# Winston Churchill Trust Fellowship 2006

# "THE ROLE OF LOVE IN PALLIATIVE CARE"

by Gemini Adams

Primary Aim: To explore the approach, attitudes and application of the conscious use of 'love' within palliative care organisations in the USA.

Destination: United States of America/Latin America
Theme: Care of the Dying
Duration: 10 weeks

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# Introduction

My interest in palliative care, and more significantly "love", began when I lost my mother to cancer after a two-year battle against the disease. I was just eighteen when she was diagnosed with secondary lung and liver cancer. I was twenty-one when she died. My interests prior to this had been typical of a young adult. My time was filled with studies and the normal busy activities of university life. I certainly wasn't interested in death, dying or the bereaved. I typically perceived my family and I to be 'immortal', imagining that we would all lead full and vibrant lives. Consequently, after my mother's death I took quite a fall from this naive pedestal. As a result, my attitude, and interests changed considerably.

Ten years of grief ensued and slowly I came to terms with a life absent of my mother. It wasn't an easy journey and despite what I had lost I discovered that I learnt a lot along the way. I realised that in my wisdom perhaps there was something I could contribute to others. So I began to write a book.

My aim was to help individuals prepare better for death. Firstly by accepting that death will happen, and secondly, by helping people recognise the value of their 'emotional assets'. The key theme to the book is the message that by creating a Legacy of Love, prior to death, that you can help to reduce some of the suffering and impacts of grief on your loved ones.

As I had no prior experience working in the field of nursing, bereavement or hospice care, I spent a good deal of time conducting desk research and interviewing others who worked in the field. This gave me the background and context that I needed for this work, together with more insight and experience.

Whilst researching the book, my interest and understanding around love deepened. I began to feel that it was my purpose to write, explore and talk about the subject. This came from a strong intuitive sense that there is a craving for love in what has become a 'loveless' society. This is especially true during times of trauma, such as the death of a relative or friend.

The only problem with the subject of love is how you quantify it. How do you define it? And how do you prove it has any kind of benefit? It became my desire to explore questions such as these, to study and research love. And to gain a much deeper understanding of how love can help on a physical, mental, emotional and spiritual level. At the time that this desire was emerging I was a part-time writer, working also as a marketing consultant to make ends meet. How on earth did I cross the bridge to become a 'love' investigator? This question was permanently on my mind. Until serendipity saved the day! I was having a drink with a friend in Cambridge and he shared with me his experience as a Fellow with the Winston Churchill Trust during 2005. It sounded spectacular! He had travelled around America interviewing directors of museums. I was intriqued. He

explained the Trust accepted applications for any project within certain fields and that applicants did not require academic training in the specific field.

The following morning I jumped online and visited <a href="www.wcmt.org">www.wcmt.org</a> for the first time. Much to my amazement one of the categories was Care of the Dying. "Unbelievable!" I thought. So I hurried through the site learning more about the application process and what was required. I discovered the closing date was less than a week away! Working to deadlines is something I certainly excel at, so within five days I turned around my application and references, tucking the necessary paperwork into an envelope along with a little prayer, I popped my application into the post.

Less than two months later, I received the final letter in the post. I had already received preliminary acceptance and attended the interview in front of the panel. So here it was. The final communication was in my hand; I knew I had a 50/50 chance. Acceptance or rejection! It was worse than getting my exam results. I have to confess I wasn't an avid academic during my teens and cared little about my results. But this was really important to me. This was my opportunity to explore something that I felt could benefit the country and the rest of the world.

#### The Task Ahead

After opening that envelope and reading he words 'Congratulations', I was jubilant! And incredibly excited that I was now able to further explore this subject that is so dear to my heart, I immediately began planning and researching. I wanted to go as son as possible. So, I set the departure date for early May of 2006. That gave me just three months to prepare.

My plan was always to move around. I wanted to meet as many people as possible, and gain diversity in opinions and experiences. So I set myself the task of visiting 30 organisations in ten weeks. Covering thousands of miles across the states, then followed by a trip to Latin America to visit an Amazonian medical research project and a shamanistic tribe. There is nothing like a challenge! By the beginning of May I was ready for the off. Bags packed and goodbyes to friends and family, I headed for American shores with the following objectives in mind:

# **Primary Objectives**

- Identify specific benefits of the conscious application of 'love' in palliative care.
- Explore the cross-cultural attitudes towards the use and understanding of love in palliative care.
- Gain a better understanding of individual attitudes and understandings of what 'love' means amongst palliative care directors and workers.

I had the advantage of my book as way of an introduction, even though it isn't due for publication until June 2007. I knew that my lack of qualification in the 'field' could otherwise have put people off. And even though the WCMT is well known in the UK, and I am sure other parts of the world, I found that on many occasions I had to explain the aims and activities of the Trust. But no one turned me away. I was always obliging, and in this field of work understanding of the sensitivities of screening individuals, knowing I would be coming into contact with people who were in the final stage of life. I knew this was a great honour.

Of the organisations and individuals I had short-listed only a few were unavailable for interview. You have to remain flexible while doing a Fellowship. Anything can happen, so it's always good to have a plan B. If I couldn't meet someone on the day planned, I just shifted everything around, and would move 'relax' days (of which there were few!) around to compensate. I did have one or two key people cancel, one was sick, and the other had to take care of a sick relative. One severely affected my plans as I was only going to Miami to meet with him. However, instead I extended my stay in Portland and met some great people. Somehow things always worked out.

## The Fellowship

My aims for the fellowship were to conduct open research into the 'Role of Love in Palliative Care'. Despite my ongoing studies around love for my book, I knew little about palliative care and even less about the two subjects in combination.

My reason for choosing America was because I had learned from my earlier research that the approach to hospice and palliative care was more holistic in the states than in the UK. There is also an emphasis on emotional and spiritual care. I believed that there was much to be learnt from those institutions that had made this a priority and a practise. Another key benefit of America was that it is an English speaking country. This meant that I could get more knowledge from the experience. My choice to visit Latin America came from an interest in the Shamanistic approach to death. Their unconditional love of plants, the planet and people was, and still is, fascinating to me.

My aim to do open research meant that I set the goal to meet as many people and visit as many institutions as was feasible with the time and resources available. I had considered spending the entire fellowship in one location to gain an in-depth experience of how carers deliver love in palliative care. However, I felt I would gain far more by commencing with a broad spectrum of disciplines, institutions and care organisations. I took the approach of an exploratory study, combining desk research with interviews, meeting directors, carers and patients in leading palliative care and educational organisations. Along the way I also watched films, attended seminars, spiritual services, read books and occasionally took a break to do some sightseeing!

My itinerary (Appendix 1) took me to Boston, Portland, New York, Los Angeles, San Francisco, Washington and finally Peru. I conducted over 30 interviews, each taking 1 – 6 hours and spent considerable time observing the practises within these organisations. To document all of this would be impossible within the boundaries of this report. However, I did record my interviews as I went along. But for the purpose of this report, I felt that the greatest benefit I could offer would be to identify the key findings of this research. Providing a guide, both for the premise of further research and to assist those who are keen to explore the subject or even to actively implement love within a palliative care setting. The following section outlines these key findings. Offering a proactive philosophy and benchmarks for implementing and developing a loving environment in hospices, hospitals and palliative care units. I have also identified what was achieved in relation to the objectives.

I am incredibly grateful for this opportunity to gain such wisdom, to meet some of the most inspiring leaders in this field and to begin the journey of living my life's purpose. Hopefully this will give individual carers and directors of palliative care organisations in the UK the information, the philosophy and the practises to make a difference to the lives of their patients and their families.

# **Definitions and Understandings**

One of the most difficult things to do in the context of my work is to define love. We all have different experiences of love, and attach our own meaning to the word. In its simplest form, it means to care or to show affection. If this were the interpretation, then you would automatically assume that love already exists within any palliative care unit, as this is surely the reason for their existence. However, this is not the case.

Love comes in many forms, and can be expressed in many ways. Love works miracles, hence why God and love are frequently perceived as synonymous. Yet as human beings we frequently find that to love is the hardest task of all. But love is the one thing we seek above all else. It doesn't matter whether we are healthy and happy, or ill, depressed and lonely. Love is our fuel. We need it to survive and if we receive it in abundance we thrive. It doesn't matter what age we are, our need for love never dies.

I came across the following prayer on my travels. Sixteen year old Emily (the author) does a wonderful job of illuminating the role that love plays in allaying her fears and loneliness and how the love of another helped her to feel strong, protected, safe, connected and not alone.

# A Child's Prayer

Will you hug me mummy?
Will you wrap me in your arms
And press your face to mine
And whisper happy memories in my ear.

For when shadows dace around me And I feel alone in the dark, I need to recall your gentle touch And know that you are near.

Will you hold me Daddy?
Will you take my hand
And weave strong fingers into mine,
And tell me how you love me.

For when the monsters invade my dreams And I feel helpless and afraid, I need to remember your powerful hands And feel your strong protection.

Emily (Aged 16)

Within this prayer, Emily unknowingly pinpoints the key emotional challenges faced by those in palliative care. Being a child and having a terminal or long-term illness has many similarities. There is a strong need for physical touch and connection. A desire to be protected against the unknown, a need to have familiar faces close by. A desire to have fears of loneliness and a sense of helplessness dispelled. As Emily notes all of these fears and negative emotions can be cured with love. Whether it be the loving presence, action or embrace of another.

The title for my fellowship was 'The role of love in palliative care', which is interpreted as, can love play a part in allaying the fears and negative emotions experienced by the terminally ill? Before I answer this question, let me introduce what Dr. Gary Chapman defines as the five languages of love. These are the ways in which we can express love and experience ourselves as being loved by another person.

- Words of Affirmation
- Giving and Receiving Gifts
- Quality Time

- Acts of Service
- Physical Touch

The reason I share this definition, is that I have discovered that love is required as an action. In passive form it can provide great benefits. But when practised, acted on, intended and expressed, in a conscious manner, then the benefits are magnified. Not just for the receiver, but also the giver. The aim of the Fellowship was to understand how we can improve palliative care through an awareness of love, and a practical application of love. Why? Because, love heals, love inspires, love brings peace, laughter and joy. Experiences and emotions that I have discovered are vital to those who are suffering.

During my fellowship I interviewed a number of patients who were resident in hospices, cancer wards, hospitals and palliative care units. They were lucky enough to be in the care of individuals who consciously practised love as an integral part of their palliative care work. Within these organisations, the focus is the 'whole' person. There was a critical understanding that physical care didn't just mean clinical care or pain management, but the treatment of the emotional, spiritual and mental needs of the patients. The result was that the patients resident in these places emitted something wonderful. They had dignity. They had hope. Even if they knew they were dying. They glowed. There hope was not of living but a hope in humanity. Hope for their families. They experienced joy and laughter on a daily basis, even when they were suffering immense pain. They had a sense of calm, of inner peace. And most of all they knew they were loved.

This feeling of being loved didn't just come from knowing that their family and friends were there to support them. It was because they knew that even in their worst state, when they had lost their hair through chemotherapy, or were unable to do the most simple tasks, like washing or visiting the bathroom, unable to hold a spoon to their mouths, that the person, the carer who is their guardian is holding their hand and loving them in their thoughts expression, actions and their words. This all-inclusive expression of love by the carers gave these patients and their families a great gift; one that many had never previously received, the knowledge that they were good, and loveable human beings.

I cannot define the benefits to these patients in a better way without a study documenting quantifiable results. The effects of the carers practise of 'conscious love' was recognisable by their sunny attitude, the depth of their compassion, and the care they gave to even the most mundane of tasks. On one unit I visited in Portland the nurses push a 'Comfort Cart' around once a day -- patients can pick from a choice of books, music, poems, relaxation aids and aromatherapy oils amongst other items - the result of this was fascinating. An entire ward of patients was left with serene smiles as they were lovingly transported away to a place of peace by the loving words, sounds and touch of the authors behind the comforting poetry and lyrics. This was one of the carer's ideas for how they could extend their loving service when the wards were quiet.

At the Calvary Hospital in New York an emphasis is placed on lovingly 'beautifying' the patients each day. This is always an invitation; nothing is ever inflicted in the organisations where conscious love is present. The ladies have their finger nails painted, their faces gently washed, facepacks applied, their hair done, make-up put on, and nice clothes are worn. Dr. Robert Breschia explains how this gives people a sense of self. "People feel ugly when they are dying. They fear being abandoned because they are no longer self-reliant, they aren't strong or beautiful or intelligent enough anymore. This fear causes a huge amount of emotional and spiritual stress and suffering. By treating them as if they are special, making them look good, it helps them to feel good, to feel loved."

At Calvary the aim is to provide exquisite care. This has resounding positive impact on the patients. Sue (not her real name) a terminal cancer patient spent the last three months of her life at Calvary. She had a tough life. Orphaned, made homeless and addicted to drugs. She had tried to commit suicide twice. She was thirty-five when she was diagnosed with cancer of the oesophagus. Before she died, she told Dr. Breschia that the last three months spent in Calvary were the best of her entire life. She explained that her life had been loveless. How finally she had found at Calvary what she had spent her whole life seeking and now she could die fulfilled, happy and in peace. How many Sue's might there be if exquisite and active loving care was practised in all palliative care units?

Sue is one of many glowing examples of the effect of love in palliative care that I discovered during my fellowship. Each gave me more evidence that there is a much-needed role for love in palliative care. How love is implied, implemented, quantified and measured is something that is beyond the parameters of this research. However, what I was able to do during my fellowship was to identify how specific individuals and organisations have found ways to 'love consciously' within palliative care which has resulted in resounding positive impact on patients and their families.

The following points are the key findings gained from this research; ideas, actions, philosophies, and practical concepts, which can be adapted for use in a care environment to improve emotional and spiritual care of patients.

## **Key Findings & Recommendations**

This section presents the key findings of my fellowship. I plan to share these with colleagues in the palliative care community in the United Kingdom and am currently in the process of launching a website to support my forthcoming book where I will also host this report, and articles discussing these findings.

- 1 It should not be assumed that just because a palliative care department exists that love is automatically practised within this environment. Love needs to be established as a core value of the organisation and carers require ongoing training in how to demonstrate love within their work.
- 2 Palliative care workers need to be shown how to give love in their work, and it must become a conscious intention of the organisation and the individuals to create a loving community and practise. One of the most successful ways of achieving this is to introduce a meditation, or moment of prayer before nurses/workers commence a shift. This does not require a religious element. It can be observed as a time for silence and space, giving nurses, doctors and carers the opportunity to remove their energies from the everyday, and to set their loving intention, before commencing work and interacting with patients. This is a time to tap-in to compassion, to ones reserve of love, to God, to be open to experiencing the pain, confusion and suffering of others and to remove yourself from your own troubles, so that you can give 100% focus to those in your care.
- 3 In addition to creating a core-value of love within the organisation and setting an intent to 'be loving', there are values of great importance required to provide a cohesive and comprehensively loving environment. The table overleaf provides suggestions, many of which featured in the mission statements, core values and beliefs of the organisations I visited. It is helpful if values such as these are selected by the carers within the palliative community rather than imposed by regulators or directors. Once agreed, they should be published, and placed in a visible place where everyone will see them on a daily basis.

Dignity - Love - Acknowledgement

Compassion
 Selflessness
 Oneness
 Spiritual Practise
 Inclusion
 Equanimity
 Honesty
 Communication
 Reciprocation
 Reflection
 Individuality
 Innovation
 Listening
 Peace
 Reflection
 Divinity

4 - In support of these values, rewards and recognition can be awarded to those who demonstrate a consistent implementation of the values. This is a highly effective motivational tool that I witnessed in many of the places I visited. In one instance, a ward of nurses had worked double shifts, back to back, to enable the nurses on another ward to have the day off so that they could attend the funeral of one of their colleagues. They were rewarded for their compassionate and selfless service with recognition. Money and gifts are not always what people seek in return for their efforts. Often the kind words from a senior member of staff mean more than an extra day holiday in lieu. However, it is also beneficial to provide tangible rewards as a way to motivate and encourage a team to develop their own loving practise, and to express this through their work.

5 - Love has different meanings to everyone. It is vital that the subject of love is discussed within palliative care communities. in small care teams it is important that the group learns what love represents to each of the individuals within their relationships and religions. Everyone has a different capacity and understanding of love. When individuals have a negative concept or experience of love, this can be improved through training, discussion, support and practise. Love cannot be prescribed, but it can be taught by example. In a number of units where love is a core value, carers who have negative behaviours are mentored with those who have a more developed approach to loving practise. Talks, seminars, debates and discussions around love and its application in the care environment can be held on a regular basis to promote an interest and awareness of the issues around the subject.

6 - Love expressed, as physical touch is something that we increasingly shy away from in all care environments. Legislation and fears around physical abuse mean that teachers, doctors, counsellors and nurses are frequently afraid of expressing emotional compassion towards their subjects. However, in order for patients to feel love, and to establish a connection, they must experience physical contact. This is critical when they are suffering from a fear that they are not loveable because of the way they look, or because their failing faculties means that their identity has dissolved. The George Washington Institute for Spirituality in Healthcare are doing an excellent job of re-educating the medical community about this need for physical connection with patients. They are helping doctors to gain an understanding of the benefits of this on the emotional and spiritual state of the patient. Palliative care units should have a clear policy on physical contact to prevent problems, while encouraging hugs, hand holding, massage and forehead stroking wherever possible. The physical expression of love in this

way is one of the most powerful methods for showing love and is especially important for those without living relatives or those whose friends and family are too scared to touch the dying. Carers should also be educated in how to cope with their own emotions surrounding this, as many fear their emergence of their own emotions if they reach-out to their patients in this way.

7 – Patients within Palliative care departments who were encouraged to perform and reflect on acts of self-love were generally more hopeful and content than whose who were not encouraged to do this. Many of the directors I spoke with, noted that a lack of self-love in patients prevents them from feeling that they have any sense of completion with their life. This can cause extreme emotional and spiritual suffering. Working with patients, and helping them to recognise that they are loved, that they have given love, and have left some kind of legacy, is vital for achieving completion, contentment and satisfaction at the end of life. Once again this is something that many carers are trained in and should be considered as another active and conscious way in which love can play a role in palliative care.

8 - In addition to recognising their own contribution, it is critical that individuals feel that they are, or have been loved. One of the primary questions asked by those in palliative care is; am I still loveable? Illness changes an individual's identity; it affects their self-esteem, their confidence, and their ability for selfreliance, frequently breeding a fear of abandonment. These influences mean that patients are desperately in need of love. Previously they may have received this abundantly from their friends and family, but when a debilitating, frightening terminal-illness takes hold, sometimes even the most loving families and individuals are frozen with fear. Where they could once easily hug someone, now they are terrified. They stand back, are unable to talk, afraid of expressing their own fears. In such scenarios the pain for patients is far more than the physical suffering associated with their illness. They experience a loss. A loss of relationship, a loss of a self, and worst of all a loss of love. Some never even have an experience of love to lose. Take the example of Sue, the orphan who became homeless and suicidal. Thankfully she ended up in a palliative care unit where love was conscious intention of the nurses and consequently the last three months of her life were the best. Love is a form of medicine. It doesn't necessarily heal external wounds, but it does heal the emotional ones. Many of the nurses working in these leading establishments cited that many patients have never been loved in this way before, the result is often tears of joy, smiles, hugs, laughter and a sense of peace, and contentment. They are all united in their belief, that to give love to those who are at the end of life is a gift.

9 - At the Zen Hospice Centre in San Francisco I discovered an interesting approach. Here the staff are all practicing Buddhists who volunteer their time. Buddhism is never forced on the residents who go there of their own accord, knowing they will spend their final days there. Everything that they do at this hospice is an invitation. There is no agenda to educate, include or convince anyone to do anything. There is a total respect and honour for the individual. Rev. Jennifer Block explained that dying is hard work. It is not a passive process.

Death involves a biochemical, biological, physical, mental, emotional and spiritual process. With the trials of illness, and the journey towards death, patients are not in a state for taking onboard anything new. This is a very important consideration to make when exploring how to express, or involve patients, in loving acts or work within palliative care.

- 10 One of the key challenges regarding the integration of love into palliative care is an individual's belief vis-à-vis religion and spirituality. Love is frequently associated with religion, especially within the Christian faith. Yet when people are facing death, their faith is often challenged. Talking about what love means to an individual can create additional stress, especially where a patient feels that God is unloving because he/she is taking their life away. Carers who have a strong faith must be considerate of treating patients who do not share this faith. Saying things like "god loves you" may be very unhelpful and inconsiderate. Many of the directors I met explained that individuals are asked about their beliefs and opinions, and that this does not affect the loving practise employed in these palliative care organisations. The fact that love is practised often helps create tangible evidence for those who are seeking deeper answers to the reasons for their illness, or the experience of dying.
- 11 Taking a loving approach to palliative care should be inclusive, not only of the carers, and the patients, but also the family of the patients. Terminal illness changes everything for everyone. Affecting relationships, communications, and all areas of their lives. Both the family and the patient begin to experience grief from the day a terminal illness is diagnosed. This results in multiple changes to everyday life, as well as, emotional, and spiritual trauma. Family members need to feel that they also have a loving space where they can comfortably share their experience. This is especially important if the patient is their primary source of love and they have no one else. In many of the palliative care organisations that I visited, the family and the patient were treated as one organism with a strong emphasis placed on care of the whole; the whole person and the whole family.
- 12 Part of the loving care of the family should include the creation of an opportunity to say goodbye. It is widely understood in the bereavement community that those who do not have the chance to tell a dying person that they are loved, or to say goodbye, will result in immense suffering, guilt and emotional pain. Those in palliative care have the opportunity to engage family members and encourage them to share their feelings and love for patients. It is imperative that the family are therefore aware of the transition when someone moves from living to dying and that an appropriate level of love is given to help the family through this process.
- 13 Love as a practical application can come through many mediums. I witnessed this in a variety of forms at the organisations I visited. In all cases these practical applications were in addition to the active love provided by the carers, and would perhaps have not been so effective if offered in isolation of this. The

best of these methods included using artwork, poetry, meditation, music, colour, reiki, and nature in the form of plants and flowers, animals and food.

- 14 One of the key concepts that continuously emerged in my interviews was the individual capacity to love. Not everyone is Jesus or the Buddha! In nearly these entire palliative care units it was not assumed that an individual carer knew how to give active love to a patient. Nor was it assumed that patients were able, or ready, to receive love. Individuality was honoured, and nothing was ever inflicted upon either the carer or patient. Everything given by the carer to the patient was a loving invitation. "Would you like me to hold your hand? Would you like me to stroke your forehead? Would you like to have your hair brushed today?" This gave the patients the understanding that they were respected as individuals and that they could have as much, or as little love, as they were capable of receiving in that specific moment,
- 15 A carer's capacity for love, to both give, and receive is the most critical aspect of providing love within palliative care. Working on the basis that everyone's capacity is different, according to his or her prior experience of love, it is vital that 'active love' is practised. Individuals need to be educated on how to do this, through mentoring, role-playing, discussion, education and support. Most of the directors I interviewed agreed that love is expressed in everything that they do; through the eyes, the voice, the ears, the heart and the hands. You do not actively love someone if you are stroking their hand but in your head you are thinking about how annoyed you are with your husband because he didn't do the washing up! Active love requires presence. At the Zen hospice Center one activity on their regular training programmes is the role-play of lovingly peeling an orange. I was at first somewhat bemused by this idea, but as Rev. Block explained, the more I began to understand. When a patient can no longer taste food, or cannot smell, feel, or see, the world is unrecognisable to them. If you shove a peeled orange in front of them, you rob them of a familiar and enjoyable experience. By learning to peel the orange in front of them, carefully describing to them the smell, the feel, the experience, then you share the encounter with them lovingly.
- 16 In all the organisations I visited where love was a core value, and practised consciously by the carers, the individual capacity for love was naturally and purposefully developed on a daily basis. Staff were required to attend regular workshops, and spend time connecting with fellow carers or meditating before each shift, taking a moment to tap-in to their individual compassion. All of the nurses, carers and doctors that I met said that working in this environment was an incredible experience. Demonstrated by the fact that the majority had worked in these organisations for ten, twenty and thirty years. But the job satisfaction wasn't the only benefit. Everyone I interviewed said, that in some way, the increase in their individual capacity for love had had immeasurable benefits on their private life, helping them to gain a higher level of patience, compassion, love, tenderness and joy in their relationships with family and friends.

#### Conclusion

While I was unable to ascertain any quantifiable proof that the role of love in palliative care provides immeasurable benefit, my research gave me enough evidence to be certain that there is an essential need for love in these environments. I was both touched, and inspired, by what I saw in these leading institutions. I really hope that this report will help inspire others to further explore this area, and consider how they might instil active and loving practise within their own palliative care units.

# **Fellowship Recommendations**

My suggestions to benefit future fellows based on learning's from my own experience are outlined below:

Give yourself six to eight months for advance preparation and planning. This does however depend on the nature of your fellowship, but certainly in my case I found that obtaining the time of project and organisation directors was sometimes difficult at such short notice. Many are booked up six months in advance.

Telecommunications are an obvious necessity for completing a fellowship, especially when visiting major cities. But they are also expensive. I would recommend a short-term rental on a contract mobile phone, rather than pay-as-you-go phone. These are especially expensive in the States. Alternatively use Skype to make calls. Internet access costs can also add up fast. Despite discovering free access on my laptop in Central Park in New York, which lowered my costs for a few days, this necessity really ate into my budget (\$15 a day in hotels and \$1 for 30 mins in internet cafes). It is much more cost effective if you can find someone whose office you can borrow or use libraries to access the internet.

If a fellowship involves travelling to numerous locations, involving various time zones and air travel it is advisable to incorporate time for relaxation. Travelling can be very tiring and it definitely takes a day or two to adjust to a new city. I found that it took a day or two to find my way around and familiarise myself with each location. Fellows would be well advised to have one or two days off at each city to relax and enjoy area of local interest. I was sometimes wiped out by jet-lag and the intensity of my work.

Travelling alone can also be quite lonesome. It helps if you can stay in bed and breakfasts or hostels where you are in contact with other travellers, otherwise you can find that you gain little human contact outside of your meetings.

#### APPENDIX 1

# **Fellowship Itinerary**

#### New York, NY (June 2006)

Library of Life, Henry Chamberlain, Director Columbia University & FDNY, Dr. Heidi Horsley Project on Death in America, (Soros Foundation) Mary Callaway, Director Calvary Hospital, Dr, Robert Breschia, Director of Hospice and Psychiatry School of Practical Philosophy, Lewis Solomon, Director St Pauls Church, Rev. Michael Sholts

## Washington, DC (June 2006)

Wend Center for Loss and Healing, Karen Puritano, Director of Programmes Institute for Spirituality in Healthcare, (GWISH) Christine Puchalski, Founder Center to Improve Care of the Dying, Joanne Lynn, Education Director

## Boston, MA (June 2006)

Harvard University/Boston Theological Institute, Professor Thomas Butler,

Compassionate Friends, Sarah Burns, Director

# San Francisco, CA (July 2006)

Zen Hospice Project, Rev. Jennifer Block, MA
Healing the Grieving Heart, Dr. Heidi Horsley, Founder & Director
The Awakening Centre, Ron Valle, Director
Living and Dying Project, Dale Borglum, Director
Hospice of Contra Costa, Jim Stark, Programme Coordinator
Sacred Dying Foundation, Rev. Megory Anderson, Founder & Director

#### Portland, OR (July 2006)

Death with Dignity Centre, Barbara Coombs Lee, President Compassion and Dying, Susanne Brooks, Executive Director The Dougy Centre, Donna Sherman, National Director Supportive Care Coalition, Karin Dufault, Executive Director Providence Healthcare, Center for Ethics, Rev. John F. Tuohey, Ph.D, Director

# Los Angeles, CA (July 2006)

Agape, International Spiritual Center, Rev. Coco Aman Kada, Sacred Healer & Hospice Worker Grief Recovery Institute, Russel Friedman, Director Trinity Care Hospice, Claire Tehan, Founder Project on Being with Dying, Joan Halifax, Director Music Thanatologist, Providence Healthcare, Sheila Harris

# Peru, Chimbote

St James Hospice, Sr. Juanita Albracht, Founder & Director

# Peru, Cusco

Wanamey, Centro Medicina Tradicional, Prof. Julius Borerro Alejandro Bolantrio, Head of the Q-ero Shamanistic Tribe