## Journeying with the dying: Spirituality and the human encounter in suffering"

Helen Cox RN, PhD. Providence St Vincent Medical Centre pastoral Care Dept Spiritual Care Conference, Oregon, 16<sup>th</sup> October 2006.

In this paper I want to present some of the work that surrounded the actual research that I spoke about in me previous paper: aspects of the literature, some sense making and some personal reflections. From my reading, personal observation and experience, and I imagine in all of your experience also, it seems in our 21<sup>st</sup> century world, that we are deeply uneasy about death and that presents a dilemma for those of who work with people who are dying. It seems to me that despite our personal acquaintance with death amongst family and friends; despite the carnage we see on our television screens nightly, despite the books, and the courses available to study death, dying and grief; despite the careers that make death an industry, so that in our logical brains we know that death is ever present and inevitable; despite all this witnessing, evidence and apparent open discussion - there lies a deep discomfort with death.

Ram Dass (2000: 148) writes about this deep discomfort and argues that despite all we know from those who have tried to teach us - Elisabeth Kubler Ross, Stephen and Ondrea Levine, Cicely Saunders, for example - we remain a society that considers death as enemy, to "be hidden or shunned, and separated, physically and philosophically, as much as possible from living."

In the past, death was considered part of life. Some religions in particular still celebrate death as reaching the final accomplishment, and moving toward that which the person has striven for all of their lives; reunion with the Creator. With the secularisation of society in the West, however, things have changed. In an article titled "Dismounting the boundaries between life and death" Sydney University academic Glennys Howarth (2000) argues that there is a modernist scientific – rational approach to social problems that has created dualisms: segregating the sick in hospitals, protecting the healthy; segregating the dead from the living in mortuaries and cemeteries. As Howarth states, "the modernist desire to exercise control over mortality has been fundamental to its sequestration from life" (2000: 128).

Such scientific – rational approaches cast death as the enemy: and so daily we see medicine doing battle for patients, death being more feared than celebrated, dying being silenced and dying people being, more often than not, hidden away, relegated to a medical struggle that is inevitably, ultimately, lost.

Death and dying have become a private matter, almost an anonymous matter. Even in the face of strong movements to hospice care, research indicates that most people die in hospital (Higginson et al 1998). This is despite the studies that indicate most people would prefer to die at home (Tang 2003). In an acute environment, treatment remains the dominant concern, and frequently active treatment continues until death occurs (Simmonds 1997). Hospitalisation means isolation from people important to the dying person, and the dying person is surrounded by routine tasks and ritualised care practices that are unfamiliar to those visiting. Death is seldom talked about in this alien environment. That may be because relatives are overwhelmed by the milieu, or because there are others in the same room. Or it may be that active treatment instils hope that means death does not need to be spoken of.

There is often a great deal of suffering in a dying process. In writing about their research into the experiences of cancer patients in Israel, Blinderman and Cherny (2005) explain that suffering includes the experience of severe pain, side effects and complications of treatments, loss of roles, loss of perceived future, and from "existential and spiritual concerns." In this latter category, they include "hopelessness, futility, meaninglessness, disappointment, remorse, death anxiety and disruption of personal identity" (2005:371). It is this less acknowledged existential suffering that gets hidden when the dying process is itself hidden. Perhaps it is an apparent inability to 'be with' this existential suffering of another that contributes to people's inability to speak of or be with death.

Through years of study and observation Eric Cassell concluded that suffering is a "state of distress induced by the threat of loss of intactness or the disintegration of a person, whatever the cause" (1992:3). He believes we know little of suffering, partly because it is generally a personal and private matter; the personal and private are out of public view.

But also because of the reductive methods of science, which are so useful in other domains, but lead away from such an understanding in human persons. Science would look at the parts but not comprehend the whole. Science can look at the body but not the person. Cassel argues that it is not bodies that suffer, it is people who suffer (Cassell 2004).

We are all here in this room today because we have some concern for the journey of the dying, we have experience of being with terminally ill people and we have some insight into the loneliness and the suffering that can occur. We have a commitment to making a difference through the ways we journey alongside the dying person. By our presence we hope to ease the suffering. We all share this concern and hope.

Back home there is a woman called Caroline Jones who used to host a program called "the Search for Meaning' on the Australian Broadcasting Commission station Radio National. In the eight years that her radio program ran, she interviewed hundreds of people who told their stories about what for them was the point of their life; how they'd come through the hard times; what sustained them; what they'd celebrated; what they believed in and what made them human. Some of the stories that we, her audience, listened to were about living with difference, going mad, going blind, being imprisoned, being wealthy, stories about the highs of love, the fear of being alone, stories about dying.

Caroline wrote a book about these stories, called 'An Authentic Life: Finding meaning and spirituality in everyday life'. In it she told us that people spoke from the heart and it was like hearing secret thoughts out loud – convictions about what really matters in life (Jones 1998).

Caroline writes that she now carries other people's stories with her like a 'sacred library' a lovely term that I have adopted because that is what we all have, sacred libraries we hold within that are our shared experience with people we have cared for. That's the way it is for people who work with others as they deal with illness, pain and suffering.

As a nurse I understand that the end-of-life journey can be filled with suffering and anguish. But I also know that it doesn't have to be like that. I came to these understandings through experience and so I have amassed my own sacred library over time. But you know, even though it is a long time ago, I don't recall as an undergraduate student ever participating in discussions about suffering, and the human journey. I don't recall discussions about the possibility that suffering could be other than physical and that as a nurse, I might have some role in such situations. I don't recall ever participating in discussions about how to *be* with someone who is suffering. There was precious little in post graduate studies also.

In a speech to medical graduates, the psychiatrist and Chancellor at the University of Massachusetts Medical Centre, Aaron Lazare (1999: 89) said that suffering is "neither an aberration nor a stroke of misfortune. It is part of the human condition. It is to be expected. You cannot be a human and not suffer, it is absolutely unavoidable." Eric Cassell (1992: 9) thinks that it is in compassion that we come to understand another's suffering. We may not know the complexities that underlie why they are suffering, but we can know that they are suffering and respond. This ability to have compassionate knowledge has many sources.

- It may be because we can see the visible signs of distress, but those are often hidden.
- We may know because people tell us about their distress, but that too is often silent. We know, Cassell thinks, because it is possible to directly experience another's desperation and disintegration. He describes this as similar to how parents can experience the emotions of their children. Brallier who writes of suffering in cancer, acknowledges this when she describes the work of carers as enriched by meaningful work and "by helping relieve some of the suffering we witness and *empathically know*" (1992: 204, emphasis added). We as humans can transcend our physical boundaries to experience others. This is not uncommon in the every day, Cassell argues, it is simply not part of our every day language and certainly not part of medical discourse, certainly in my experience, not a part of nursing discourse back in those days. I am not sure it is different now.

I have cared for countless people who suffered, probably in more ways than I ever knew, though I learned over time. I have so many experiences of being with people as they died, sometimes the only one with them, so that death became something I grew very familiar with. I have so many experiences of telling shocked relatives that their loved one has died. Sometimes unexpectedly, sometimes expected but deeply painful nevertheless. I have had privileged times where I know that my being there made so much difference. Living life taught me; experiences of clinical nursing practice taught me; sadly, nursing school did not teach me and as an academic that knowledge has guided me significantly as I have taught others, and as I have thought about, and written about, the human journey and the contribution of nursing.

I would like to share some personal journeying with you today, little excerpts from my library. I do this from a sense of humility and gratefulness for the lessons learned and the shaping of me as a person. There may be something in my stories that speaks to you.

My first story happened many years ago, and is about how I learned that it was ok to care deeply enough about Spirit that I could cut through others exclusion of Spirit.

I was a final year student nurse in a male medical ward at St Vincent's Hospital in Melbourne Australia. The ward was a long Nightingale ward with probably 24 beds in two long lines facing each other, with only curtains separating them. The man in my story was somewhere in the middle of this long ward. He had throat cancer and was dying, He was a middle-aged man with a family. He had obstructed and went into cardiac arrest. I was standing by his bed watching helplessly as the doctors tried to resuscitate him with cardiac massage and intubation. On the inside I was screaming that this was not the way the end should be for him, but I was still a student, I was way too scared to say anything.

The charge nurse came in through the curtains, watched for a moment and then she went to the bedside, bent over this man and said a prayer into his ear, soft, but loud enough for all of us to hear, and she asked for a safe passage to heaven for his soul. As she spoke her prayer, everyone became quiet, one by one people stopped their resuscitation efforts and

stood back. They realised that this was not a cardiac arrest, this was an anticipated death, unfolding as it was always going to, and it did not have to happen in denial and struggle.

That was the first time I thought about the difference between cardiac arrest needing resuscitation and death as the anticipated end of life. It was the first time I understood about medicalisation; the denial of death; the emphasis of the physical over the existential; the need to care about Spirit. None of this was about deliberate exclusion, and I am not passing negative judgements here. I understand it completely, it was simply about things like getting lost in a medical moment and perceived roles. I have remembered this event forever, I call it a "moment of consequence" and I often wonder what effect it had on those men and their doctoring. I am sure it must have helped them like it helped me.

I learned not only about dying with grace, but I learned about being assertive in that moment. I remember that charge nurse as a gentle, humorous woman with strong religious conviction. I remember her as courageous and she taught me a great many things. I was so lucky to have worked under her guidance, though having said that, I guess I was guided to her as part of my unfoldment as a nurse and a human, living my own life and sharing other people's journeys.

In the palliative care setting, studies have indicated the importance of acknowledging existential issues (Blinderman and Cherny 2005; Moadel et al 1999; Cohen et al 1996). One study (Moadel et al 1999) indicates that 51% of patients desired help with overcoming fear, 42% with finding hope, 40% with finding meaning in life and 30% with finding spiritual resources. From multiple studies, researchers conclude that existential wellbeing is important to quality of life (Cohen et al (1996), You might say that we didn't need research to tell us that, but I guess an outcome of the evidence base movement is that objective measurement is seen as the only reliable method of truly knowing anything. The gold standard for knowledge development today excludes the ways in which the knowing in our hearts teaches us. Maybe I am too cynical?

It was the isolating consequence of suffering that became a core function of the hospice movement which purports to operate from a perspective that includes existential well being. Hospice has a trinity of values:

- Palliation and the relief of suffering
- Enhancing personal control and autonomy, and
- Healing or making whole. (Jennings (1997).

Marjorie Dobratz from the University of Washington argues however, that there has been a contemporary shift from hospice to palliative care units in hospitals where there is more of a focus on physical care and medical response.

The loneliness of suffering is well recognised, but in the acute, medicalised environment of hospitals, even in palliative care wards, it is difficult to address. This leads inevitably to an emphasis on the physical and a de-emhasising of things like 'the healing and making whole' value mentioned in respect of hospice. McNamara (2004) calls this the 'good enough death', and he states that "whilst pain is managed and physical symptoms are controlled, palliative care practitioners are often unable to facilitate a death that includes the carative work of 'healing and making whole'." (McNamara in Dobratz 2005). This phrase "a good enough death" makes me shiver, but I know it well, and I imagine that many, if not all of you here, also know exactly what it means.

I am aware that right now, back in Australia, one of our palliative care units has just appointed a new medical director and the immediate shift to a strongly medicalised approach has been astonishing and disappointing really. Patients are now only to be admitted to the palliative care unit if there is something that medicine can offer them. The need for nursing and pastoral services are not a sufficient reason for admittance. Managing their death now occurs somewhere else, probably in a nursing home if the family can't cope at home. I wonder and I fear that this might turn out to be a shift toward 'good enough'.

My second story is about the 'good enough' death, and occurred the year after the story I told you before. This one tells you how my lessons about existential suffering and caring

for Spirit manifested in my life as a clinical nurse. Now I am a first year graduate nurse and again, back in that same ward, but with a very different charge nurse. I was caring for a man who was dying of cancer with secondaries all over the place. He was conscious but very sick. In the course of doing a treatment with him he asked me if he was dying. It was a frozen moment for me. Nurses were not allowed to give that kind of information in those days. It was seen as diagnosing which was out of our scope of practice. I knew intuitively though, that this man was suffering through more than his cancer, and I felt a little anger that he had not been told he was so close to death. He was still being actively treated but everyone on staff knew he was close to death. I hesitated and then I drew strength from my role model in the charge nurse of the year before, and I said "yes, I am sorry, you are dying, this cancer is very advanced". He was relieved, I guess he knew on the inside.

I knew something of his history, he was a middle-aged man, single and estranged from his brother, his only relative. I asked him if he would like me to try to find his brother, maybe he had some unfinished business that he could attend to in the time he had left. He wanted to think about that. Later he said that he would like me to try to find him and ask if he would come in to visit. It was not so hard to find him, and when I rang and spoke to him, he was a bit terse, but he did come the next day, they did connect and my patient was relieved that he had mended this rift. He was close to death. He asked me how long it would be and I said I was not sure but not long, not days. I said I would do my best to make him comfortable and I would try to see that he did not die alone. Instead of going home when my shift ended, I sat by him and held his hand. It didn't take long.

I cried when I left him and the new charge nurse berated me for showing emotion. I went home, but I did not ever forget. He sits solidly in my sacred library. I knew that in a very simple way I changed his death from loneliness and isolation and fear, to readiness and acceptance just by being honest and compassionate and being willing to stay. That moment when I decided to respond to his spiritual pain honestly was another "moment of consequence".

Anyone who works with people at the raw edge of experience has these stories. I am sure that everyone in this room has. Many of the stories we hold hurt us deeply. It is good to become aware of the stories locked away inside our hearts, and also to become aware of the deep grief that many of us never acknowledge, far less learn to manage. And I am aware that we not only hold this grief as individuals, we hold it collectively. It is one of the things that unites all of us. I have this sense that speaking our stories, taking them out and looking at them, sharing them with others who listen with respect and care helps us to take what we can to learn from them. We can then put them gently back in their place with a little more understanding and with a little less pain.

Lindholm and Eriksson are two Swedish nurse academics who write:

In the 'drama of suffering' the patient longs for genuine compassion. The answer to this longing is a sensitive listener who can cooperate with the patient in the drama of suffering and be someone who can sustain the mission of compassion in a courageous and powerful way, by being 'an enduring surrounding' (2001 in Rehnsfeldt and Eriksson 2004:266).

I watched Peter Roberts be an enduring surrounding so many times, and I know that is what I was on that day. This is about what Strozzi-Heckler calls "the simple but daring contribution of genuine presence." Charles Birch who is an Emeritus Professor of Biology at Sydney University in Australia, but who has turned his attention to ecospirituality, mentions this when writing about compassion. He defines compassion as 'feeling with', and the necessary condition of "a genuine relationship is to be *completely* present, one to the other." (1997: 25). As an aside, Professor Birch is now considered by scientist colleagues, as having 'gone ferral'. I think he likes the title, but it says a lot about science, a rationalist view and going back to the earlier comment by Eric Cassell it should not surprise us that science could not comprehend the whole that is the human soul of Charles Birch.

It is sometimes difficult to find the language to help and to be able to stay with suffering. For health professionals who experience this difficulty themselves, it is near impossible to help relatives to find the language and stay with suffering, and yet this is exactly what is needed to reduce the existential loneliness and create time for good endings. Levine (1984) writes of his experiences with dying people and their relatives. Often he found

relatives who were encouraging them through all manner of things, to 'hold on'. He writes, "Often I find I am the only one in the room for whom it is really ok that the person is dying". Robert Sardello (1999:115) acknowledges that visitors to terminally ill people often come to express sympathy and then talk about what is going on in their own lives and the world, catching the sick person up with events that they are missing. "If we are lucky," he writes, "not every visitor who comes is so uncomfortable at the sight of our suffering that he diverts attention away from the intense reality on to other subjects. At least one person, we hope, is able to lament, mourn, cry out with us in our suffering, and indeed help us to enter it even more deeply." Phyllida Anam Aire from Findhorn in Scotland, has written a poem that beautifully captures this need people have for someone to connect in this real way. We used a section of her poem, with her permission, in our report:

Can you be with me in the cold morning of dying? When the fire in me is out and nothing warms my blood Can you watch with the eye of a mother? When the candle is burnt and all the friends have gone? Can you just be, not wishing any more breath in me?... (2005: 22, Copyright permission given January 2006).

This notion of complete presence is also described by Ram Dass in his early work of sitting with the dying. He recalls being appalled at the "cultural pathology" surrounding death, where "the dying person was surrounded by lies and hypocrisy" where people may not be told that they are dying either by medicine or by families who hold it in the best interests of the dying person not to have hope removed. He discovered that all he needed to do was to keep his soul open and found himself in great demand to be present at people's dying. He found also that relatives brought him their pain and grief and anger. He discovered that what he had to offer had nothing to do with wise utterances, but with his Soul presence. He writes, "Sitting in *genuine peace* (original emphasis) with people who were dying seemed to have a contagious effect; the spaciousness of resting in my soul, rather than in my ego, seemed to magnetize the consciousness of those I sat with, leading them toward silence and their own Soul's embrace" (2000: 177).

As a witness to Peter's work of music-thanatology, he seemed to me to be sitting in this genuine peace, completely outside his ego, not denying this death process in front of him, but embracing it and offering his soul in comfort.

I have always known, and Peter reinforced this knowing for me: that genuine presence is not about what we do, it is about who we are, and it is something we must all find the courage for if we are truly to make a difference. I said earlier that this willingness to stay, 'to be with' is the remit of music-thanatology, but the point I want to reinforce for you today, is that this is the remit of **anyone** who works with people who are suffering from any cause and at any level.

Let me repeat what Strozzi Heckler wrote: 'The simple but daring contribution of genuine presence' I have spoken of the idea of genuine presence, but what of this 'simple' bit? Is it so simple, and if it is why do we not see it all around us?

For me simple is exactly the word. If you consider that genuine presence is a way of being, it is remarkably simple, just **be it**, and let the **not being it** go. It takes energy, work, to not be it.

I was having a conversation with my daughter the other day, and we were talking about yoga and meditation, and having things rise up in us. My daughter Nicole teaches yoga teachers and one of her students had been grappling with what you do with things that rise up - thoughts, confusions, conflicts that rise up in you in yoga practice. The woman was looking for a recipe, some sort of technique for how to deal with these things. Nicole's instruction was to 'simply let it go, note it, do not engage with it, do not give it substance that would hook you into it, just let it go'. Her student was perplexed and said 'But how do I just let it go, how physically do I do that?' Nicole thought for a moment and then she said, "think about when you burp! When you burp, the burp just rises, you aware of it but you do not normally do anything about it do you?" the woman said 'No'. Nicole then said, 'well it is just the same, it rises, you know it is there, you do not stop it

or try to do anything else with it, you just let it go. It is exactly the same with these things that arise in your yoga practice, just let them go'. Her student got it.

That made sense to me when I think of how I hold my hands to play the harp. At the end of a movement I let all substance in my hands go and my hands are empty. Not just having nothing in my **hands**, but nothing **in** my hands, no tension in the bones or muscles, all hollow and completely empty. It took me ages to get that, then one day I did, my version of the burp I guess. It was so simple once I understood it.

The simple in simple genuine presence is just like that. It arises from the heart, it is part of who you are that led you to the work you do in the first place. It is the space you occupy, maybe you and the enduring surrounding of yourself? Things that get in the way, the business and the distractions that would move you out of the space can be let go of – see them, understand them and let them go - the burp or the empty hands. I think this is what Ram Dass is saying when he tells us he sits in genuine peace. There is no struggle in genuine presence, one simply 'is'. How to convey this to people who talk about burn out and distancing? How to find this understanding for ourselves and help others to find it too?

Having said that, there is no doubt that what we might call 'right relationship' as a health care professional is difficult. I don't know anyone who can be gentle and serene all of the time. Maybe some Buddhists I know I suppose. I do think that staying with someone else's pain and distress is one of the hardest things that we do. That is why we need to do everything we can to nurture our ability to stay; our own ability and that of others around us. We need to structure our work roles, our environments and our relationships so as to keep our spirit of caring alive. The last thing we need, just because sometimes it hurts, is to activate our immunity, to desensitise, take the antihistamines in whatever form that might occur.

Research in nursing highlights the language nurses use to describe their work in hospice where their encounters with death are "constant and unremitting" (Froggat 1998: 334). Emotional pain was described either as a drain, or creating a burden.

By being a drain, nurses were expressing a metaphorical flowing out of the resources they have to work well. By working well, nurses generally mean "being there" for people, again, this notion of genuine presence.

Creating a burden was about heavy load – that load being the constant taking on of people's issues so that they were weighed down.

Nurses manage their emotion in a variety of ways: Switching off, distancing and hardening are some. They either have to plug the drain or stop excess emotion filling them up. Either way, this implies the need to put up boundaries. In the putting up of boundaries, genuine presence is impossible and the very ideal that these nurses would espouse is defeated. So we need somehow, to learn how to live with it, because it is what we do. The urgent need then, if this powerful existential encounter work is to continue, is to create sustaining mechanisms for all those involved in caring encounters.

At the 13th International Association for Human Caring Conference in 1991, the Rev. John Karl gave a paper titled 'Being There: Who Do You Bring To Practice?' In this paper he acknowledged how difficult it is sometimes to really 'be there well' for someone, and he focussed on what it would mean to care for the wellbeing of practitioners so that they in turn may reach out to others. Here we are 15 years later still learning these lessons. Karl began by recounting the myth of the jewelled net of Indra, which stretches out to infinity and which has a magnificent jewel in each 'eye' of the net. Each jewel reflecting the infinity of jewels. He used the net as a metaphor, suggesting that the strands connect things and when the connections are not nurtured they become damaged and tear. The holes that appear are where '[1]ife falls through' (1992: 2) and suggests that the holes need highlighting and the strands need nurturing to keep them supple and strong and need to be rewoven where they tear.

Karl rested the discussion in his paper on the fundamental assumption that 'the more practitioners are rooted in sources that animate their being, the greater the capacity to be

there' (1992: 5), and the less likely they are to fall through the holes in the net. He categorised these sources as being balanced, being held, and being sustained.

**Being balanced** is about caring for the body, mind, spirit and relationships on the understanding that the more balanced one is, the more one can reach out.

**Being held** is about 'holding environments', places and situations where those things occur which are emotionally and physically nourishing. As children we are held, as adults we hold, but even as adults we also need to be held and awareness of the need to create holding environments for each other in clinical partnerships creates a very different space from that where each practitioner works in isolation without regard for the other.

**Being sustained** is about the individual's subjective experience of being held.

Sister Simone Roach responded to the Rev. Karl's paper by making the point that to be able to be a holder or a sustainer for others is a sacred trust. Roach paraphrases Taylor Caldwell, who considers that the most urgent need that exists in society today is not for medical advancement, new cures, new ways of living, new anything — the real need is for someone to listen 'as a human soul' (Caldwell 1960 in Roach 1992). That takes us right back to the notion of enduring surroundings, only now we can add to the ways we understand that, now we are including being an enduring surrounding for each other in our caring practice. Having someone to talk to about the things that are really real, the confusions, the chaos, the bewilderments of life, is to have someone to help the balancing, the holding and the sustaining.

Francelyn Reeder also responded to Karl's paper, and she reminded her audience that one does not need to be physically present with clients to 'be there well'; that practice needs to be broadly defined. She is actually referring to administrators and those planning services, in respect of how they carry understandings in their hearts which lead them to set up Karl's 'holding environments' for staff; their caring occurs in what they establish, as much as from how they are with members of their staff.

Wouldn't it be amazing if the contemporary literature about leadership in our economically driven system contained the imperative to create holding environments and foster individuals and institutions as enduring surroundings!

Some do. In my experience I see it more profoundly in the Catholic health care system than in other sectors, maybe you see it in some places also.

## To conclude:

We wrote in the report that is a matter of ethical demand that dying patients are to be 'met' at the level of their spiritual and existential situatedness in the moment. In other words, those caring for them need to understand where they are on their journey and how the journey is affecting them. This is not just intuited knowledge. It arises from a deep knowing of the human journey and that everyone suffers as a necessary condition of being human.

In our report we write of the arguments for the shift to humanistic medicine, and for nurses and others to connect in genuine compassion. The wise practitioner, to use the Polish ecophilosopher Henryk Skolimoswki's language, has deep compassion born of suffering and through compassion responds with deep and genuine presence. There are arguments for health professionals to use their knowing and wisdom to tutor relatives through the final journey of a loved one, to find the words, to be able to stay with the suffering, to grieve, mourn, cry, not for but with the suffering and to move beyond the suffering.

The study that we did on music-thanatology discusses medicalisation at end-of-life and how dominant models make it difficult to implement values such as those the hospice movement espouses, that patients need and that would be held dear by palliative care staff had they choice. The nurses in our study in particular lamented the busyness of their day where they cared for post surgical patients as well as their palliative care patients close to death. They were well aware that on a daily basis, they were not able to do the things that they believed were intrinsic to palliative care and to caring well for the dying. Sadly, nurses recognise the term 'good enough death' and when they get the message of simple but daring genuine presence, its absence creates dissatisfaction with their working lives. Sometimes we lose them. And if all we have left are those who have created successful barriers for drain and burden then we are in a far more impoverished place.

It is important though, not to vilify hospitals or medicine, great good is done in hospitals where as Ram Dass (2000) says, the profoundly spiritual ideal of relieving suffering lies behind action. Many patients prefer to die in hospital rather than burden family or to hide their undignified decline. The issue is how can the hospital create the environment for the 'good death' rather than the 'good enough death'? because a 'good death' can occur in institutionalised settings. How can palliative care staff with all of their good intent but the realities of their working day, attend to the healing and making whole as well as palliation and relief of the suffering that has its roots in pain and discomfort? That is the challenge for the staff in palliative care services – the nurses, the medical staff, the allied health staff and the pastoral care staff.

This busy attention to the physical is the reality of the acute hospital environment and other means need to be found in order to meet this ethical demand of journeying with dying people in those settings. This is a question that needs addressing by a larger audience than the executive of a hospital, Somehow contemporary society needs to revert to seeing dying as a familiar event where everyone collaborates to create a loving environment, where death can be talked about, needs expressed, plans made. This of course goes to the core of contemporary culture. The fundamental change is to removing the failure associated with death and restoring death as "the only way humans acquire the fullness of life" (Liebanas 2002:38).

## REFERENCE LIST

Anam Aire P. (2005) A Celtic book of dying: Watching with the dying, travelling with the dead. Findhorn Press, Forres, Scotland.

Birch C. 1993) *Regaining compassion for humanity and nature*. New South Wales University Press, Kensington NSW Australia.

Blinderman C. & Cherny N. (2005) Existential issues do not necessarily result in existential suffering: Lessons from cancer patients in Israel. *Palliative Medicine* 19:371-380.

Brallier L. (1992) The suffering of terminal illness: cancer. In P. Starck & J. McGovern *The hidden dimension of illness: Human suffering*. NLN Press, New York

Cassell E (1992) The nature of suffering: Physical, psychological, social and spiritual aspects in P. Stark & J. McGovern, Eds *The hidden dimension of illness: Human suffering*. NLN Press, New York.

Cassell E. (2003) *The nature of suffering and the goals of medicine* 2<sup>nd</sup> ed. New York, Oxford University Press.

Cohen S. Mount B. Thomas J. Mount L. (1996) Existential well-being is an important determinate of quality of life. *Cancer* 77:576-586

Dass Ram (2000) Still here: Embracing aging, changing and dying. Hodder, Sydney, Australia.

Dobratz M. (2005) Gently into the light: A call for the critical analysis of end-of-life outcomes. *Advances in Nursing Science* 28(2): 116-126.

Froggat K. (1998) The place of metaphor and language in exploring nurses' emotional work. *Journal of Advanced Nursing* 28(2); 332-338.

Higginson I. Astin P & Dolan S. (1998) Where do cancer patients die? Ten year trends in the place of death in England. *Palliative Medicine* 12:253-263.

Howarth G. (2000) Dismantling the boundaries between life and death. *Mortality* 5(2):127-138.

Jenning B. (1997) Individual rights and human good in hospice. Hospice Journal 12(2): 1-7.

Jones, C. (1998), An Authentic Life: Finding Meaning and Spirituality in Everyday Life. ABC Books, Sydney.

Karl Rev J. (1992) Being there: who do you bring to practice? In D. Gaut (Ed). *The presence of caring in nursing*. (Pp1-13) National League for Nursing. New York.

Lazare A. Reflections on suffering. In S. Bertman (Ed). (1999) *Grief and the healing arts: Creativity as therapy*. Pp 89-92. Baywood Publishing Co Inc., Amityville, New York.

Levine S. (1984) Meetings at the edge: Dialogues with the grieving and the dying, the healing and the healed. Gateway Books, Bath, UK.

Liebanas R.M (2992) Shame, death and dying. *Pastoral Psychology* 51(1):27-40.

Moadel A. Morgan C. Fatone A et al (1999) Seeking meaning and hope: Self reported spiritual and existential needs among an ethnically diverse cancer patient population. *Psych-Oncology* 8:378-385.

Reeder F. (1992) Response to "Being there: Who do you bring to practice. In D.A Gaut (Ed) The presence of caring in nursing (pp18-23). New York, NLN.

Rehnsfeldt A. & Eriksson K. (2004) The progression of suffering implies alleviated suffering. *Scandinavian Journal of Caring Science* 18:264-272.

Roach Sr S. (1992) Response to "Being there: Who do you bring to practice. In D.A Gaut (Ed) The presence of caring in nursing (pp14-17). New York, NLN.

Sardello R. 1999) Freeing the soul from fear. Riverhead Books, New York.

Simmonds A. (1997) Pastoral perspectives in intensive care: Experiences of doctors and nurses with dying patients. *The Journal of Pastoral Care* 51(3): 271-281.

Skolimowski H. (1992) Living philosophy: Eco-philosophy as a tree of life. London, Arkana.

Strozzi-Heckler R. (1997) *Holding the centre: Sanctuary in a time of confusion*. Frog Ltd, Berkeley, California.

Tang S. (2003) When death is imminent: Where terminally ill patients with cancer prefer to die and why. *Cancer Nursing* 26(3): 245-251.