

Report to
The Winston Churchill Memorial
Trust

Spiritual Care of Cancer
Patients

by

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Preface

This poem found at St Christopher's Hospice, sums up the spiritual pain of people with cancer.

*O God, O nameless Someone
That which contains all things yet is not contained,
Be there.
What is this in me that cares, that prizes caring above all material things,
But You?
What is this that feels there should be meaning?
Something through and beyond the pain and cruelty
Ravaging this world?
Is it You?*

*What is this that is so deeply personal?
That longs for that intimate closeness
That yet can be separate?
That seeks to create, to bring out of chaos
An order that is not confined?
That loves beauty and laughter
And that sheer zest of living?
Is it You?*

*And is it You in the darkness of our minds,
The injustice, the cruelty, the hurricane?
Can it be You in the evil?
Are You buried there?
You Who permeate the universe and the beyond,
Gloriously transcendent and yet immediately immanent
Within the minutest particle?
O God, O Nameless Someone,
Be there.*

*For apart from You, the ground of being
And the transcendent mystery,
There is no meaning.
And cruelty and evil remain,
And pain itself is meaningless.
O God, O Nameless Someone,
Help me to trust:
Not blindly, still walking in uncertainty,
But in trust for the journey
In, through, and out of the desert.
O God, O Nameless Someone,
Be there.*

P. Thornborough (1970)

Index

Introduction	p. 2
Executive Summary	p. 3
The Journey	p. 4
Sharing the Journey - Insights Gained	p. 11
Conclusions	p. 21

Introduction

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Acknowledgments

The award of a Churchill Fellowship for 1995, to study the Spiritual Care to Cancer Patients, made it possible to travel to Italy, England, Scotland, Wales, Canada and the USA (East and West Coasts) for a period of 11 weeks. This provided the opportunity to gather information on the operations of 17 hospices; to participate in five conferences; to meet with educators from eleven universities and training centres; to see an amazing range of scenery; and to meet many people who gave incredible warmth and hospitality.

Having never travelled overseas before, I am deeply grateful to the Winston Churchill Memorial Trust Fund for providing such an amazing opportunity to gain the insights that only visiting other countries and experiencing different cultures can give. My thanks go to the officers of the Trust for their interest and support and to Mr Frank Blain of QANTAS for his assistance in planning the itinerary.

It was a great help that I could be accompanied by my husband, Rev Dr Ian Mavor, who as Secretary and co-founder of *Hopewell* has similar interests. This trip added greatly to our shared roles in the training and educating of pastoral carers; as Directors of the *St Clare Centre for Health and Spirituality*; in the responsibility for training hospice volunteers; and in educating school guidance officers and counsellors on identifying spiritual pain and grief in children. As Principal Policy Officer, Health and Personal Development, in the Queensland Department of Education, Ian was assisted by an Award from the British Council under the Academic Links and Interchange Scheme.

As has emerged within the *Hopewell* community, attention to issues relating to death, dying and spirituality draws people together across divisions often created by differences in culture and beliefs. To all who helped us along the way, who took a personal interest in us and gave so generously of their time, I offer my heartfelt thanks.

Executive Summary

Project Description:

The opportunity for travel overseas provided access to institutions and models of hospices, chaplaincy services, health and wellbeing programs and training programs that are well established. In particular, the aim was to study the alleviation of spiritual pain in health care, through the investigation of hospice training programs and spiritual care to the dying and the bereaved, including children.

1. Hospice Services

The hospices visited included a course at St Christopher's in London which is a large (62 beds) institution with highly diverse services, including a Day Centre and Home Care programs; several hospices with 22-26 beds and full medical services; some with no accommodation and totally involved in home care; some with a specific focus, such as on children or AIDS patients; some with an emphasis on providing home-style accommodation and hospitality for people who lack carers at home; and even a hospice called *Hopewell House* in Portland, Oregon.

2. Children and Grief

Issues of grief and bereavement were a major emphasis at the conference in Canada on "Helping Children Cope with Death". With 600 participants and speakers from many backgrounds, this provided much information and inspiration. Among the keynote speakers was Elie Wiesel, Nobel Prize Winner and author. He is a man who knows personal suffering and bereavement as a survivor of Auschwitz and a man who will not let the world forget. It was fitting that he be the keynote speaker at this conference as he has spent decades of his life fighting for children, the children of Bosnia, Biafra, Argentina.

The challenges of this conference were developed further through visits to special agencies such as the Acorns Children's Hospice in Birmingham, England. *Hopewell* is committed to developing children's programs for grief and bereavement, as well as a hospice and respite facility for children.

3. Spirituality and Health

A pilgrimage to Assisi near Rome, home of St Francis and St Clare, strengthened the sense of influence within the development of *Hopewell* from these two remarkable people whose life of hardship, joy and loving service has inspired so many. Communities such as those founded by St Clare and St Francis were known as hospices - they existed to live out the gospel message of love for God, neighbour and self. In them, the practice of prayer and meditation leading to a rich spiritual life was married to a life of material poverty and service to the poor, the sick, the suffering and the needy.

From that visit there continued to be a sense of pilgrimage about the total journey, as I explored the links between spirituality and health in many different contexts.

4. Mind/Body Links in Health and Illness

Another special interest was in programs designed to assist people in working on their emotional and spiritual issues so that the natural healing capacities of the body might work as well as possible. These included a Wellness Program at Riverside Church in New York; the Getting Well Centre in Orlando, Florida; a Behavioural Medicine program in Louisville; the Attitudinal Healing Centre in San Francisco, and the Process Oriented Psychology Centre in Portland, Oregon.

Some of the many ideas gathered about hospice activities generally, and about spiritual care in particular, are being implemented through the *St Clare Centre of Health and Spirituality* as part of the range of services offered by *Hopewell*. These include health and wellbeing programs.

The Journey

To study spiritual care of cancer patients, I visited hospices and training centres, and participated in conferences in UK and North America. Key areas of interest were different patterns of hospice operations, the nature of spiritual care, approaches to caring for the whole person through developing body-mind links, and ways of supporting children through experiences of grief and bereavement.

18-23 April: Brisbane to London via Italy

Rome: Two days of walking and touring this magnificent reminder of the beginnings of and continuation of the movement of Christianity - Plaza della Republica; Baths of Diocletian, with a section remodelled by Michaelangelo into a large church; Basilica Santa Maria Maggiore; Basilica St John Lateran; Plaza Victor Emmanuel II; Spanish Steps; Pantheon; Church of Ignatius Loyola; Trevi Fountain; St Peter's Basilica; Trajan Market; Capitol Hill; the Forum; Colosseum; Arch of Constantine; Basilica of St Peter's in Chains; Basilica of St Paul's Outside the Walls; Trastevere, etc., etc.

Assisi: From Rome by bus, through Spoleto, Trevi, Foligno and the Umbrian Hills. This was a pilgrimage to the places where St Francis and St Clare lived out their calling to simplicity, service and community. A sense of pilgrimage - a presence of awe and holiness. The town is on a hill and on the plain below the Basilica di Santa Maria Degli Angeli has been built over the Portiuncula, a small stone chapel near which Francis lived and where he died. In the town, the Basilica of St Francis contains his tomb and the upper and lower churches both have many frescoes by Giotto and others.

At the other end of the small and lovely town is the Church of St Clare (S. Chiara), with her tomb. Assisi, with only 1,000 permanent residents, is like a medieval village preserved in the spirit of St Francis, despite many patisseries and tourists - up to ten thousand in summer months. *Hopewell Hospice Services Inc* has two Patron Saints, Clare and Francis of Assisi and the *St Clare Centre for Health and Spirituality* is a tribute to these two Christians who lived out God's vision of love in the world.

23 April - 7 May: England and Scotland

London: Accommodation and discussions with Dr Geoff Sharp, medical GP who had organised a visit to Princess Alice Hospice; Sight-seeing walk in the city - Harrods, Hyde Park, Sloan Square, Belgravia, Buckingham Palace, St James Park, Westminster Hall, Westminster Abbey, Winston Churchill Memorial, Houses of Parliament.

Princess Alice Hospice, Esher, Surrey: Tour and interviews, Rev. David Cardew, Chaplain; Dr Andrew Hoy, Medical Director; Sheila Cook, Lecturer/Practitioner.

Notes from the Conference of the Association of Hospice Chaplains

All Saints Pastoral Centre, London Colney, near St Albans. Three days. The theme, "Chaplains at a Loss", dealt with the tensions between being supportive of the losses of others, and dealing with one's own experiences of loss and sense of inadequacy in the face of human need and suffering. Speakers: Canon Ian Ainsworth-Smith, Chaplain, St George's Hospital, author of *Letting Go*; Carolyn Brobribb, St Luke's Hospice and Social Work Faculty, University of Plymouth; Jeannette Gascoigne, Northern Ireland Hospice. Visit to St Alban's town and Cathedral.

Canon Ian Ainsworth-Smith: The role of spiritual care in hospices, like the prophets of old, is a balance between comforting the disturbed, and disturbing the comfortable with the message that we are finite; as spiritual care workers, we need to validate feelings; we often call people depressed and ask for psychiatric intervention, when we are mistaking the emotion that is real sadness at loss and

letting go of all that is loving and beloved; people are bereft and full of feelings, whereas depression is empty of feeling.

The loss experience is both personal and professional. Although chaplains are vocationally led, some areas are more risky than others. Hope is always humble and frequently disappointed, but cannot be separated from its theological sisters, Faith and Love; to love is to be vulnerable; hospice work is costly love; taking the analogy of a wounded cat with a thorn in its paw, if you remove it, it will attack you; the more vulnerable people are, the more likely to attack.

Patients we minister to are very much in the grip of their shadow, and the raw and infantile feelings can be experienced in powerful ways, and displaced on seemingly insignificant issues. However, our role is touching, anointing, holding, unlike the medical model. If the people to whom we minister are unconditionally accepted and God is where we are at, we are resourced and sustained and develop a sense of identity and can go on; in chaplaincy, “being” is more important than “doing”; we may be comfortable being with others and accepting where they are at, but are we comfortable accepting where we are ourselves? Are we ever listened to? Who will hear us?

Hospice is a bit like an animal, and can be quite unruly. Each hospice has a history; people there in the beginning may not see it through all the processes of growth and change; you can build hospices or hospitals, but we are all powerless in the face of death; Christian faith is a message not a religion; chaplains need to spend as much time with nurses as with patients.

Travel north to Scotland: By car, with visits to York City and Cathedral; the North Yorkshire Moors and the town of Whitby, home of Captain James Cook; Durham; Newcastle-on-Tyne; Berwick-on-Tweed and Edinburgh, to Dundee. Daffodils and wild flowers in profusion.

Newcastle-on-Tyne: St Oswald’s Hospice; interviews: Rev. David Gynes, Chaplain; Dr Claud Regnard, Medical Director; Alison Cuthbert, Schools and Sponsorship Fundraiser.

Dundee: Accommodation and discussions with Dr James Urquhart, formerly District Medical Officer with the Tayside Health Board, and closely involved in the establishment of the Roxburgh House Hospice, linked to Ninewells Hospital in Dundee. Also with Nora Urquhart, retired nurse and Health Visitor; Bishop Edward Luscombe; and Rev. William McAusland, concerning hospital chaplaincy. Visits to Glamis Castle and St Andrews.

Glasgow: Prince and Princess of Wales Hospice, visit and gather information.

Notes from Acorns Children’s Hospice, Birmingham

Tour and interviews with Brian Warr, Director, and Madelyn Coyne. This was one of the most memorable parts of the entire journey stimulating the idea for *Hopewell* to develop a children’s hospice as part of its overall plan.

Acorns is a 10 bed hospice, with room for parents, families and siblings. They are just putting in a hydrotherapy pool which was donated. In the corridor lies the hospice dog, herself a failed guide dog, who kept sitting down in the middle of a busy road. The General Manager’s voice was hushed as he imparted this information - this is a sensitive dog! For a while nurses couldn’t get used to bones left lying in corridor. The Manager reported that it takes six months to train nurses out of a hospital model of busy-ness into the hospice model of taking time to be with individual children.

Acorns Hospice works with 174 children and families in the community but the hospice residential facility is used mainly for respite. Sometimes parents have very little sleep in fourteen years of a life-limited child’s life and have never had a holiday. One memorable thing was the child’s room, where the body is placed when a child dies. The temperature is kept cold so the little body is preserved. When the parents come in, the air is warmed up so that they can stay, hold, wash and dress their child.

University of Birmingham, School of Education: Discussions with Dr Michael Grimmitt and Prof. John Hull, who is also editor-in-chief of the British Journal of Religious Education and convenor of the International Seminar on Religious Education and Values (ISREV). John has written several books, including *Touching the Rock: An Experience of Blindness*, which describes in depth his own personal encounter with blindness.

5-26 May: USA and Canada

New York City: Accommodation at Union Theological Seminary: Visit Riverside Church, with an extensive social action program and ministry of healing - discussion with Rev. Fanny Erickson, Coordinator of the Wellness Center.

Jacksonville, Florida: Visits to the Hospice of NE Florida, and the Methodist Medical Center, which includes a Center for Getting Well; St John's Horizon House providing accommodation and programs for people with HIV/AIDS; and a Hospice Program with a respite ward and home support teams.

Travel to Canada and return: By Greyhound Bus; Atlanta, Olympics preparations and Martin Luther King Jr tomb; Louisville, Kentucky; Niagara Falls, with tulip gardens in full bloom; London, Ontario; Detroit; Washington, DC; Jacksonville, Florida.

Louisville, Kentucky: Discussions with Dr James Hyde, Executive Director, Wayne E. Oates Institute for Study of Spirituality, Ethics and Pastoral Care, and Associate Professor in Psychiatry teaching an Ethics and Pastoral Counselling program, in the Department of Psychiatry at the University of Louisville School of Medicine. Meeting with Dr Wayne E. Oates, retired Professor of Pastoral Care and international leader in the fields of psychological, spiritual and medical healing for over 50 years, writing over 75 books.

Hospice of Louisville: Seminars to discuss holistic approaches to patient care: Dr James Hyde; Joan Pauley, secretary, Wayne E. Oates Institute; Dr Jane Thibault, Geriatric Evaluation and Treatment Unit, with interests in spirituality and gerontology; Dr Robert Ellis, physician and chair of the Board of the Institute; Dr Leah Dickstein, psychiatrist, Arts and Medicine Program; Dr Clifford Kuhn, psychiatrist and coordinator of the Genesis Program in Behavioural and Attitudinal Medicine, which includes programs for sufferers of chronic pain; Vicki Runnion, hospice social worker developing programs to address holistic/spiritual needs of patients and families; Rev. Dr Joy Berger, hospice musicare program, who has researched music, pastoral care and grief; Donna Urbansky, Director of Volunteers; Debby Thompson, nurse and coordinator of hospice inter-disciplinary teams; Tony Heitzman, Director of Pastoral Care.

Notes from the Conference "Helping Children Cope with Death", London, Ontario

International Conference on Death, Dying and Bereavement, at the Center on Grief and Bereavement Education, King's College. Four days, with some 600 participants. Keynote speakers included: Dr Eli Wiesel, Auschwitz survivor, author and Nobel Prize winner, "The Eternal Question of Suffering and Evil"; Dr Diane Komp, "Care of the Dying Child"; Dr Patricia McGrath, "Children and Pain"; Dr Yael Danieli, "The War against Children"; Drs Charles and Donna Corr, "Responding to Children's Questions about Death"; Sr Francis Dominica, Helen House, Oxford, "Learning from the Experts - Supporting Families of Dying Children"; Dr Gerald Koocher, "A Preventative Intervention following a Child's Death"; Dr David Balk, "Coping with Bereavement during Adolescence"; Dr Dora Black, "Intervention with Bereaved Children: Can We Prevent Long-term Illness?"; Dr Dennis Klass, "Parental Grief: Resolution and Solace". Pre-conference Workshop: "Reading the Image - Art Therapy, Symbolic Language and Dying Children", Judy Bertioia.

Other workshop and seminar sessions included: Play Therapy to Help Bereaved Children: Care of the Dying Child; Creating a Healing Environment for Children of all ages; Using Humour, Art and Music with Children faced with Death and Dying; Spiritual Care of Terminally Ill Children; Integrating Gestalt Techniques Into Traditional Grief Counselling with Children; Reducing Emotional Distress and Coping following the Death of a Child; Teaching Health Professionals About Children and Death; Creating the Bereavement Program for a New Children's Hospice: Problems Encountered and Lessons Learned; A Reason for Living: to Make Meaning out of Loss.

Dr Elie Wiesel, left a lasting impression and a resolution to help heal the children of the world. The Conference's central theme was summed up by Dr Wiesel; born in Hungary in 1928, he was deported with his family to Auschwitz then Buchenwald while still a boy, where his parents and younger sister died. His first book, *Night*, is this memoir. He is a Nobel Prize Winner and author who knows personal suffering and bereavement as a survivor of Auschwitz and he will not let the world forget.

Elie Wiesel has spent decades of his life fighting for children, the children of Bosnia, Biafra, Argentina. He spoke on the universal and eternal question of suffering and evil, described in that book of the lyricist of lamentation, Job. The questions raised by Job haunt those who are passionately religious, and leads us to the question: How can we save the children - our children, who are the hope of the world. The victims of our society are the children, those who die and are murdered, and those who are conditioned to inflict suffering. He asked the question, "What is worse - to see a child being killed - or to see the children do the killing?"; then added, "Adults make the wars and the children die - we drive them to drugs, to cults, to suicide. We are killing the children. We have to give them back the right to be children."

Washington, DC: Contact the National Hospice Centre for resource materials; visit the Holocaust Museum, with a special display for the 50th Anniversary of the opening of the death camps.

Orlando, Florida: Spent a day participating with a "Getting Well" group. This 28-day behavioural medicine program has been developed by Deirdre Davis Brigham and is described in her recent book *Imagery for Getting Well*. Designed for people with cancer and other chronic diseases, the program draws on insights from psychoneuroimmunology to help participants "to enhance their medical treatment, to thrive, to live with love rather than fear, and to create a life of meaning and peace".

26 May - 17 June: England and Wales

Travel in England and Wales: By car; Brighton, Chichester, the New Forest, Lymington, Salisbury, Stonehenge, Lyme Regis, Exmouth, Dartmoor, Plymouth, Polperro, Falmouth, Penzance, Land's End, St Ives, Tintagel, Ilfracombe, Exmoor, Glastonbury, Wells, Bath, Bradford-on-Avon, Bristol, Pembroke, St David's, Aberystwyth, Caernarfon, Snowdon, Llangollen, Tamworth, Nottingham, the Peak District, Chester, London. The Queen also visited Falmouth and St David's, Wales, but I didn't manage to arrange an interview! The rhododendrons were at their best and roses blooming.

Brighton: Visit the Sussex Beacon, a respite and convalescent residence for people with AIDS; discussion with Dr Joanne Doran.

Exmouth: Discussions with Dr Mark Halstead, Coordinator of the University of Plymouth's Centre for Research into Moral, Spiritual and Cultural Understanding and Education (RIMSCUE); also with education faculty members Dr Jeannette Gill and Valerie Cark, who is researching "Spiritual and moral development in children following childhood bereavement". Another visitor to the Centre at the time was Dr Timothy MacNaught, Churchill Fellow from Melbourne, studying spirituality and religious education.

Bath: Tour and discussions at the Dorothy House Foundation, a hospice moving from a residence in Bath to larger facilities at Winsley. Meet with Rev. Robert Rees, Chaplain; Kim Rogers, Education Manager; Angela Barnard, Volunteer Coordinator.

University of Nottingham: Accommodation and discussions with Professor Roger Murphy, Head of Research and Staff Development, School of Education, and Dr Elizabeth Murphy, Lecturer and Director of Research Training, School of Social Studies; discussions with Rev. Roly Reim, University Chaplain; Sr Teresa Duffy, counsellor and lecturer, with a particular interest in evolving forms of community life; Aru Narayanasamy, doing research on the role of religion in the care of terminally ill patients. Led a seminar at the Medical School on "Spiritual Care of Terminally Ill Patients".

St Columba Fellowship: Annual Conference at Foxhill Conference Centre near Chester, for three days. The St Columba Fellowship is an association of hospice chaplains and staff who meet yearly to support each other and provide other spiritual growth opportunities. Speakers included Carol Rose and Jan Sutcliffe, professional entertainers who work in hospitals and hospices; Rev. Harold ter Blanche, Chaplain, Grimsby; Prue Clench, Director, Thames Valley Hospice; and Gretchen Hanson, Executive Director, Tamarisk Resources, USA.

London: Walk through more of the city - Marble Arch, Baker Street, St Marylebone Church, Charing Cross Road, the West End Theatre District, Leicester Square, Trafalgar Square, St Martin's-in-the-Fields, the Strand, St Clement Danes, Australia House, St Paul's Cathedral, the Monument - recalling the Great Fire, and London Bridge.

St Marylebone Church: Centre for Healing and Counselling offering counselling, befriending, crisis listening and referral, group work and spiritual direction: “The Centre is committed to providing a variety of therapeutic activities to enable people to deal with issues and problems in their lives so as to live more satisfactorily. All those who work at the Centre have an awareness of the significance of spirituality in their own lives, and offer their services in a non-judgmental atmosphere, accepting people as they are, and not expecting them to hold a particular faith or values.” This has similarities to some of the activities of the *St Clare Centre for Health and Wellbeing*.

St Martin’s-in-the-Fields Church: An inner city church with a strong social justice emphasis as well as a rich musical tradition. The crypt was a lively scene of brass rubbing, art show and refectory. The evening services use four alternative liturgies: The offering of the world of work; Taize prayer; a healing service; and the offering of our relationships.

Notes from the Multi-Disciplinary Course at St Christopher’s Hospice, Sydenham

The five-day Course on “Multi-disciplinary Approaches to Hospice Care” was led by staff of the hospice, and attended by five medical doctors, eight nurses, four social workers and three chaplains; with nine from England and others from Poland, Slovenia, USA, Malaysia, Austria, Portugal, Northern Ireland, Germany, Hong Kong and Australia. St Christopher’s, founded by Dame Cicely Saunders, had a major role in stimulating the modern hospice movement and the development of hospices in many countries. It has 62 beds, a home support program, a large day care centre and many educational programs, as well as being the location of the Hospice Information Service.

The Multi-Disciplinary Course drew on diverse approaches and was enriched by differences among the participants; including approaches to death and dying experiences in various cultural contexts. At weekly Ward Rounds, members of a Multi-Disciplinary Team discuss specific patients and their treatment, with more detailed attention to new patients. The team could include doctors, nurses, physiotherapists, occupational therapists, social workers, day centre staff and chaplains. The two staff chaplains cover two wards each, so do not attend all rounds. Areas covered include physical diagnosis; family details and key relationship issues; symptoms; areas of pain and contributing factors; spiritual factors, such as religious links, level of involvement, attitudes to the present experience of illness; levels of awareness of the diagnosis and responses to it.

Pain control was approached from holistic perspectives. In leading the discussion, Dr Nigel Sykes asked questions which sought to go behind the details given, e.g. “What is the anxiety about?”; “Does the pain have meaning for him?” To the report that a patient had said, “I’ve had enough”, Nigel asked: “What’s he had enough of?” There was also discussion of levels of insight, and the value of helping patients distinguish between the sleep of rest and the sleep of death. There was an acceptance that some may prefer denial, but a warning about colluding in denial, e.g. agreeing with falsehoods in a way that is patronising or heightens later disappointment: “Sure you’re going to beat it.” The alternative suggested is to adopt a more neutral stance and to affirm the person.

Cases included a man with a brain tumour and spiritual distress that God has failed him in spite of his work in the church. His short-term memory loss made discussion difficult; and his apparent improvements gave the family hope that was then dashed. It was affirmed that the family should be well informed about treatment and particularly about changes, such as the introduction of morphine or use of a syringe driver, which may be thought to signal a final stage of the dying process. It was also stressed that when things are getting tough all the family should hear the same details, to avoid them being misreported. Another area of discussion related to a man’s behaviour and whether it may have reflected depression, sadness or onset of Parkinson’s Disease.

The Ward reviewed had 18 beds, with three teams of nurses (red, blue and green - with appropriate coloured binders for reports). Each team, with a leader and a mix of registered and auxiliary nurses, cares for six of the patients to provide continuity of care. There are four bays of four beds each, and two side rooms. In the staff room, symbols on a board indicate which members of the Multi-Disciplinary Team are involved with each patient. When someone is dying, they remain in the Ward. Others may have their curtain drawn and, if necessary, may receive support in working through their anxiety.

Patients at St Christopher's mostly have cancer, a few have HIV/AIDS and some with Motor Neurone Disease, although the latter can be demanding. The Day Centre is available for resident use as well as for patients covered by the Home Care Teams. Some other home care organisations in the area also use the Day Centre. Volunteers have an important part to play, both in specialist roles, such as nurses, physiotherapists and chaplains; and in a wide range of general roles, such as driving people to the Day Centre, arranging flowers, making beds and helping with meal orders. There is a Volunteer Coordinator, with secretary, and some 600 volunteers.

18 June - 1 July: USA and Canada

Travel on West Coast: By Greyhound Bus; San Francisco, Sausalito, Monterey, Big Sur, California; Portland, Oregon; Seattle, Washington; Vancouver, British Columbia, for return home.

San Francisco: Visits to St Francis Dolores Mission, Twin Peaks, Golden Gate Park, Golden Gate Bridge; Fisherman's Wharf, Gharelli Square, Nob Hill, Chinatown, etc., etc. The city was preparing for a celebrations for the 50th Anniversary of the meetings held there which led to the formation of the United Nations Organisation. President Bill Clinton came to San Francisco for a function, then followed me to Portland (but not by Greyhound Bus).

Grace Episcopal Cathedral: Discussion with Canon Carl Gracely, chaplain at Marin County Hospice, and Dean Alan Jones former Director of the Center for Christian Spirituality, New York, and author in the area of spirituality; recently published *The Soul's Journey: Exploring the Three Passages of the Spiritual Life with Dante as a Guide*.

Shanti Project: Visit the office to gather information; one of a number of agencies providing services for people with AIDS, no residential facility; focus on enhancing quality of life and independence, such as assistance with transport.

Hospice by the Bay: Visit the office for discussions with staff; focus on home care support; not attached directly to a hospital. Developing a residence, but much delay in trying to meet requirements of local, state and federal agencies.

Zen Hospice Project: Visit and discussions with Frank Ostaseski, Director; providing home-style accommodation in four rooms for people without other carers, and training volunteers to work with destitute people dying in a state-run institution for the aged.

Esalen Institute, Big Sur: Weekend Seminar on principles underlying the Zen Hospice Project and Buddhist approaches: "Caring for the Dying: What Really Works?" the focus was on the practice of meditation and self-awareness as preparation for being with others in times of life transition.

Notes from the Zen Hospice Project, Dr Frank Ostaseski, Director

The Zen Hospice Project was at the opposite end of the spectrum from St Christopher's Hospice. It provided a practical example of the approach that has been emerging for *Hopewell*, but for which we have had difficulty in gaining acceptance because of its differences from other patterns in Australia.

The accommodation component is located upstairs in a Victorian-era home in a residential street in San Francisco. The emphasis is on a home-style operation, with four spacious bedrooms. Nursing services are provided by visiting nurses, and other care is provided by volunteers and members of the Zen community. All volunteers are expected to be involved in a personal spiritual practice, mostly Buddhist or Christian, with an emphasis on meditation and sitting still. Residents are poor or lack carers, and are in the final weeks of life. Volunteers also work in Laguna Honda Hospice, a 28-bed hospice and AIDS unit in the largest public long-term care facility in the USA.

A key emphasis for volunteers is on learning to see the person behind the disease, by attending to personal awareness and affirming their own personal needs that are part of the motivation to be helpful. The act of service then has mutual benefit. "We recognise that the work we do with our clients is also work on ourselves... If I can come in and be clear that this is work on myself, that this is a way for me to really pay attention and stay present with myself - then I can see others for who they are, not for their symbolic value." This also helps break down the gap and the power differential that can exist between helper and helped.

The Buddha's teachings about the impermanence of life - that coming together inevitably means parting - provided a basis for reflecting on death. "People talk about getting over grief, but not of getting over joy. Why the difference? Grief lasts a lifetime, it is here to stay. Invite it in and allow it to inform our actions. It can be the doorway to great joy." The exploration of grief also develops the capacity to act with compassion.

Attitudinal Healing Center, Sausalito: Visited the Center, founded by Dr Jerry Jampolski; talk with staff members and gather extensive literature; Jennifer Andrews, Volunteer Coordinator, Louise Franklin, Development and Young Adult Program, Sharon Pair-Taylor, Adult Program Director, Cheryl Shohan, Home and Hospital Director.

Hospice of Springfield: Discussion with Janet Overstreet, Volunteer Coordinator for the Hospice linked to the McKenzie-Willamette Hospital, Oregon.

Portland: Visits to the Process Work Center; the "Angels and Us" Angel Gallery; and the musical "Miss Saigon" with its haunting plea for the children who are offspring of wars. At Hopewell House Hospice: Visit and discussion; Colleen Lyman, Director; sponsored by Ecumenical Ministries of Oregon, a coalition of 13 churches in that State.

Nearing the end of the trip I decided to do something not connected with death or dying, grief or bereavement and take in some entertainment! "Miss Saigon" was another reminder, however, that in the midst of life, and many years after the Vietnam war, the children of the world are still suffering and we adults are responsible. As Elie Wiesel says: "The adults make the wars and the children suffer, the future of the world lies in the hands of the children." We need to be committed to the education and care and support of children who are dying, or who are grieving the death of a parent or sibling. How they grieve, shapes their future health and well being.

Process Work Center of Portland: The Center provides training courses and promotes workshops based on the work of Dr Arnold Mindell, founder of Process Oriented Psychology; meet with Dr Renate Ackerman, a hospice volunteer studying ways people live with a life-threatening illness, and Sylvia Camastral with a research focus on skin disorders. Arny Mindell's latest book, *Sitting in the Fire: Large group transformations using conflict and diversity*, deals with the dynamics underlying disputes, to provide understanding, not just 'agreement', and to produce more satisfactory and enduring resolutions of conflict.

Seattle, Washington, and Vancouver, BC: Contacts had been made with hospices and other programs in these cities, but time was not available to follow up on them.

Sharing the Journey - Insights Gained

As part of my report for the Churchill Fellowship, (Spiritual Care of Cancer Patients, 1995) I would like to share aspects of my journey with you, the reader. I would like to talk to you about what a hospice is, what form spiritual care takes, and how the life of a cancer patient, or one of their loved ones, is similar to a journey to a strange country. It is like going into the unknown. Every new day is tentative, offering promise and hope, yet has to be held in balance with the shadowy partners of cancer: fear and despair.

As Founding President of the Gold Coast's only Hospice, indeed the only hospice between Newcastle and Brisbane, its process of 'becoming' has been similar to a person newly diagnosed with cancer. The experience is filled with hope, anxiety, learning, growing, and wanting to find out everything about the process: sometimes elated as when the blood counts are up, or the funds come in; sometimes in depression, as when the grants get refused, or the cell count is down. Yet to the person with cancer, as to any hospice program, spiritual care is vital, an integral part of the healing process. And healing can come to the patient and the loved ones surrounding them, even if cure does not occur. Palliative care or hospice care exists to ensure quality of life, and to alleviate the pain of the whole person and their entire family, physically, emotionally, socially and spiritually .

I will weave in a few stories about my first trip overseas to illustrate what is meant by spiritual care. These insights gained from the Churchill Fellowship have helped me to see more clearly the need for hospice in every community and have provided a richer understanding of what we have been doing already.

In this section of the Report, I will focus particularly on Christian perspectives, as that is the background that I bring to my work. At the same time, my travels covered a wide range of approaches to the spiritual care of cancer patients, and I am very conscious of the need to meet people on their own terms and with full respect for their particular beliefs when providing spiritual care.

Because I have been immersed in palliative care and hospice care for the past twelve years, I tend to assume that everybody knows what hospice is. Recently I heard two people talking about what a hospice might be. One thought it was a club like Zonta and he thought his mother belonged to one, the other thought it was a painful nerve in the back of the neck.

Neither are quite true, although, over the past few years, I have at times wanted to describe it as a pain in the neck! Like any birthing process there is pain, but there is also the promise of new life.

Reflections on hospice care from a Christian perspective

Hospices are about community and they are about pain. They are about relationships, they are about love. Community life is not an easy life, but personal differences are secondary to the outcome of a deep involvement in the purpose for which community ultimately exists. This is true of the Christian community, which exists as the body of Christ, and of the hospice community, for both exist to be love in action.

There will always be differences of opinion wherever community forms, because we are all people of unique and differing gifts. If the caring community is to be a sign of the reign of God, however, it must reveal a new kind of humanity. It is not just those with a personal faith who are called to be alongside the sick and wounded. Many are coming, called from all walks of life to share their journey, and to walk alongside those who are in pain and are oppressed by the fear and loneliness of disease. They answer, and they come, because all share the human journey of finitude and powerlessness in the face of death which connects us. Hospices in communities raise the awareness of all people to these eternal spiritual questions.

Hospices deal with pain because hospices exist to care for the pain of a person with a terminal illness and their family, and the pain involved is total pain. This is another phrase coined by Dame Cicely Saunders, founder of St Christopher's Hospice in London, where I attended the five day multi-disciplinary course. Total pain is the physical, emotional, social, spiritual pain suffered by the patient and all who love them.

Because we human beings are not machines with parts that wear out, we are more than body or, as St Paul says, we are *soma*, body/spirit. Our pain is experienced totally, in our body, our mind, our spirit and, because we exist in relationship with one another, we suffer for one another. Hospices care for the entire family unit, who are suffering spiritual pain as they prepare to say good-bye to their loved one.

Hospice exists to live out the command of Jesus to "love God and neighbour as self." Unlike the days when hospices first began, many people today have confused notions of God, rarely know their neighbour, and have not begun to understand their deepest self. Dame Cicely Saunders says that "hospices give people time". Time to find out who they really are; time for reconciliation; time for forgiveness; time for loving and time for revealing fears and pains; time for holding on, and time for letting go and moving on.

Experiences of hospitality

Originally hospices were resting places for pilgrims on their journey to the Holy Land. They were places where weary travellers could find rest and refreshment for their body and their soul. On my trip overseas, I reflected on my journey and the incredible hospitality that I encountered. I was a stranger and people gave up their beds for me. They picked me up early from Greyhound buses - a dirty, weary traveller, a stranger arriving from the night, far from home. They met me at airports, at bus stations, took me home and gave me great hospitality. 'Hospitality' is the meaning of the word hospice, and it means both guest and host, and each person is treated as a pilgrim on their quest.

Hospices have existed since the fourth century when Fabiola, a Roman lady, was converted to Christianity because of the way she saw the early Christians caring for the sick and the wounded. She herself then took sick and dying people into her home. In the Middle Ages, hospices existed wherever Christian communities gathered together and cared for the sick, the wounded, the lonely, or the brokenhearted allowing them to stay, if necessary, in that caring, compassionate community until they died.

Hospice workers are advocates for those who are vulnerable, and try to talk to the authorities saying that patients and their families want their illness explained to them; they want to be consulted about treatment; they want to retain their dignity and keep some control over their lives. Patients want to be empowered. The hospice movement listens to the cries of the people and tries to speak for them, relaying to the authorities that patients want to be treated as individuals worthy of respect and value. They want a choice of where to die, they want to die with dignity.

Hospice work is about helping people to live as fully, and with as much quality of life as is possible until they die. Dame Cicely Saunders, of St Christopher's, now the largest and most famous teaching hospice in the world, tells her patients: "You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die."

Perhaps I will just give some simple examples of spiritual care as hospitality. I was called into hospital one Sunday afternoon. One of our palliative care staff who knew me thought I might be able to do something with a 90 year old woman who was biting and kicking and attacking the nurses. When I got there they had tied her up. She was quite beside herself with rage. Her daughter had put her into hospital to wait a nursing home placement because she could no longer manage her. The nurse said "Here's Deirdre, she's from the church." Laura spat at me and said, "If you're from the Church, you'll untie me." I thought, well, that is what we are to do, free people from all that binds them, so I simply said something like: "You must feel very trapped," and she burst into tears. It took a while for her to settle down, she wanted to die, she asked someone to put her out of her misery - anyone!

She did the same thing in the nursing home which she eventually went to, and still I kept visiting her. She went on a hunger strike and wouldn't eat, we talked about what she would have eaten if she were enjoying life, and not wanting to be dead, and she told me her story. Her story was of a time long ago when she owned a 'pub', and loved cheese and red wine, the ingredients of parties, company and life, so I bought her some. It wasn't a miracle, but she did eat a tiny bit of cheese, and drank some wine and talked some, and went on talking a bit more about her story over the next couple of weeks, and ate a little more. Weeks later when I visited her I saw that she was playing bingo and ordering everyone in the room around. She didn't see me and didn't need me, so I crept away. She had started to live. Her life had started to have quality. She had mattered to someone, and had been allowed to express her rage and anger and pain and loss. She had time to find out who she was. She had revisited her life and told her story.

I remember visiting Gay, who wasn't at all religious, and I don't think the subject of God or death ever came up, until one day, after two years she suddenly said "Deirdre, you have been caring for my soul, will you go on doing so when I die?" It took this long for her to set the agenda. She died soon afterwards, but her last wish was a bottle of French Champagne (an elegant woman, of impeccable taste!) I took her some with two beautiful glasses and, although she couldn't drink much and it dribbled down her chin, she tried. I drank some for her and together we shared this communion, this community, this final step of her journey.

Hospice care as spiritual care is a concept that can be carried out *anywhere*, in a nursing home or hospital, or in the person's own home. The quality of care, and the compassionate listening, listening, always listening for the spiritual pain behind the symptom, is what differentiates it from the cold, detached and paternalistic clinical treatment that only focuses on the body and that often passes for health care.

Listening is a vital part of spiritual care, as well as being part of the total pain control of the person. A patient told Cicely Saunders that it seemed that the pain went while she listened. Hospice spiritual care programs also emphasise the need for the carer not to intrude or impose a belief system on the patient. We meet the patient where they are and not where we happen to be. The patient is to be accepted, respected, listened to and allowed to set the agenda. Our travellers are often very weak and vulnerable, and must be protected from those who would seek to convert the dying before it is "too late".

The hospice carer must have moved into a faith dimension that goes beyond condemnation or judgment. The parable of the prodigal son exemplifies the actions of the God of Love, with its depiction of the father running to meet the son who had long been lost. This story needs to be embraced and acted out by the hospice volunteer.

Dame Cicely Saunders says that the measure of a hospice is in the quality of its spiritual care. Spiritual care is not a separate part of the hospice program, but is an integral part of the total service. Hospice exists to live out the command of Jesus to love neighbour as self. As Mother Teresa says, every person we meet is Christ, no matter in what distressing disguise or in what disease form they appear. It does not matter whether that person is rich and lives in a high rise building and is alone and afraid, or whether that person is alone and living in a caravan - it doesn't matter whether that child is suffering from grief and loss from a parent's death or whether that mother is anguishing over her son's death - we exist to serve those who are battered and beaten by the crisis of illness and death. Often, times of crisis and disease are the times when people turn to matters of spirituality and meaning and purpose in life for the very first time.

These questions mostly arise at funerals, when the reality of death confronts us so blatantly that we cannot turn from it. Some people have to face their crisis when a diagnosis of a terminal illness hits the patient and their family with shock and disbelief. We need to be there to support them when this happens. People need the support of family or community at such times. By sharing this dark time, by understanding hospice as a place of strength through weakness, where one accepts suffering and bears one's cross for others and where prayers to God are offered with a sense of humility and powerlessness, we are able to come close to that understanding of solidarity that is true community.

The need for community is very strong in our individualistic society and, in hospice care, solidarity with our neighbour is a component of health. Grief and anger need to be shared, and then can be transformed into a new life and springboard for personal growth and deeper relationships.

Dealing with the reality of death

When illness strikes, most people are inadequately equipped to deal with questions of suffering and meaning. We have come to believe that science can cure everything, even death. Well, it cannot. But death has become a word that means failure, rather than a natural process or, in the case of our Christian belief, a promise of new life and of transformation. We have become separated from God and each other, separated from that promise of the Love that does not end.

At Niagara Falls, on my way to Canada to the Conference on "Helping Children Cope with Death," I was told almost casually that in another 300,000 years the Falls would reach Buffalo. Isn't that alone a cause for reflection on our own brief existence? Perhaps not for most tourists, but it was for me, and I thought: that staggering mass of thundering water is like having a hospice in the middle of the Gold Coast. The immensity and wonder of that driving enduring force of nature made me again realise that our lives are like the profusion of flowers that were blooming in the northern Spring: flowers that blaze for such a short while and then die.

We know that we were all born, therefore we all will die. I saw a man standing in New York with a sandwich board on his back saying: 'the end is nigh', and I thought yes, so it is. There is hysteria growing everywhere about the year 2000 and prophecies of the end of the world. Yet everybody's world ends in death. The end of this world will occur for everyone. But the word death is spoken of so little. We use the words abortion, euthanasia, mercy killing, all words relating to death, all subjects for news releases and debates, yet the word death, a natural process for all of us, is not used very often.

Many nurses I know in the Palliative Care Ward of the public hospital where I work still use euphemisms such as: "She 'passed away' last night" or "He passed on". We are afraid of the word "death", because for so many it speaks of suffering, of ending, of loss and of pain. Elie Wiesel, concentration camp survivor and Nobel Prize Winner, spoke at the Canada Conference on the age old question of suffering and evil. Atrocities were committed by members of the human race against their own kind, while others who knew that these things were happening, including the church, stood by and did nothing.

And yet we humans are also capable of celebrating life: love, joy, kindness, justice, peace, truth, integrity and passion. The two sides of humanity exist side by side - life and death. The message that hospices

convey embodies the Christian affirmation: That every person is unique, created by God, made in God's image and matters until their very last moment, and beyond, because of the word of God that Love is eternal.

Clare of Assisi (who along with her beloved St Francis, are Patron Saints of *Hopewell*) knew that death was not the end of life but the beginning of eternal life. Just as the early disciples knew that death was not the end for Jesus, that resurrection occurs through death, hospices exist to accompany those on this journey, to pray for those who are dying, and for those who are left behind. And prayer is often simply "being there" - the ministry of presence, accepting all who come, meeting them where they are on their journey, breaking bread with them, weeping with them, offering hope for the journey, and shelter for however long the journey takes. I say this because in some countries money is so short for the dying, that it is only available for a few weeks. In America, if a patient does not die in the allocated time, if they go into remission, Government funding does not allow them to go back onto the hospice program

Hospices are about relationships: letting go, suffering, loss, compassion and yes, even joy and celebration, moving on and transformation. In the early days of Christianity, it was easier to believe in the dying process as a moving on into a new life. St Francis embraced Death as a Sister.

Far from being the terror encountered at the end of life, Sister Death was the companion and friend who walked with him through life. This was not a shadow leading to despair or withdrawal or passivity, but the basis for being and doing in the world because it enabled him to see and live every single moment with new appreciation and delight and wonder and awe at all of creation. St Clare, as she lay dying, told her sister that she would be soon joining her - a cause for celebration. That is not so today. We would be filled with fear if we were told that. What has changed? What has changed is that we have separated body from spirit, life from death?

About two hundred years ago, the Christian church objected to advances in surgery, because it was believed that cutting into the body would damage the spirit. Descartes dealt with the objection by emphasising the difference between the spirit and the body. This allowed surgery to go ahead, and surgery and science have done wonderful things for the world. If my appendix burst, I would want a surgeon, not a hospice, but the balance has tipped too far the other way.

Not only have we separated body from spirit, the essence of what it is to be human, but we have isolated entire races from one another by conflict. We have treated people of spirit as objects to be disposed of. The world recently commemorated the 50th anniversary of the horrific death of 70,000 people instantly vaporised by the bombing of Hiroshima, and of the 150,000 innocent victims who died soon after of unbelievable mutilation. Victims of the vicious, vindictive unaware competitive madness of humankind that is called "war", The very birds of the air - to whom St Francis preached sermons about love and creation - were on fire - ablaze, not with the Glory of God, but the evil of which we are all capable.

What has this got to do with Hospice? This also is death. A death that is unbelievably shocking. In the face of such horror, why do we go on and on about the need for hospice care with an emphasis on the importance of the individual, and their family? Sometimes people ask me, "Deirdre why are you so worried about people dying in a hospice? There are many other things you could be doing - why don't you give up?"

To me there is a connectedness, between any kind of death, because we are members of the human race, and thus connected one to another. In every part of the world, wherever we are, we are called to profess our vocation. Sometimes I think we need to go back to the origin of the word "professional", which means professing one's own deepest conviction. I think that we have once again become unbalanced and think that it means detachment, apathy, indifference. From *Hopewell's* perspective our professing is to follow the way of Jesus, living out the command to love God, neighbour and self.

And we must not be indifferent. We must not be indifferent to the death of 70,000 people or to the death of one. Elie Wiesel, survivor of Auschwitz, in which his family were exterminated, has spent the rest of his life helping children, the children of Biafra, Argentina, Bosnia. He will not let the world forget that a holocaust could happen again.

Wiesel says the opposite of love is not hate, it is indifference. The world will never be changed by indifference. At any time the word could have been given to liberate the Jews, but nobody spoke it. The

future of the planet lies in the hands of our children. The Catholic Archbishop of Paris, himself born a Jew, has said, "Wiesel takes us back, not to the horror of the past, but to the threshold of our responsibility for the future. He warns us about the nature of the danger that can always surface again."

I made a pilgrimage to the Smithsonian Institute in Washington DC, to see the Holocaust Museum - a reminder of the evil, hatred, indifference, and inhumanity of which human beings are capable. On the wall is written this message: "Only guard yourself and guard your soul carefully, lest you forget the things your eyes saw, and lest these things depart your heart all the days of your life. And you shall make them known to your children, and to your children's children."

Hospice bears witness to the frailty of life, the need for living life fully, for teaching our children about the sacredness and brevity of life so that they can live it fully and act justly, love kindly and walk humbly in cooperation with the God of all creation, so that a holocaust or Hiroshima does not happen again.

Death is different now. Bodies are whisked away in blue mortuary bags immediately a death occurs in a hospital, and children are not given the privilege of saying good-bye to someone they loved dearly. In Western societies where hospices exist, future generations of children will have been able to release their grief, learn once again that emotions are healing and death as a natural process will once again be seen as a natural part of the life cycle and spoken of without fear.

I visited the Zen Hospice, a beautiful old home in San Francisco, where they told of a young woman who had died. Her father was flying in from Texas, and was to land at ten that night. She knew this, had waited long, but died just on ten o'clock. He was unable to go in to see her. To him death was an evil spectre who had changed his daughter into a stranger. He walked around and around the garden talking and crying, and raging and crying again. Finally, the next night, he was ready and went into her room. She had been washed and covered with rose petals by the volunteers, and the father was left alone with her. An hour later, the Director went to see how he was doing. He was sitting on the bed, with one hand eating a hamburger which a volunteer had prepared, was making funeral arrangements over the phone (tucked under his ear), and with the daughter's hand held in his other one. He needed that time to voice his pain, his rage, his fear, before he could be reunited with his daughter. Hospices give people time.

A physician stated in the book, *Anatomy of an Illness*, "A warm smile and an outstretched hand are valued above modern science, but the latter is more accessible than the former." Sister Frances Dominica, an Anglican nun who founded the first children's hospice in England, spoke at the Conference on Helping Children Cope with Death. She noted that hospice takes us a long way backward, where intuition and compassion were valued.

Sister Frances told of a young mother struggling to bring up two small girls, both with terminal illnesses. One day the youngest one died, aged only three years. Her four-year-old sister watched the little body going down the drive and said "I wanted to die first so I could be there to meet her." Well, she died three days later.

Sister Frances stayed with that mother, whose spiritual pain must have been almost unbearable, through the weeks preceding and after her children's death. Because of that first little girl, named Helen, 'Helen House' was founded, and parents and brothers and sisters of children with a terminal illness are cared for with as much love as the dying children. That same nun, went to South Africa to talk about children's hospices. She saw a black baby, dying. He had been found, half drowned in a toilet. She begged to be allowed to take him back to England to die in her hospice. Fourteen years later, that baby is at school, adopted by her, taller than her now, and causing great delight and consternation by saying that his mother is a nun. That is what hospice care is about: a sort of crazy, divine madness, that doesn't count the cost.

At Acorns Children's Hospice, the Manager, Brian Warr, told us about a Christmas Day when a baby died, and the mother could get neither priest or doctor to visit. Not because they were uncaring, but because they cared too much and simply could not face this mother's anguish on such a holy day. (They later rang to explain this.) Brian picked the child up in a blanket, rang the support volunteer who had loved her, who was 100 miles away, and with the parent went to the hospice where they washed and dressed and kept the child until the support person arrived.

The mother was able to stay with that child, holding it in her arms, and walking around the garden with her for three days, until she had said her good-byes. Brian said that he appreciates his own three sons so

much more for doing this work. Hospices give people that time. In our public hospitals at the moment, in our children's wards, we do not have the time or space to allow this ritual, this type of care to happen.

Hospice is not a place, just as the church is not a place. They are both messages of love to be lived out in community, by community. These are ways to be followed: of love of God, neighbour and self. These are ways of believing, a way of hospitality that receives others as lively images of God, or God's messengers, regardless of whether they are believers or not. What matters is that we act out this way and do not just pay lip service to it.

These messages of love and relationship can be carried out in buildings, and often are - but it doesn't matter whether these buildings are public hospitals, at *Hopewell's* Glory Farm, in people's homes, in churches or cathedrals or hospices throughout the world. Hospice simply means hospitality. Wherever this happens, it is a sign of God's compassionate, lavish, wasteful love.

Love that is compassionate and wasteful is also costly. It is costly to us because it taps so deeply into our innermost being, into our own uncertainties about our faith, our life, our purpose, our mission. Hospice care is costly to the health systems in power because these dying people can contribute no more to society. Yet God's love is like this love - God's love does not count the cost - it is generous, wasteful love that shines on good and bad alike; pays those who come last to work in the vineyards as much as the first; throws parties, banquets even, for those who have appeared to be wasteful and who wandered far from home.

This love overturns all the notions of health care that we think is acceptable in 1995, that has to fit into strategic plans and models, and standards that exist just to establish credibility for accreditation purposes. This model of love is one of generosity, "Friend, lend me three loaves" was a most natural request for Jesus to make at midnight on someone else's behalf, and he expected people to lend boat or beast as unhesitatingly as he would have handed over coat and cloak to them. No rules, only God, no systems or power, only the Reign of God, which is the reign of Love. "It is no good patching the old coat", he says, "the old skins will never do for new wine". (John V. Taylor, *The Go-Between God*.)

The old ways, the unfulfilled, the spoiled the second best must be exposed, he said, and they were. For the Church, it is no different today. The message of Jesus is happening all around the world, wherever walls are crumbling, advocates are speaking up, people are lamenting and being empowered. There is enough unavoidable suffering in the world, through earthquakes, famines, war and drought, not to do something about avoidable suffering.

Hospice exists to overcome the masochism that allows suffering to go on: it draws attention to community apathy or indifference; it laments the things that are not of compassionate care, and speaks to the community of the things that should be and could be. Hospice with its myriad of supporters and volunteers provide solidarity as we work together to change the system that disempowers and diminishes people, whether it be in our hospitals or prisons or nursing homes or schools. Hospices exist to follow this way of surprising love.

Sydney Carter has summed this up through his tribute to the woman who "wasted" her costly ointment on Jesus shortly before his death.

*No revolution will come in time
to alter this man's life
except the one surprise
of being loved.
He has no interest in Civil Rights,
neo-Marxism,
psychiatry,
or any kind of sex.
He has only twelve more hours to live,
so never mind about
a cure for cancer, smoking, leprosy,
or osteoarthritis.*

*Over this dead loss to society
you pour your precious ointment,
call the bluff,
and laugh at the
fat and clock-faced gravity
of our economy.
You wash the feet that
will not walk tomorrow.
Come levity of love,
Show him, show me,
in this last step of time,
Eternity, leaping and capering.*

This poem, to me, sums up what the ideal of hospice care is about - compassionate, community caring. I am reminded of how Mary poured the expensive perfume over the feet of Jesus, and was rebuked by the people present, yet praised by Jesus. Many were indignant, but Jesus rebuked their meanness of spirit by saying that she had anointed his body before burying, and from then on, wherever the gospel was preached in the whole world, "what she has done will be told in memory of her." (Mark 14:9)

Jesus empowered all the people who reached out to touch him. When people are dying, they need this empowering of their spirit. They want us to be honest, and compassionate, warm and humble. They also want us to act as advocate for them and cry out about the injustice of a depersonalising high tech, scientific health system. They want empathy, someone to walk in their shoes with them in their darkness, in their anger, fear and distress at giving up all that they have loved. They want permission to cry, to rage, to feel.

Hospice helps people fulfil their potential, dance their dance, sing their song, sometimes for the first time. Hospice work is about helping people to become fully alive even in the final stage of growth which is death. What, then, is a really alive person?

"A really alive person is not merely someone who has a taste for life, but somebody who spreads that taste, showering it, as it were, around them; and a person who is really alive in this way has, quite apart from any tangible achievements, something essentially creative about him or her." (*Mud and Stars*, p. 221.) All of us at *Hopewell*, have met these creative people - at Glory Farm, in their own homes and amongst the volunteers with whom *Hopewell* has built relationships.

I can remember how fully alive Jerry was until he died. Before I left for overseas, he was organising his funeral, arranging for someone to fill in for me in case I didn't make it back in time, telling me how the hospice should be run! The night before he died, he was telling his friend how to market her real estate. Dying people can be as fully alive, or indeed more so than many members of our affluent society who, despite material wealth often appear half-dead. We are fully human, fully alive when we love God and neighbour as ourselves, this is how God has made us to be.

As hospice workers care for others, they become the cared for and receive healing and a new self-understanding of what it means to be human. The basic message of hospice care is: We will not abandon you, and you are important to us. The Christian element of hospice care, which perhaps differentiates it from other professional care, is the belief in the promise of God's unconditional love at each moment of existence, whether in this life or after death. The Christian promise in the resurrection is that life does not end, and love overcomes and goes beyond death. The prodigal son story and the story of the workers in the vineyard both testify to this promise.

Spirituality

Spirituality is a way of reflecting, transcending, and creating. It is an awareness of the past and the present and the ongoing process of life. It is the life force which lures us on, beyond despair, toward hope and fulfilment. It is the celebration of life and the finding of meaning in all of life's events whether joyous or painful. It is, as the mystics say, the knowledge that despite appearances to the contrary, all in the end will be well. Spirituality rejoices in the interdependence of all things. It is the art of making connections, as St Francis did, with all of creation and, as St Clare did, with life and death and with eternity, which begins now.

Many of the people I meet in the palliative care ward at the Gold Coast Hospital are not religious people, but they are all people of spirit, created in the image of God. The word 'spiritual' embraces the essence of what it means to be human, and we are all human. For many people, however, the crisis of cancer is a time of awakening, when spiritual sensitivities are most aroused. Spiritual care represents the God of comfort who walks with people through the valley of the shadow. Spiritual care supports people as they move through this time of darkness. It does not take away the pain, but helps people travel through it toward the light.

I remember Richard, who was so depressed when they asked me in to see him. Couldn't eat, wouldn't speak. He sat looking down at his feet. They had called the psychiatrist, but he didn't improve. I noticed him looking at his feet. As far as I can remember all I said was, "You look as if you would like them to carry you out of here." He nodded. I sat on the floor and massaged his feet and he cried. He wasn't

depressed, he was sad. He spoke of how he had dreamed of playing golf, of retiring, of living many quiet years after an exhausting career, of enjoying his retirement years. Of how he had left everybody behind to come to this beautiful Golden Coast of beaches and holidays and was now dying, alone and separated from his story, his past, his friends and family.

Hospice care has often been described as “low tech and high touch”. Touch is a vital part of spiritual care. Adrienne Rich, one of our fine theological writers, says that “a touch is enough to let us know we’re not alone in the universe, even in sleep”.

I remember Michael, single, eighty years old, I had been looking after him for about two years. He lay dying and I realised how much I was going to miss him. He was in a coma, and didn’t know I was there (what really matters in spiritual care is not being left alone as so often people are), and I held his hand and said “I’m going to miss you, I really love you”. He opened his eyes and said, “Nobody’s ever said that before.”

Spiritual care is risk taking, saying the things that come from the heart, speaking the truth, seizing opportunities before it is too late. All of our volunteers could tell stories like this, and many more will be told over the years. Spiritual care is about storytelling of lives well lived and sometimes not well lived. Of all the different stages of life, and the thousands of stories that make up the fabric of our lives.

Elie Wiesel puts it well: “I’ve tried to do something with my life to help others do something with theirs. Helping others, that’s the main thing. The only way for us to help ourselves is to help others and to listen to each other’s stories.” (p. 146, *American Heroes*)

Spiritual care involves the ministry of presence, putting an emphasis on being rather than doing. We spent an entire weekend working with the Zen Hospice in San Francisco, learning how to sit and breathe with our patients, so that they would feel connected. Breath, from the Hebrew word *ruach* is another word for the Spirit of God. Often I have touched a patient in a deep coma, and they have breathed a heavy sigh. One patient had a very distressing facial cancer, half her face had been eaten away and the nurses were finding it difficult to go in to her. They asked me to see her and as I walked into the room, the smell was overpowering. I prayed. It was all I could do and, as I did, I remembered St Francis who kissed the leper and realised it was the Christ. As I touched her hand, she sighed deeply and died. She, maybe, was waiting for reassurance, a breath, a touch, the knowledge that she was not alone.

Overseas, I was reminded that there an increasing number of patients who are adherents of faiths other than Christianity. When helping those of faith different from one’s own, it requires awareness and sensitivity to their needs, trying to understand their problems, and taking seriously their religious tradition with its riches and resources. As Mother Teresa says, “My job is to be faithful to the gospel, not to be successful.” She does not need to convert her patients, she is there is love and wash and care for them. Hospice as a spiritual program, provides a way of expressing the Christian belief that the source of all reality, the depth of our being, is revealed in the life, death and resurrection of Jesus.

Spiritual care follows the ministry of Jesus who represented fully the wholeness of God in humanity, healing, liberating and with full awareness of all creation. So we come to serve all patients with a sense of privilege and awe at the mystery of individual personhood, with a meaning, purpose and spirituality unique to each life.

In the last analysis, hospice goes beyond skills, techniques and psychology. It is sharing with another in the experience of grace, a surprising unsought gift of love. It aims to be the embodiment of God’s love given freely to all people because they are all seen as being of complete worth. I believe that every ending, even death, brings transformation and growth. This hope is an essential ingredient of hospice care.

As patients review and reflect on their life experiences and find meaning and purpose in them, then they are freed to live and love fully, even as they are letting go of this life, and to move with creative potential into the future, beyond death.

For this very reason, hospice care negates the need for euthanasia. Hospice palliative care is about the care that is given to the total person, body, mind and spirit. If spiritual pain is eased, the passage through death becomes one of having lived a life full of meaning and purpose and love. As Cicely Saunders says, when anyone asks for euthanasia, someone or society as a whole has failed that person.

A recent article in the British Medical Journal, from a pharmacist who spoke about how he had followed with interest the debate about euthanasia. He spoke of his approval, as an atheist, of the evolution of more liberal attitudes toward euthanasia, especially when intolerable pain and other suffering in incurable illness was involved. Then his young wife developed cancer and eventually died of it. While his wife lay dying, however, he had to hold her up to clean her teeth, and this act itself became sacrament, a way of living more intensely. She would lift her arms up to put around his neck, and then it would become a lingering loose embrace. He asked, "Would she, racked by a cough with every breath, helping her hold her head up to help her spit, cleaning up after her over and over again, would she have given up one of those hugs, to have died a day earlier? No."

He posed the question, "How much value does a hug have against a wretchedly low quality of life by any usual standard?" Sometimes she would wake out of a sleep to smile. "Would it have been right to extinguish those last smiles a few days earlier in the name of humanity: I can't believe it, and think that even in this last period of prolonged suffering from bedridden discomfort, fear, painful medical interventions, the loss of personal integrity, and the racking cough with all its nuisances, there were valuable moments for us both, our family and even for the nurses." He said, "Maybe I'm being selfish, but I cannot now accept as glibly as before the prescription that abysmal quality of life equals euthanasia. Or maybe a hug is an irrational number on the quality of life scale?"

For Jerry, for Fran, (and when I met Jerry two years ago he couldn't see any reason to go on living) the last squeeze of the hand that he gave Fran, the smile and peace on his face, speaks more powerfully against the euthanasia request than any bill that may be passed. Palliative care, hospice care, that values the life being lived, the story being told, and controls the total pain of the person is what is needed in this world.

Hospice care and spiritual care have one common aim: to express the love of God to all, in every possible way:

- physically, by skilled, competent and compassionate nursing and medical care;
- emotionally and socially, by understanding, listening and empathic consideration for patients and their families;
- spiritually, by caring for the whole person, as part of the larger community, in body, mind and spirit.

The parable of the compassionate Samaritan and the well-known quotation, "Anything you did for one of my brothers or sisters you did for me" have inspired Christians in every generation to minister to the destitute and dying. On the Gold Coast, in 1995, *Hopewell Hospice Services*, as a concept of care, attempts to follow that way of Jesus.

This poem, from *Solitude* by Henri Nouwen, expresses this spirit of care.

Philosophy of a Volunteer

Every human being has a great gift,
A gift to care;
To be compassionate,
to become present to the other,
To listen, to hear and receive.
As that gift is set free and made available,
Miracles take place.

Those who really can receive bread from a
stranger,
and smile in gratitude,
Can feed many without even realising it.

Those who can sit in silence with another person;
Not knowing what to say,
But knowing that they should be there,
Can bring new life to a dying heart.

Those who are not afraid to hold a hand
in gratitude,
To shed tears in grief,
And to let a sigh of distress
arise from the heart;
Can break through paralysing boundaries
and witness the birth of a new friendship,
The friendship of the broken.

When I care,
I first of all empty my own cup, and
Allow the other to come close to me.
I take away the many barriers which prevent me
from entering into communion with the other.

In recognising my humanness,
I can participate in the care of the God
who came, not to the powerful but the powerless,
Not to take our pain away but to share it.

Conclusions

The opportunity to travel and undertake research through by the Churchill Fellowship has provided many insights. These are being disseminated through written reports, media articles and talks to various groups. The major channel through which these benefits are being implemented is my work with *Hopewell Hospice Services Inc.* on the Gold Coast.

Hopewell is a non-profit, charitable organisation with an ecumenical outlook. Our Patron, Archbishop Peter Hollingworth makes the statement that sums up our philosophy: “The ultimate measure of a compassionate society is the way it treats its most vulnerable members.” People facing the crisis of illness and their families are vulnerable and *Hopewell’s* aim is to provide a compassionate supportive community to all who reach out for help.

In summing up the conclusions of the overseas journey, it seems most appropriate to do so in terms of how I am seeking to guide their implementation through the Hospice Services provided by *Hopewell* and in its fundamental principles.

1. Hospice is a spiritual program which affirms life

As Dame Cicely Saunders has said, the measure of a good hospice lies in the quality of its spiritual care. We regard the spiritual dimension of life as the integrating component, holding together the physical, psychological and social dimensions. It is concerned with finding meaning and purpose, energy and creativity in life.

Hopewell is dedicated to pursuing this ideal, drawing its inspiration and name from the well that Jesus spoke of: the spiritual well of living water. Hope is a dimension of our humanity and it is part of our faith journey that, even if hope for this life has to end, our hope lies in the things that are unseen, the message that Jesus left with us - eternal life. In a world that is essentially materialistic, *Hopewell* provides the hope for ongoing life, even after death - life to the full for the mourners as they share their darkness, and hope that the loved one who has moved beyond death will grow into that perfect Love that is God with us.

While hospice includes nursing care, it is not primarily a nursing service. We believe that nursing, to be effective, has to be holistic, treating the whole person and not just the symptoms. Hospice offers specialised training so that nurses learn the multi-disciplinary skills needed for palliative care. It emphasises, for example, their own inner being and the need to deal with their own grief and loss issues, so that they can effectively treat the whole person. Within *Hopewell’s* services, the *St Clare Centre for Health and Spirituality* promotes discussion and research into concepts of health and illness, and the spiritual dimension of human wellbeing.

2. Hospice exists to alleviate suffering

Suffering is the anguish of the whole person or, to use a phrase coined by Dame Cicely Saunders, the “total pain” of the intense crisis that the threat of death brings forth. Such suffering cannot be controlled by medication alone. Concentration camp survivors knew suffering after their liberation, even though they may not have been in physical pain. As one survivor said, “We had been liberated, but to what - we had lost everything, there was no one to hug.” Many dying people feel the same.

Hospice provides the hugs. Helplessness, vulnerability, guilt, fear and frustration are all part of the suffering that a crisis such as cancer brings. People who have to watch their loved one suffer, are also in total pain. They, too, are suffering, although their body may not experience pain. Yet the suppression of the emotions of watching another suffer can lead to physical disorders in the living. Hospice care is primary preventative health care, because it deals not only with the total pain of the dying person, but with that of their whole family. Suffering or total pain is eased by the supportive community of hospice.

3. Hospice offers education and death awareness in a society where death is denied and seen as a failure

Death is a natural process and hospice takes us back to a time when compassion and intuition were valued. *Hopewell* encourages a sense of community, of supporting each other on the life journey that lasts such a little while. Our volunteer training and educational programs are directed toward developing an awareness of our own life and death process, to overcome the fears that may prevent us becoming close to another who is facing their own death.

Children can accept death, but adults often have been so socialised that they cannot. *Hopewell* offers an educational program to schools, particularly to teachers and guidance officers. If teachers have not dealt with their own death awareness issues, then they are not able to be there for the children and they are likely to suppress emotions in the children which it would be more healthy to express. Our programs help children reflect on their own illness experience, to realise it is a part of their own body that they are dealing with. This is ultimately teaching preventative health care. To assist this process, we have been given a grant by Queensland Health to run a seminar for guidance officers and class teachers to help children cope with a death in the family, to recognise signs of grieving and to produce a resource kit to be an ongoing tool for Queensland schools.

Even in a short time, our social functions and articles in papers have reached many thousands of people. They are starting to ask “What is a hospice?” and “Why do we need one?” We are able to reply: “Because we are all vulnerable and finite people, and we can all support one another”. Because people matter, they matter until the last moment of their existence, and the ongoing health of the mourners may depend on those who care being there.

At two recent cocktail parties to raise funds for *Hopewell*, 650 people on the Gold Coast heard the word “death” mentioned in relationship to a natural process happening amongst them. Where else, other than at a funeral, can we set in motion this theological reflection on life, on living and loving and letting go into the new life beyond this world, where we continue to grow into the reality that is God? Communities need hospices amongst them so that this reflection can once again bring us back to a sense of commonality of the natural process of life into death, away from the futility of materialism that has crept like a cancerous growth into our present world view.

4. Hospice cares for all age levels

In the past, children shared homes with parents and grandparents and were allowed to kiss their parents, grandparents or siblings good-bye as they lay in their homes after death waiting for loved ones to come and pay their respects. *Hopewell* program of Children’s Educational Services seeks to raise the awareness of teachers and school counsellors in regard to signs of spiritual pain, grief and bereavement in children and to offer programs as primary preventative health care.

Hopewell has plans for a children’s wing, where parents and children with terminal illness can come for respite. Often parents do not have an unbroken night’s sleep in as many as ten or fifteen years of a dying child’s life. Many children from all parts of Australia express a wish to come to the Gold Coast to places of holiday fantasies and fun. Places such as Dreamworld, Seaworld, and Movie World are high priorities among dying children’s wishes. On Hope Island, near these resorts, Glory Farm can provide care for these children and security and peace of mind for their parents.

Marriages of parents of dying children are at risk, one in two couples break up. *Hopewell* offers counselling and support groups for these parents who are struggling with loss and grief in one of the most profoundly spiritual life experiences they will ever face. If grief is not resolved, illness occurs and this can be offset by offering supportive community and bereavement follow-up.

Hopewell is developing a range of services for dying and for grieving children. Expressive therapies for children can facilitate understanding of both processes, so that educators, parents and members of the healing profession can enter the child’s world. Art therapy for children can be extremely helpful, with drawing able to describe the child’s inner knowledge and spirituality. Children know when they are dying, and often it is necessary for parents to understand this through a therapist interpreting the child’s knowledge to the parent, so they can let go of their dying child. Children can also express a lot of about

sickness and let intense or violent feelings out through drawing. The spirit knows where it needs to go if they are given a safe place for healing.

A perspective which is deserving of more detailed research is the potential to give attention to the life experiences of grief, loss and illness which occur for most students during the years of childhood. There is a tendency to regard these as unfortunate intrusions into the simplicity of childhood or as interruptions to learning. This fails to acknowledge the power of such experiences and their potential to provide content which could enrich the learning process. The difficulty that most adults have in facing illness, loss and grief may reflect inadequacies in their health education at school.

5. All involved in hospice have something to give and something to learn

This principle is summed up in *Hopewell's* Mission Statement that: *Hopewell offers a haven, and other practical and spiritual support, to people facing the prospect of death. All involved with Hopewell are encouraged to explore issues of life and death, and to provide a service based on compassion, unconditional love and hope. At Hopewell, our guests become our hosts, our teachers about life and the inevitability of life's end. Our journey is a communal one, we cannot do it alone, and hospice ensures that this final step on the journey is not walked alone.*

Frank Ostaseski, in describing his involvement in the Zen Hospice Project in San Francisco, noted that: "The Project brings together people practising awareness, and people in need." and he referred to those who had died at the hospice as: "These very wise teachers that I've had the honour of accompanying as they die."

6. Hospice offers quality of life for those who are dying and those who are living

Hospice, in the spiritual sense, is not about numbers, days or weeks to live in order to fit the criteria for economic viability. It is about quality of life - for however long life lasts for that person to come to the end of their individual journey. *Hopewell* offers a choice, so that patients do not have to go into hospital to die. If people choose to stay at home, they can be supported. For others, *Hopewell's* guest house, Glory Farm, offers a haven for people in a crisis of illness, but it is not 'the' hospice. Hospice is the total program of care for all people in the community.

Hospice assists our guests, their families and the people in the community with a choice of where to go. Ultimately we leave the decision to them. Even if we feel they choose unwisely that is not our business. If we think we know best, we are guilty of paternalism, even if benevolent paternalism. We are here to empower patients to make their own choices and to be responsible for their own health, both in dying and in living. We establish a role model of how to live. That is why we emphasise that all people involved with *Hopewell* study their own motives and needs, so that we are not there to rescue people or to remove their sense of responsibility.

7. Hospice exists to form supportive community

Hopewell provides supportive community by offering support throughout the illness, so that death is embraced by the patient and the family as the ending of a journey that has been one of quality and dignity. I came back from overseas to find that one of my dear friends had died, but he had been able to stay at home with *Hopewell's* support and there was a sense of peace and rightness about the timing of his death. Because the fear of death had been vanquished, he was able to stay in his own bed, long after he died, until his son and grandchildren arrived. His little grandson was able to hop on the bed and kiss 'poppy' good-bye, as naturally as children who are close to the kingdom of God do.

One way in which we do this is by training pastoral carers and volunteers and nurses to recognise the total pain of a dying person and their family. This enables them to be there as a ministry of presence, in whatever way is best for the family unit. Time is something that hospice offers. There is no pressure to be somewhere else, because hospice does not have to watch the clock as far as cost goes.

Hopewell Hospice Services is at present undertaking its fourth volunteer training program. This provides people with skills in communication and listening as well as personal growth and awareness about death and dying. These benefits flow on to their families and surrounding community members. Our volunteers are involved in fund raising, transporting, counselling, nursing, cleaning and support for patients and carers as well as conducting funeral services and memorial services.

There are over 250 Day Centres in Great Britain, and *Hopewell* is developing and has applied for funding from Queensland Health to provide Day Respite for cancer patients on the Gold Coast. This service will provide respite for patients and carers, reduce social isolation that a lot of patients feel, and allow partners, parents or children to continue their employment.

8. Hospice offers bereavement support

In every hospice we visited overseas recently, volunteers and bereavement support workers were integral parts of the program. Bereavement support prevents disease in the living. Once again, our training program emphasises the fact that if our volunteers and counsellors have not dealt with their own death and bereavement issues, they are not able to be there for another.

From several speakers at the Conference in Canada came the call for schools to make better provision for the needs of children in regard to experiences of grief and loss. Research with children has indicated the high prevalence of such experiences, their potential to disrupt the natural processes of emotional development and academic advancement, and their long-term impact on physical and emotional health. There was recognition of the need for schools to attend more closely to the continuing presence of these factors, as well as preparing for crisis times. The proposals for the latter included the development of regional response teams trained in post-traumatic stress debriefing. In addition, the pairing of schools enables personnel from one school to provide support for another when an emergency arises, taking account of the needs of both students and teachers.

9. Hospice offers pastoral care

We affirm that all people are people of spirit and worthy of spiritual care, no matter what their faith dimension or world view. It is simply not good enough that so many are missing out on this vital aspect of health care. The World Health Organisation says that spiritual care is an integral part of cancer care, and it should be an integral part of all health care, because any illness can create a crisis with spiritual implications.

Unfortunately, the Gold Coast Hospital has no chaplaincy department. There are visiting clergy and the palliative care ward has ecumenical pastoral care workers, but spiritual care for everyone is not yet available. *Hopewell* is training pastoral care workers to provide spiritual care in the community, including hospitals and nursing homes.

Spiritual issues that arise often relate to issues such as: the meaning and purpose of life; the value of money, material possessions and social position; why a person has to suffer; how to be forgiven for things done wrong, and on which there is now time to reflect; whether there is a God; whether ideas of God are inadequate and need to be revised; and whether there is life after death. Such questions can open the door to significant personal growth when there is skilled pastoral support for reflecting on them.

Spiritual care is not a separate part of the hospice program, but is an integral part of the total service. *Hopewell's* spiritual care program exists to serve the poor, the sick, the homeless and the broken-hearted by offering loving, compassionate care to the person with a terminal illness and their entire family.

Several patterns for spiritual care were observed overseas.

- In some hospices, the chaplaincy model involved a minister or similar person attending to religious aspects of care. The central emphasis, however was on medical care.
- Some has a more multi-disciplinary approach, in which specialists such as chaplains and social workers participate as full members of the care team. Even then, the major focus for planning, staffing and pain control is often through the provision of medical services.
- An alternative pattern was that in which the hospice team seeks to provide a home-style environment, to serve as the “family” of the person being supported, and to give a strong spiritual emphasis in the motivation to care and in the training of volunteers. In this case, the medical treatment could be viewed as supporting the spiritual program, rather than the other way around.
- Programs based on concepts of behavioural medicine have an emphasis on holistic health care in which specific activities seek to provide for the full range of factors to control pain and to enhance the quality of life, including attention to the physical, emotional, social, mental and

spiritual dimensions of human functioning. This is a model which *Hopewell* is developing, and the first Health and Wellbeing Program of the *St Clare Centre for Health and Spirituality* is already running for cancer patients and family members.

10. Hospice offers health and wellbeing programs

Dame Cicely says that hospice gives people time to find out who they really are. In our present ward system, it is almost impossible to start helping people to express the suppressed anger and rage, tears and grief that have built up over so many years. We provide meditation and relaxation classes so that people can reconnect with their deepest self and with one another. Spiritual care is helping people discover this again, so that healing can occur, even if cure is impossible.

The research findings being drawn together under titles such as “Behavioural Medicine” and “Psychoneuroimmunology” offer enriched perspectives for dealing with a range of illnesses, some of which are life-threatening. From this perspective, it could be helpful to change some of the metaphors commonly associated with the concepts of health and illness in western societies. This approach recognises the success that allopathic medicine has achieved in dealing with ailments with a clear causative factor, while seeking a wider and more holistic perspective. It takes account of the complex involvement of physical, social, moral, emotional, mental, spiritual and environmental factors in many ailments. There is also attention to the significance that an illness experience has for each unique individual at that particular stage of a person’s life. The recent establishment of a Diploma in Behavioural Medicine in Australia offers the possibility of further research in this area.

These programs have implications for hospices seeking to care for the whole person, to provide holistic pain control and to assist the completion of significant personal tasks in the final stages of life. They also have important implications for the development of health education programs, in terms of the extent to which these assist children in dealing with their actual experiences of illness during their years of schooling. Much work has yet to be done to develop this aspect of the curriculum and to provide teachers with the necessary skills to support children in dealing with and learning from their life experiences in areas such as grief, bereavement and illness. In addition, recognition of the impact of emotions such as fear in limiting human wellbeing suggests that it is not conducive to long term good health when schools resort to the use of fear in attempts to motivate or discipline students.

Completing the Journey

Ultimately, spiritual care in a hospice program expresses one’s philosophy of life. I believe we are all frail, vulnerable people on a journey of growth into God. On the way, we meet many obstacles, and yet we see great beauty and are surrounded by glory. Whether our life ends in cancer or any other illness, we can only trust in the embrace of the God who accompanies us in, through and out of the desert.

Like the God who accompanies us, hospice exists to be with our fellow travellers, sharing the journey, ensuring that pain is not meaningless and that life has quality until the last moment of existence. Our role, like the God who came, not to the powerful but to the powerless, is to do the same by representing that love in action in the world.

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