dreaming — whether in pleasant reverie or nightmarish angst — has long been accepted not only as a real physiological phenomenon but as a common human experience. But when the dying describe open-eyed visions of long-dead relatives and friends, those who don't "see" the extra people in the room usually grow skeptical.

Death with dignity debate
Years after Oregon voters gave citizens the right to end their own lives, other states are jumping on board to bring the option closer to home. In California, a similar bill is currently being considered in the state Senate. The controversial legislation is bringing out polar viewpoints, but also support from local religious groups.

Learning from the Dying
Teaching about end-of-life care was virtually nonexistent when we attended medical school and trained in residencies more than 20 years ago. We cared for many dying patients, but both the formal curriculum — what was overtly taught in the classroom and in structured settings on the wards — and the informal or "hidden" curriculum — the implicit values and attitudes of our peers and teachers, as expressed in their behavior — conveyed a distinct sense that end-of-life care held no great clinical interest and required no special expertise.

How do you know it's time (for hospice)?
How do I know when my mother has come to the end of her life? How do I know when she isn't going to get any better and has suffered enough? How do I know it's time to call in the folks at hospice, the ones that will hold my hand and my mother's as she takes her final journey?

Will We Ever Arrive at the Good Death?
NY Times - Hospice today is as different from its grass-roots origins as Charles Meys is from Florence Nightingale. It began in the 1960's as an antiestablishment, largely volunteer movement advocating a gentle death as an alternative to the medicalized death many people had come to dread. People still dread those deaths; surveys show most of us want to die at home, not in a hospital, and want to die naturally, not hooked up to life support. But in recent years, hospice itself has become institutionalized, and it no longer means quite what most people take it to mean. Today there are hospice patients on ventilators, hospice patients with feeding tubes, hospice patients getting pacemakers, hospice patients receiving blood transfusions and cardiopulmonary resuscitation, hospice patients who panic when they can't breathe and call 911. It's all part of the new trend in hospice toward "open access," meaning that terminally ill patients can continue chemotherapy and other treatments and still get hospice benefits through Medicare.

[EOL Care] return to News menu
Study uncovers what matters most in end-of-life care
How Canadians die is far more important than where they die, according to a new Canadian Institutes of Health Research (CIHR) funded study on the quality of end-of-life care.

End-of-life care in a home-like setting
This article reflects on the increasing trend toward developing residential hospices. As Lifespan hospice looked at their hospice program, they realized that there was still something more they could be doing. After much discussion during the past decade, their board and staff concurred that what the community lacked was a hospice residence - a place where those too sick to stay in their own homes or without caregivers, could receive dignified, supportive end-of-life care.

End-of-life column evokes strong feelings from readers
A recent column about the need to provide terminally ill patients with quality end-of-life "palliative care," instead of focusing on physician-assisted suicide, drew a passionate response. Hospice nurses, doctors, members of the clergy and people who had lost a family member to a long illness agreed that most hospitals do not have a clear mission to treat the physical and psychological symptoms of dying patients, and there is far too little access to hospice care. They were frustrated by the intense media attention given to physician-assisted suicide since research and their own experience have shown that when dying patients receive good palliative care, very few end up wanting to kill themselves.

Hospice care is about helping people to live
Even as there is a sadness about loss, there is a tremendous desire for, and celebration of, life. And that is the essential paradox of Hospice and end-of-life care. It's easy to miss that, to focus only on the dying and lament it. But we all die. It is part of the human condition. And what if that awareness were to power, energize and inform our living? That's really what hospice care is all about - bringing all the strengths of medicine, technology and human understanding to support a person as they lament dying and celebrate living.

Sickness unto death, without despair
"If the day comes when a doctor tells me that I am terminally ill, I don't think I will be so courageous, and I am sure I will go through a serious grieving period. But then, I hope, I will be able to find support at an compassionate and competent place like Connecticut Hospice. I would also be sure to call everybody I have ever loved to say that I love them, and apologize to everybody I owe an apology to." These are the words of Natsuko Utsumi, a Japanese reporter who came to the US to learn about EOL Care by visiting Connecticut Hospice.

End-of-Life Care in U.S. Found Lacking
The United States does a poor job when it comes to providing quality care to people at the end of their lives. That's the conclusion of a study in the Jan. 7, 2004 issue of the Journal of the American Medical Association . Researchers found less than 50 percent of the relatives of people who died in an institutional setting would rate the care given to their loved ones as "excellent." That fact is particularly important because the study also found that nearly 70 percent died in an institutional setting, such as a hospital or a nursing home, compared to about 31 percent who passed away at home. However, family members gave high marks to hospice care offered to loved ones nearing death.

Research Identifies Areas for Improvement in End-of-Life Care
The frustrating vignette of dying in an institution can be markedly improved if clear standards of palliative care are identified and existing care patterns are continually measured against those standards, according to Joan Teno, MD, MS, who presented her findings here at the annual joint meeting of the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association. "Too many people dying in institutions have unmet needs for symptom amelioration, physician communication, emotional support, and being treated with respect," Dr. Teno said in her presentation. She is a professor of community health and medicine at Brown Medical School in Providence, Rhode Island. However, she asserted that this chasm of unmet needs can be effectively breached by a systematic approach that brings the hospice approach to any facility that attends to the dying and their loved ones.

What Are We Going To Do With Dad?
America is getting older, and older Americans are living longer. What has not changed is the dysfunction and illness that usually accompany aging. Geriatrician Jerald Winakur looks at the "vast inland sea of elders" that is building and wonders where the doctors will come from to care for them. Writing as the son of an eighty-six-year-old man with dementia, Winakur also details the nittygritty of caring for an increasingly debilitated parent. In both of his roles — loving son and highly skilled professional — he is hard pressed to alter a course that punishes his dad and tears at his family. Even as medical
This book, written by Margaret Ledger, a volunteer coordinator and a bereavement coordinator with the Hospice of the Nashoba Nursing Service, describes the process of dying and the process of grieving in a gentle, openhearted way.

She explains how hospice can offer support to patients and their families along their journeys.

Margaret shares stories that illustrate and illuminate the paths others have taken.

Here are some comments on the book:

Extract from the forward by Ira Byock M.D., director of palliative care at Dartmouth-Hitchcock Medical Center and author of Dying Well and The Four Things That Matter Most.

"As Margaret Ledger’s personal experiences and stories illustrate, in drawing close to death many people enter a realm in which the past and the present interwine and death is separated from life by the sheerest of films."

September 16, 2005
Reviewer: Christina C. Killoran
(Westford, MA, USA)

A very informative, uplifting, and inspirational book

Science extends life, the future seen through his eyes is fraught with clinical and moral quandaries.

[Ethics] return to News menu

It Takes a Team to Choose the Most Dignified Death

Australia - A doctor rang me to talk about her patient - a frail, elderly but alert man struggling to breathe. She performed an urgent tracheotomy. He had recently finished radiation therapy for throat cancer. In the next few days, the doctor will have to decide whether to insert a feeding tube and perform other life-saving procedures. Without treatment he will die. Palliative care can make him comfortable and allow him a dignified death. With treatment he may gain some time, but his quality of life will be awful; cluttered by feeding and breathing tubes, his dignity lost.

For the End of Life, Hospital Pairs Ethics and Medicine

While many doctors and nurses have been trained in resolving disputes and many hospitals have bioethicists on their staff for consultation, Montefiore is innovative in giving its bioethicists a central role in mediating end-of-life issues among doctors, nurses, patients and family members, said Dr. Leonard J. Marcus, director of the program for health care negotiation and conflict resolution at the Harvard School of Public Health.

[Healthcare] return to News menu

Death with dignity debate

Years after Oregon voters gave citizens the right to end their own lives, other states are jumping on board to bring the option closer to home. In California, a similar bill is currently being considered in the state Senate. The controversial legislation is bringing out polar viewpoints, but also support from local religious groups.

[Healthcare] return to News menu

Families gain some respite, George Mark hospice relieves tired caregivers

Medical Director Dr. Barbara Beach, who co-founded George Mark with Dr. Kathy Hull, said much of what the house provides is respite care for families who get little to no breaks caring for their terminally ill children. Since George Mark opened, 79 children have been admitted into the house. Of these, 72 were there for respite services while the other seven used the facility for end-of-life care.

Improving coping skills benefits family caregivers of hospice patients with cancer

Caregivers of cancer patients dying at home significantly benefited from supportive educational sessions in which hospice nurses taught the caregivers how to cope with distressing patient symptoms, researchers at the University of South Florida report.

The Last Dance

Today we attempt to defy death with medical marvels that transcend what anyone even a generation ago could ever have imagined--technologies that only postpone the inevitable. Eventually, we will find ourselves at the bedside of a dear one, our eyes focused on those numerical and mechanistic quantifiers of life--oxygenation, heartbeat, blood pressure--while we subconsciously await the arrival of the angel.

Understanding Family Responses to Life-Limiting Illness

In-Depth Interviews With Hospice Patients and Their Family Members: Understanding family dynamics is a key component in providing comprehensive care for persons with progressive illnesses and their caregivers. The purpose of this study was to investigate what families experience during an advancing illness and to describe their patterns of response.

[Healthcare] return to News menu

New Therapy Reduces Suffering, Distress in Cancer Patients Nearing Death

"Tell me about your life" is the question more health care professionals should be asking cancer patients nearing the end of their life, according to a study by a Canadian Cancer Society researcher, one of Canada's leading palliative care experts. "This new therapy shows great promise for filling a gap in end-of-life cancer care by addressing the emotional needs of patients - the need for a sense of closure and enhanced communication with the people they love," says Dr. Barbara Whylie, CEO, Canadian Cancer Society.

In the Hospital, a Degrading Shift From Person to Patient

Entering the medical system, whether a hospital, a nursing home or a clinic, is often degrading. At the hospital where Ms. Duffy was a patient and at many others the small courtesies that help lubricate and dignify civil society are neglected precisely when they are needed most, when people are feeling acutely cut off from others and betrayed by their own bodies.
Awash in Information, Patients Face a Lonely, Uncertain Road
A generation ago, patients argued for more information, more choice and more say about treatment. To a great extent, that is exactly what they have received: a superabundance of information, often several treatment options and the right to choose among them. As this new responsibility dawns on patients, some embrace it with a sense of pride and furious determination. But many find the job of being a modern patient, with its slog through medical uncertainty, to be lonely, frightening and overwhelming.

Home Funerals

Simple funerals in the home begin to make a comeback
Very few Americans opt for funerals in their homes — there’s no firm number of how many, exactly — but interest is growing as consumers yearn for a more personal way to bid their loved ones adieu, and are frustrated by sometimes high-priced, cookie-cutter services. "The primary focus is bringing the family into the whole thing," said Jerri Lyons, who is considered one of the pioneers of the home funeral movement. "It's making death intimate again."

A Movement to Bring Grief Back Home
After Richard Saul died of Lou Gehrig's disease just before Christmas last year at age 77, neighbors and friends gathered at his Cleveland Park home to extend sympathies to his widow, Judy, and their sons and grandson. Many were surprised to learn that they could also pay their respects to Richard. His body, washed and dressed in his favorite clothes, lay in the master bedroom, cooled by dry ice and open windows, and surrounded by fresh flowers, burning candles, family photographs and mementos of his many years as a lawyer, civil servant and father of four. Like a small number of other bereaved in the Washington area and nationally, Judy Saul chose to care for her husband's body for several days at home.

Hospice workers bring caring, dignity to patients' last days
"He died in the hospital, and for a very long time the memory of how he died stuck with me," said Doris Vaughans, R.N., nurse director with Hospice of Montgomery. "Now I work very hard to make sure the families are informed, because we were not informed. I knew my dad had cancer and would eventually die, but I didn't know he was going to die yet. We were never offered hospice. I felt very cheated and angry at the doctor, at the system. Why didn't we know?" The experience affected Vaughans so profoundly that she eventually turned her nursing career toward the specialty of hospice. It's a field that's not for everyone, she said, but one that many professionals are drawn to work in, as she was, because of intensely personal motivations.

Hospice nurse works hard for better world
Glendale, Arizona resident Christine Armenta, 44, is a single mother of two teenagers, a Hospice of the Valley nurse and a college student pursuing two master's degrees concurrently. She was among five Hispanic women in the University of Arizona's Mel and Enid Zuckerman College of Public Health to win a $4,000 scholarship for demonstrating academic success and a commitment to serving the state's Latino population.

A dying choice
The case of a Redlands physician accused of hastening the death of an ailing, elderly patient three years ago has grabbed the attention of the medical community, as well as death-with-dignity groups. The state sought last year to revoke the medical license of Dr. Harold Luke, a family-practice physician who earned his medical degree at Loma Linda University in 1972 and has practiced medicine for 32 years. The case illuminates the dilemma facing doctors who want to ease patients' suffering, but whose motives can easily be questioned if the patient dies.

Palliative Pain Management: When Both Pain and Suffering Hurt
With the disciplined assessment and alternative multidisciplinary palliative approach, the quality of life of terminally ill cancer patients with intractable pain could be enhanced, and unnecessary interventions and escalation of medications avoided. The synergistic work of an interdisciplinary team, such as the integration of the psychiatric nursing service and the medical palliative care service, may contribute substantially to the benefits achieved. Daily psychological counselling has the potential to enable the patient to express emotions in words rather than exclusively in physical language, and to integrate emotional issues with the concerns of bringing life to a close.

Pet Hospice

Pet Hospice Comes Through in the End
"There's a consumer need for this," says Tom Allen, a CSU veterinary student and, along
with fellow student Debra Stirling, project manager for the hospice program. "A lot of people want the opportunity to have their pets at home during the last days of their life so they can say goodbye, have the family home to say goodbye, then have an end-of-life experience that's in a familiar environment. We do pretty well here at the teaching hospital in how we deal with end-of-life issues, but there's nothing like being able to have a loved one at home."

**Hospice Care - Ending Life with Compassion**
There may come a point, when a pet is fighting a terminal disease, where the cost of treatment can become more than its benefit. In the advanced stages of diseases such as cancer, kidney failure, or neurological disorders, sometimes treatments cause pets pain or make them ill, without any hope of curing their disease. At this point, owners should make a decision about which is more important for their pet: quality of life or quantity of life. Pet owners have the option of stopping aggressive treatment and letting their pets end their life comfortably in the intimate, caring surroundings of their own home through hospice care.

**[Philosophy & Death] return to News menu**

**Why immortality would be a dead loss for humanity**
Would you want to live for ever? This used to be a schoolchild's essay subject or the sort of thing dinner party guests might ask each other after the third bottle of wine had been uncorked. Recently, though, you may have detected a subtle change in the wording of the question. It is becoming less a case of "Would you?" than "Do you?".

**[Prison Hospice] return to News menu**

**Inmates get training in hospice care**
Despite the fact officials from York Correctional Institution in Niantic could not reach family members of a dying inmate last month, she was surrounded by the love of her peers, fellow inmate Deborah Jones, 37, said. "She looked forward to us being there everyday," said Jones, a fellow choir member and friend serving a 13-year sentence.

**Hospice eases inmates' deaths**
When Herbie Schnee gasped his last breath March 5, he departed the Iowa State Penitentiary the only way society would permit him to leave. Schnee, 64, a Dubuque native serving life behind bars for first-degree murder, died of cancer of the larynx. His passing had special significance here because he was the first inmate admitted to the newly established hospice program at the state's toughest prison. He spent the final days of his life in the care of fellow prisoners who treated him like a family member.

**[Psychology] return to News menu**

**Majority of ALS Patients Are Not Depressed**
Contrary to what you might think, most people with amyotrophic lateral sclerosis (ALS) are not depressed. They are also not more likely to be depressed if they want to die or hasten their own death.

**The Role of Religion and Culture on Bereavement**
Bereavement is a complex, multidimensional process, influenced by physical, psychological, social and cultural factors (Kissane, Bloch, and McKenzie, 1997a). As such it has been studied extensively by a variety of disciplines and often in combinations of more than one of these factors. From a psychological point of view bereavement is the reaction to the loss by death of a loved one, and is viewed by the public as the most stressful life event (Homes and Rahe, 1967).

**On Death & Dying (Interview)**
Elisabeth Kübler-Ross, M.D. was one of a kind. She was widely recognized as one of the foremost authorities in the field of death, dying and transition until she died, August 24, 2004. It might well be said that she invented this field as an area of legitimate discourse in the medical community. Her classic first book, On Death and Dying, is considered the master text on the subject, and is required reading in most major medical and nursing schools and graduate schools of psychiatry and theology. This 1995 interview with Elisabeth Kübler-Ross provides some insight into her life and what motivated her to become a pioneer in the movement to improve the care of the dying.

**[Rituals in Dying] return to News menu**

**Ritual for a Dying Child**
At a time of tragedy, ritual helps family members deal with the painful task of letting go. Two year old Christopher had come down with a bad case of pneumonia and had gone into a coma. By the third day, the doctors had told his parents that their son was brain dead and had put him on life support. For about six weeks he had been in the same state. Everyone was convinced there was no hope. It was time to let him die.
Easing the Fear & Loneliness of Dying
In North American culture, Megory Anderson, author of Sacred Dying, says some 80 percent of people die alone and abandoned. Attending to the dying with ritual meaningful to the person dying helps relieve fear and loneliness. As well as ministering to the individual, it returns spiritual practice to one of the most sacred transitions in human experience.

End-of-life services provide needed closure
Phil Dirkx, reporter from the San Luis Obispo Tribune, explains how his perspective on the importance of ritual has changed. "I thought it would be better to just quietly pass from the scene. I didn't want anyone to be put to any bother or expense over me. I certainly wouldn't be able to appreciate the event myself. But having buried my father, mother and sister, I've changed my mind. I've come to realize that funerals aren't for the people who have died but are for the people left behind feeling sad and lonely. A funeral or a celebration-of-life service gives the people left behind some closure."

The Role of Religion and Culture on Bereavement
Religious bereavement rites and rituals have been suggested in the literature to have quite diverse applications and effects as well. For example, Buddhist bereavement rituals have been used as treatment techniques for people suffering from posttraumatic stress (Canda and Phaobtong, 1992). Furthermore, attending the funeral of a psychiatric patient who committed suicide has been suggested as therapeutic for both the family and the therapist for whom it enabled a laying to rest of both the patient and guilty retrospection about treatment (Markowitz, 1990). Similarly, in a study of the effects of socially prescribed rituals of support to the caregivers of dying patients, Sankar (1991) found that ritual provides a broad context of meanings and routines for securing the doubts and unknowns of individual experience.

Spirited Medicine, Pastoral Care Goes Mainstream
A long lost facet of healing is returning to the bedside as health care providers find ways to deliver much needed spiritual support to patients. Dr. Daniel Aronzon, CEO of the 365-bed Vassar Brothers Medical Center in Poughkeepsie, understands better than most that "It takes more than medicine to heal." As a pediatrician, he is well aware of the inherent spiritual needs of patients and family members during a loved one's hospitalization. Aronzon reflects that with today's shortened hospital stays, spiritual needs can more easily fall through the cracks.

'Life matters, so every day is important,' chaplain says
Breathing softly with the help of narrow oxygen tubes balanced under her nose, Harper, 86, closed her eyes as the chaplain recited a prayer. "It's just been a double treat to have him come by," she said about Nail's frequent visits. "I know that goes for a lot of these people who can't speak for themselves." Hospice patients know death is near. But their family and friends often have such a hard time talking about death they gingerly avoid the topic or simply stop visiting.

Spirituality at the end of life
Many terminally ill people seek religious or spiritual guidance at the end of their lives. Spirituality is the search for the sacred and the pursuit of meaning and purpose in life. It might be described as a process of turning inward to reflect on your life, while turning outward to seek that which is beyond daily struggles. For many people, spirituality is found in religion. Others find it in nature, art, music or life in general.

Hospice Volunteer Training Institute soon to move to development stage
The Hospice Educators Affirming Life (HEAL) Project continues its efforts to create a new national training program for hospice volunteers. In 2005 HEAL surveyed volunteer coordinators in hospices across the country to get their opinions and visions as to what was important in a hospice volunteer training program. A report will soon be released to survey participants summarizing the results of this survey, which will provide the basis for the new Hospice Volunteer Training Institute (HVTI). A consortium of hospices will be formed from survey participants to formulate the curriculum and establish training methodologies.

Long-time Volunteer Learns How To Hope
For 15 years, 74 year old Joan Derr has served the local organization that honors death with dignity, reaching out to dying people and their families to help. Derr has offered company and solace to the dying and respite and a strong shoulder to their families. When she is not working directly with Hospice clients, she is in the background, giving
Volunteering makes the world go 'round for giver and receiver. Volunteer opportunities include everything from crafting gifts for patients and hospice work to fund raising and clerical work. Volunteers have always played a vital role. The local New Jersey branch of the Visiting Nurse Association, a national nonprofit, traces its roots back 94 years to the Monmouth County Organization for Social Service, a small group of volunteer nurses who championed to improve prison conditions and who worked to establish a humane approach to public assistance. Since then, it's grown to include an array of community health care services such as its in-home palliative care, mobile outreach clinics, immunization programs and special health programs for children with developmental needs. Hospice volunteers, work with a VNA team comprised of nurses, home-health aides, therapists, clergy, physicians and social workers.

HVA Events Calendar

NOTE: For more details on these events, click on the event title

March 5-8, 2006 California Hospice Foundation Spring Conference Berkeley, CA
The goal of CHF's Spring Conference 2006 is to provide an opportunity for health care professionals to receive the latest information on hospice, palliative and end-of-life care; relationships with hospitals, home health agencies, nursing homes and other health care agencies; regulatory and legal issues; promotion of hospice and end-of-life care; and management and leadership issues in a casual, relaxed and rejuvenating setting.

March 19, 2006 Spirit Alive! A Community Celebration of the Seasons Novato, CA
Welcome the Spring Equinox with Spirit Alive! A Community Celebration of the Seasons, Wisdom of the World's concert series created to celebrate the common spirit that unites us all. This evening will partially benefit the Marin Waldorf School, dedicated to education from the inside out. Featured artists include the singer/songwriter team of J.D. Martin and Jan Garrett from Colorado, multicultural storyteller Masankho Banda, vocalist Christina Quinn, Nepalese flautist Manose, percussionist Paul Cicco and special guest global fusion percussionist, Ian Dagole, all led by Artistic Director, Gary Malkin. The evening will be sure to include community participatory chant.

March 25, 2006 Creating A Loving Passage with Grace and Compassion Sebastopol, CA
This seminar by Jerriegrace Lyons, Founder & Director of Final Passages, explores: What are Home Funerals, Natural Death Care, Green Burials and why should you care? Explore with new eyes and an open mind the special time surrounding a loved one's passage. Learn options that allow families and caregivers meaningful participation following a death that could replace some or all of the services offered by mortuaries. Join Jerriegrace Lyons, nationally known leader and visionary in the arena of death and dying, as she shares stories that help reduce fears, support the grieving process and allow for more healing through creative expression and community support.

March 31-April 9, 2006 Wilderness Rite of Passage: Exploring the Depths of Life, Death, and Healing Santa Fe, NM
Instructors Joan Halifax Roshi and John Braman of the Upaya Zen Center offer a time for deep practice and a rite of passage, participants enter the wilderness in solitude and fasting to mark change and see clearly the truth about what to do with this "one wild and precious life." Preparations begin at Upaya with intensive teachings, interviews, meditation, and council. A basecamp will then be established in the New Mexican wilds, and from there, participants find a natural refuge where they spend four days alone, fasting, practicing, and being taught by the elements. In the vastness of the desert, mountain and sky, the endeavor is to know the truth of wisdom and compassion in our lives and how to bring these qualities forward to serve the world. Everyone then returns to Upaya to plumb their experience. This powerful program is for caregivers, educators and social activists. John Braman is a renowned educator and wilderness expert. Roshi is highly regarded for her wilderness solitude practice of over thirty years. Limited registration. Contact Upaya to apply.

April 5, 2006 Pain management at the End of Life: Bridging the Gap Between Knowledge and Practice Satellite Teleconference 1:30pm EDT
Designed for families and friends of the terminally ill, as well as for health-care givers and other professionals, the teleconference and local panel discussions afterward offer the chance to learn why effective pain control in people with terminal conditions has been so
hard to achieve. Moderated by Frank Sesno, Professor of Public Policy and Communication at George Mason University and Special Correspondent with CNN. Sponsored by the Hospice Foundation of America.

**April 7-8, 2006 Living from the Soul: The Everyday Experience of Calling, Mystery & Awe**  
**Mill Valley, CA**  
This public workshop by Rachel Naomi Remen, M.D. explores the deeper direction of your life and re-affirms your authentic life-long values. Through a series of experiential exercises and small group discussions using storytelling, symbolism, poetry, journal writing and imagery, Rachel will enable you to recognize the threads that weave your life together and access your own sustaining source of wisdom. Most people live closer to the soul than they know. Come prepared to find greater meaning and connection in your everyday life and remember your deeper identity.

**April 8-9, 2006 Being A Compassionate Companion**  
**Rome, Italy**  
This workshop by Frank Ostaseski of the Alaya Institute presents a mindful and compassionate approach to addressing the practical, emotional, and spiritual issues which are inherent in the unique relationship of caring for people who are dying. This workshop is open to all and may be of particular interest to professionals or those who anticipate caring for family members or friends facing life threatening illness.

**June 13-15, 2006 Everflowing Touch Skills in Hospice Care**  
**San Francisco, CA; April 28-30 Atlanta, GA**  
This training program by Everflowing founder, Irene Smith, is designed to provide techniques, skills and personal practices for adapting touch and massage into care for the dying. These skills and practices will help you revitalize your energy while working, achieve more comfort by the bedside and process the emotional impact of the work. This class will also provide you with a physical approach to clients in pain that will enhance other care modalities. Approach skills taught in this program may be incorporated into daily nursing care as well as be structured into other body work modalities.

**June 29-July 1, 2006 The Healing Power of Story: Opening to a Deeper Human Connection**  
**Mill Valley, CA**  
This workshop, open to all healthcare professionals, by Rachel Naomi Remen, M.D., teacher and master storyteller, will show you how the power of story can deepen your life and enrich your work. Rachel will lead you through a series of experiential exercises and discussions, using imagery, symbolism, poetry and journal writing to enable you to find your own story and to discover what sustains you. You will have the opportunity to remember times of loss, healing, mystery, love and grace; to share these stories with other professionals and to listen to the stories they tell in return. Come prepared to laugh, to cry, to find a deeper meaning in the work you do and to celebrate the joys and strengths of being human.

**July 28-30, 2006 5th National Conference on Volunteerism and Family Caregiving**  
**Denver, Colorado**  
Caregivers, whether family, friends, or volunteers have a lot in common; they provide compassionate, loving care to people in need...just because. These unique people are the focus of the 5th National Conference on Volunteerism and Family Caregiving. Volunteers’ and caregivers’ needs for education, knowledge of best practices, empowerment, support and encouragement will be the focus of three days of stimulating and innovative learning activities. Our theme of “inspiration and transformation” hopes to target what inspires people to do the work that they do and to recognize the potential for transformation that can be part of their experience.

**August 18-24, 2006 INNERHARMONY.COM**  
**In the Heart of Silence - Art of Presence Retreat in Assisi, Italy**  
In a Franciscan Convent in the heart of Assisi, enter into a silent practice of remembering yourself, interspersed with spoken practices in expressing the whole self. The environment of chapels and monasteries serves as a reminder of sacred practice, and the life of St. Francis and St. Clare provides a constant presence and metaphor for your inner journey. Enjoy the Sister’s garden with a view, semi-private or private bedrooms, and delicious Italian cuisine.

**Join HVA**

**SPECIAL OFFER FOR HOSPICES:** Group rates are available for your volunteers. Welcome your new volunteers to your organization by offering them a complimentary...
HVA membership upon completion of their training!!

**Individual Rate:** $40  **Group Rate:** $30 (25% discount)

[About HVA]

The Hospice Volunteer Association (HVA) was founded in January 2005 by the HEAL Project as an adjunct to its Hospice Volunteer Training Institute (HVTI). An estimated 500,000 people volunteer in the nation's 3,200 hospice organizations annually, providing more than ten million hours of service each year. The HEAL Project is sponsoring HVA for the purpose of creating a nation-wide hospice volunteer community where volunteers can support and serve each other primarily through continuing education opportunities.

[HVA's Mission]

Our mission is:

- providing a venue for hospice volunteers to come together and share their experiences with other volunteers
- offering an opportunity for volunteers to nurture and learn from each other through retreats and workshops
- establishing standards for continuing education through national and local conferences
- providing a forum to encourage more dialogue on end-of-life care issues in order that volunteers can better serve the dying
- providing services and benefits to members
- attracting more volunteers to the hospice community
- increasing the cultural and age diversity of the volunteer community

[Membership Benefits]

Membership in HVA will entitle volunteers and hospice organizations to the following benefits:

- priority registration and discounts to HVTI online courses
- advance notification of new HVTI online course offerings
- access to the quarterly online newsletter
- receive discounts on HVA retreats, seminars and workshops

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