

The spiritual and Existential Needs of Patients with a Terminal Illness

Edited version of presentation by Denis Strangman to the 10th Asian Regional Congress of CICIAMS (International Catholic Committee of Nurses and Medico-Social Assistants - Comité International Catholique des Infirmières et Assistantes Médico-Sociales), Singapore, 4 September 2010.

I am delighted to be attending your Congress and at being invited to make this presentation.

In June 2000 my wife of 26 years and the mother of our five children – Margaret, or Marg as she was known - was diagnosed with a *glioblastoma multiforme* malignant primary brain tumour and was dead within twelve months.

Prior to this diagnosis we knew nothing about brain tumours and on our way home from an initial appointment with the General Practitioner we puzzled over the Doctor's statement that the specialists believed that my wife had an **astrocytoma**.

We knew that one of our sons, Peter, had been a great fan of the television cartoon character **Astro Boy** and we were trying to work out what the connection might be between Astro Boy and an astrocytoma.

It was some time later that we discovered that an astrocytoma brain tumour had been given that name because of the star shape of its cells viewed under the microscope. Astro Boy was so named because he was a mythical character who travelled among the stars.

That is a simple illustration of the depth of my ignorance ten years ago.

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Accompanying my wife on her journey was a voyage of discovery and personal development. Afterwards I became an advocate for brain tumour patients and their caregivers and families and that has been my full-time unpaid volunteer occupation for the past seven years.

In that time I have spoken with and visited brain tumour patients and their families, and brain tumour patient advocates, in many countries, including patients at the National Neuroscience Institute in Singapore, patients and advocates in the USA, Canada, the UK, Austria, Lithuania, Sweden, Norway, Taiwan, Japan, New Zealand, etc.

In addition I answer the nationwide Freecall number for enquiries to Brain Tumour Alliance Australia and did so for its predecessor organisation several years ago – at least 300 calls in total.

I visit brain tumour patients in hospital and I am fortunate to have met many of the world's leading brain tumour specialists at scientific conferences where the International Brain Tumour Alliance (IBTA), which I Chair, often has an exhibition booth.

I am hoping that some among you may have an interest in brain tumours and that you might be able to act as a bridge between the IBTA and brain tumour patients in your country. I plan to be here until the end of the Conference and hope that any who are interested might identify themselves to me.

My knowledge of these issues therefore comes from a caregiver and advocacy involvement in the area. I am not a medical professional, nor am I an academic, although I have written and researched extensively in other fields.

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The diagnosis of a malignant primary brain tumour has been described as a “**heart sink**” event in the medical community. By that it is meant that Doctors and nurses are aware that the prognosis is not good and that for most of the adult malignant primary brain tumours there is no cure, only palliative treatment, and on hearing of the diagnosis their heart “sinks”.

It is one of the most deadly of all cancers and, unlike breast or prostate cancer, it can attack people of all ages and either sex. You cannot screen for it and it cannot be detected or prevented early on because we do not know the causes at this stage of scientific understanding. It is the only cancer to attack both the mind and the body and the mind is, after all, the centre in which your spirit and sense of being, resides. It doesn’t matter if you have lived a very healthy life, keeping fit, and eating all the right foods – you can still develop a brain tumour.

Its unexpectedness, its randomness, its rapidity and its lethality, together with its attack on both our mental and physical capacity, can result in extreme distress on the part of patients. It is not surprising therefore that brain tumour patients can find their own concepts of spirituality and existentialism being challenged. They will ask questions like: “Why me?” “What have I done to deserve this?” “How long do I have to live?” “How will I die?” “What will happen to my spouse and family?” “How could a kind a merciful God do this to me?” “What did I do in my life that may have caused this?” Indeed, **Aline Nixon and Aru Narayanasamy** in a study of UK brain tumour patients published this year, suggested that neuro-oncology patients may have unique spiritual needs compared to other patients with cancer “as they are not only facing a threat to their life but also to their personality and a potential ‘loss of self’.”

The golfing legend **Seve Ballesteros**, who has been diagnosed with a brain tumour, was reported in the media in July as saying:

“Every day I see the unbelievable things that happen to people and I don’t understand why ... I think ‘Why does it happen to these people.’ I think the same thing with myself. Why did it happen to me? It is unfair, because I have been a good person. But it happens to some people and not to others.”

Clearly, Seve Ballesteros has had existential questions thrust upon him.

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When I say that a person’s spirituality can be challenged I am not talking only about religion or religiosity. **Moon Fai Chan** from the National University of Singapore has written “... *spiritually does not necessarily mean religious dogma, but rather an individual’s philosophy, values and understanding of the meaning of life*”. **Henoch and Danielson** from Sweden acknowledge that both terms of “spirituality” and “existential concerns” seem to be used interchangeably and cite **Neil Henery** that “*the nursing literature on the existential dimension concerns the loss of personal meaning experienced by people facing death, suffering and loss*”.

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The Manual of Palliative Care distributed by the International Association of Hospice and Palliative Care (IAHPC) has a very useful section on Spiritual and Existential Distress and its website has other useful resources for palliative care.

The IAHPC Manual states that “spiritual and existential problems are an important source of clinical suffering – they may cause or aggravate pain and psychosocial problems and they can cause an anguish all their own”.

For the terminally ill the Manual groups the problems into four broad categories: “relating to the past, relating to the present, relating to the future, and relating to religion”.

My late wife experienced memories of incidents from the past which she needed to resolve before moving on in her preparation for her death.

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Recently in the American literary publication “**The New Yorker**” there was a lengthy article by a Doctor about the conflict between curative and palliative care and in which he referred to practices of the past. He wrote:

“Dying used to be accompanied by a prescribed set of customs. Guides to *ars moriendi*, the art of dying, were extraordinarily popular; a 1415 medieval Latin text was reprinted in more than a hundred editions across Europe. Reaffirming one’s faith, repenting one’s sins, and letting go of one’s worldly possessions and desires were crucial, and the guides provided families with prayers and questions for the dying in order to put them in the right frame of mind during their final hours. Last words came to hold a particular place of reverence.”

I have not yet come across a 21st Century equivalent of such a text. **The Tibetan Book of Living and Dying**, which is quite popular, understandably does not canvass a Catholic approach to dying.

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I would say that the moment that Marg understood her prognosis my wife had escalated the preparation for her death.

In a sense we were fortunate as a couple because we had both been brought close to death during our marriage and this had deepened our belief in an afterlife and underlined to us the fragility of our existence. In 1985 I suffered a **heart attack** and I can remember the cardiologist telling me that the first 24 hours were critical, if I got through that I would most likely survive.

The following year, after the birth of our youngest child, my wife developed **post-partum cardiomyopathy** where the heart muscle slowly dies and she was rushed to St Vincent’s Hospital in Sydney to be assessed for a heart transplant. Luckily the condition did not progress and she recovered.

The next year, following an operation at our local Calvary Hospital she suffered a **cardiac arrest** and I was called urgently to the hospital to find the staff applying the “paddles”. Again she recovered but this time she had a near-death experience in which she believed that God told her that she was not yet ready to come with Him and that she had more work to do with her family and in our Parish.

She therefore had this sense of living on “borrowed time” for 14 years before the brain tumour arrived in our lives.

I guess that because of her deep faith her situation was untypical, however, it illustrates that distress relating to spiritual and existential needs can affect anyone.

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Two other features of her journey, which could be regarded as having a spiritual characteristic and representing a “need”, were her prayers for the “gift of final resolution” and her endeavours to convey to people, including her family, her belief in their goodness.

She accomplished the latter by writing letters to people. The “gift of final resolution” involved a desire that as she progressed towards her death she would not abandon her belief in the goodness of God and the existence of an afterlife in which we are united with God.

If this sounds like someone who was very aware of their situation and is accepting of what is up ahead then that is correct. Sometimes, I got the distinct impression that she was impatient at having to hang around on earth while her illness took its inevitable course.

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I would like to turn now to ways in which nursing professionals and Doctors can identify unmet needs in this area and what they can do about them. I include Doctors in this requirement because I believe they cannot abdicate a responsibility to administer holistic care, rather than confining themselves to a strictly medical/technical approach. Although it is acknowledged that Doctors and nurses are time-challenged, **Anja Visser and colleagues**, in a literature review of spirituality and emotional well-being, found that patients ranked physicians and nurses as the number three and four spiritual caregivers, after family members and friends.

However, in her major survey of factors considered important at the end of life **Karen Steinhauser** found a significant difference for nine attributes considered by patients as important but less so by physicians, and two of them were – Be at peace with God (89% patients, 65% physicians) and to pray (85% patients and 55% physicians). Interestingly, coming to peace with God *and pain control* were nearly identical in importance for patients and bereaved family members.

As key members of a palliative care or hospice team doctors play an important role in the allocation of resources and the establishment of priorities for the care of patients. Perhaps this difference in perception about key attributes needs to be corrected by a refinement of the content of medical curricula? In the very comprehensive 29-page listing of recommended content headings for its **Core Curriculum Outline** for medical oncology, developed by the American Society for Clinical Oncology (ASCO), there is only one brief mention of spiritual aspects: “Spiritual Conflicts Associated With the Diagnosis and Treatment of Cancer”. In the Australian “ideal” oncology curriculum medical students are supposed to understand spiritual differences in society and spiritual issues as part of end of life issues generally.

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There has been some discussion in palliative care circles about moving away from a diagnosis and prognosis-based palliative care to a **needs based model of care**.

In Australia a **Needs Assessment Tool: Progressive Disease Cancer (NAT:PD-C)** has been developed to facilitate the initial identification and on-going assessment of whether the needs of individual cancer patients are being met.

It has a relevant question within a 24 item sheet: “Does the patient have concerns about spiritual or existential issues?” with the opportunity to rate the concern as being None – Some/Potential – Significant, and also to record the action taken. A copy of the assessment is to be placed in the patient’s medical record.

To assist in determining the rating for spiritual and existential issues it has these questions: “Is the patient feeling isolated or hopeless? Does the patient feel that life has no meaning or that his/her life has been wasted? Does the patient require assistance in finding appropriate spiritual resources or services?”

Interestingly, some of the questions designed to identify **psychological symptoms** shade into this area and one of them is “Is the patient requesting a hastened death?” I will return to that issue later.

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The questions I referred to earlier in this assessment tool really require a more in depth assessment and we are fortunate that another Australian team has developed a workshop resource directly relevant to palliative care which assists in this regard.

The project was led by **Dr Judith Murray** and the resource is freely downloadable from the Palliative Care Australia website. I have copies of the web link on a sheet of reference sources available afterwards.

Dr Murray’s group recommend starting in this way:

Be a careful observer –

Does the person have on the bedside or on their person some religious symbol?
 Do any cards from others they have displayed have religious pictures or messages?
 Do any books they have on their bedside table have a spiritual, philosophic or religious title or flavour?
 Are they watching programs on television in these veins?

You could comment –

“I see that you are reading How are you finding it I see that you are wearing adoes it have a particular significance for you? That is a beautiful card that you have been sent ... I was just wondering of the religious message on it was of importance to you?”

These are things that you could observe of the patient and say to them but do not forget that the patient is probably also observing you, sometimes very intently and, if you are Christian, there is something you can do – you can give an unobtrusive clue as to where you stand.

In the treatment or palliative care settings you can subtly convey where you might be coming from by your demeanour or your allusions to generalised topics within what might be described as the “basket” of spiritual and existential issues.

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Recently my colleague in the UK and I edited a 114 page magazine for the international brain tumour community. I was unable to arrange the freighting of sufficient copies from the UK for everyone attending this Congress but I am hopeful there will be sufficient for all the non-Singapore visitors and several reference copies will be available for Singapore residents. We designed a number of common questions around which we generated interviews from leading clinicians, neurosurgeons, nurses, patients, and patient advocates.

While we did not seek to ask our correspondents if they had spiritual beliefs, a number volunteered the information when we asked them this question:

“How do you cope with the emotional and psychological challenges to you personally arising from your work?”

This was the response by a neurosurgeon: “I pray”.

That particular neurosurgeon didn't have to reveal that information but he chose to. Sometimes you will be asked similar open-ended questions.

Here is the response from a radiation oncologist: “In the initial part of my practice I tended to get quite involved and it was especially hard occasionally. I got some solace from the Hindu philosophy of Kama and acceptance of life and death as a continuum.”

Here is the response from a very prominent neuro-oncologist: “I read the Bible every day, and I find so much comfort and hope in its pages. I have a deep faith that God has given us all tasks to serve Him, and I am constantly asking “Am I doing the right thing with this patient?”

There were similar responses from other people, including patients and health professionals, who we interviewed. But I don't want to give the impression that this kind of answer was universal.

I recall talking to an internationally prominent paediatric neuro oncologist at a conference and I asked a similar question of him. It was almost as if he knew what was on my mind and he volunteered that the motivation for working in this very challenging area – paediatric neuro-oncology – had *not* come from any religious beliefs, it had come from curiosity as a medical student.

And so, depending on the environment in which the patient finds themselves they might be met with ambiguity or evasion if they ask the staff an open-ended question that touches on spiritual subjects. How you respond requires a very delicate evaluation of your work environment and a careful understanding of the patient's question.

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Just as the golfer Seve Ballesteros struggled to understand why he had developed a brain tumour despite being “a good man”, as he said, we must be careful of not encouraging a belief in death or illness being a retribution for past actions.

The Anglo-American writer and secular humanist **Christopher Hitchens** publicly and savagely denigrated Mother Theresa and religion in his writings during the past decade. Recently he was diagnosed with oesophageal cancer and wrote of what must have been a terrifying experience: “The whole cave of my chest and thorax seemed to have been hollowed out and then refilled with slow-drying cement. I could faintly hear myself breathe but could not manage to inflate my lungs”.

I do not accept the idea that Mr Hitchens' illness, typhoons in Haiti, flooding in China and Pakistan, or tsunamis in Asia, are retribution from God.

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Returning to the Australian Workshop resource, they have some good pointers about the knowledge and skills needed:

We need to know what we may be listening for.

We need to be able to hear the story in whatever form it comes, pleasant or unpleasant, clear or confused.

At other times the invitation for you to enter this part of the dying person's world is given in a more intuitive way:

- . A meaningful silence
- . A hesitation in an answer when there had been surety before
- . A withdrawal
- . A growing withdrawal from discussions with others of religious matters or answers
- . A sense that comfort is coming less in the religious language
- . A question about what a staff member as a person may think about the afterlife or God or being punished
- . A complaint about how tired one feels when certain people visit.

They recommend:

- . Look for an invitation into the discussion
- . We need to have the courage to simply ask. It is often best to verbalize thoughts exactly as they are.
- . Cultivate a recognition of the importance of simply being able to 'sit with the pain'.
- . Learn to ask both verbally and in non-verbal ways through your physical presence and comfort with their uncertainty, *"I'm hearing what you say, but I'm not sure I understand fully what you mean. Would you be prepared to tell me more? I would like to understand"*.

They then go on to give some pointers about how one can respond.

An obvious observation to make is that there is an assumption that there is a **team approach** in existence in looking after the patient in the end stages and that this knowledge needs to be imparted to all who are part of the team: the medical and professional specialists (including social workers and pastoral care workers), the nurses and Doctors, and even the volunteer workers who may be involved, because the patient might choose any individual from a number who have dealings with them, to ask the question "Do you believe in an afterlife?"

When I visited Singapore's **Dover Park Hospice** two years ago I was struck by the deliberate attempt to ensure that it functions as a secular institution, open to all races and those with any or no belief system. People working in a secular institution do have to be careful if they are asked an open-ended question that touches on spiritual subjects. The questioner may indeed be indirectly seeking access to contact with a religious official and, if so, an appropriate person may need to be invited into the premises to counsel that patient.

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When this kind of care is being delivered in a **Catholic institution** it is imperative that there be adequate training of the staff to be alert for the signs that enable one to make an assessment of any spiritual needs that a person may have and their wish to talk about them.

I note from a report prepared for the **Pontifical Council for Health Pastoral Care** in 2004 (and updated in 2007) of the Catholic health care centres for palliative care, that while 51.4% of the Centres that responded organised training courses for pastoral care in health the remainder did not. I hope that the situation has improved.

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This leads me to the public discussion of **euthanasia and the role of health professionals** in it.

Euthanasia and physician-assisted suicide are contrary to the principles of palliative care. The **World Health Organisation** definition of palliative care states: “Palliative care ... affirms life and regards dying as a normal process; intends neither to hasten or postpone death ...”. The **Asia Pacific Hospice and Palliative Care Network** states: “We value every moment of life and do(es) not support any action that has the intention of shortening a person's life”. **Palliative Care Australia** states: “Euthanasia is not a part of palliative care practice”.

In my country much of the debate about end of life subjects is prompted by the activities of **Dr Nitschke**, otherwise known as “Dr Death”, who conducts seminars about how to end your life and is the leader of an international pro-euthanasia group called “Exit International”. He is a superb showman.

I note that you health minister **Khaw Boon Wan** said last year when the Singapore Police opposed a visit by Dr Nitschke: “A workshop to teach the terminally ill how to commit suicide, and in fact, break our law, is not welcome here ... euthanasia, which means helping the patient to commit suicide, is not what the Ministry of Health is promoting”.

Very often Dr Nitschke’s campaigning is not countered by voices from the palliative care movement. It is as though they hope he will just go away. Some palliative care practitioners have told me that it is not their job to be engaging in the public debate about euthanasia, that they have to appear publicly neutral and to be welcoming of all who may wish to spend their dying days under their care. But I believe you can be publicly firm about your philosophy while being welcoming of those who wish to avail themselves of your institution, either as an employee or a patient, if they agree to accept your ethical framework.

The problem is that it is these same people who have the accumulated knowledge and expertise to publicly oppose the arguments of people like Dr Nitschke and to advocate for palliative care and to point out that euthanasia and physician-assisted suicide have no place in palliative care.

I think some of them might be faint-hearted and over-cautious.

A question that has often crossed my mind is that some advocates of euthanasia may support it more in a theoretical manner than as a deep personal conviction and are unlikely to seek to suicide. That might therefore sound harmless but there is another side to the coin: by over-emphasising pain in their public statements, by denigrating palliative care and claiming it is useless, and ignoring psychological anxiety and depression which might arise with a terminal illness, they can make patients feel guilty and for them to think of suicide as representing the least form of inconvenience to the community.

That is why there needs to be voices that say clearly and unambiguously “Euthanasia is wrong”.

There is such a thing as the “slippery slope” and we all know what happened in the recent past when a country came to believe that there were lives not worth living.

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Anxiety and depression can be a real part of having a terminal illness. It has been identified by **JP Solano** and colleagues as one of 11 common symptoms in a review of end-stage patient symptoms across five diseases. In cancer depression can be as high as 25-35%. For the past year our brain tumour advocacy colleagues in Australia have been working with the depression

organisation “Beyond Blue” to produce a Fact Sheet about this subject which will be launched next month.

It is well known that talk about euthanasia and self-harm or suicide by a terminally ill patient might arise from anxiety and major depression brought on by their approaching death. That warrants a psychological response that will minimise the underlying anxiety, not agreement with the views being expressed.

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When will we see a “Dr Life” emerge from the medical profession to counter the work of the Dr Nitschkes of this world? I don’t believe we can leave it to successive Popes to be the only prominent people to defend Life and oppose euthanasia and deliberate killing. Those in the medical profession must also speak out clearly and firmly.

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I suspect that in a number of developed countries euthanasia has become a “touchstone”, by which I mean it has become an issue of public policy through which people indicate where they are positioned in the spectrum of contemporary moral issues. I know that in my own city, Canberra, journalists asked the local candidates in the lead up to the recent Federal Election in Australia their views on euthanasia and the two Lower House candidates who were successful in Canberra are now both pro-euthanasia.

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I fear that many people arrive at a pro-euthanasia position because they suffer from an excess of misplaced “charity” that over-rides logical thinking. You will often hear the pro-euthanasia people saying that they believe in “death with dignity”, or that you “wouldn’t allow a pet dog to suffer like that”. Often they will commit a basic error of logic – they will rationalise from the particular to the general. They may have heard about or experienced a particularly harrowing death of a family member or friend and they are determined that such events will never occur again. It should be said that often you will find that these scarifying episodes happened years ago, or the patient did not have access to appropriate palliative care.

Well we, as Catholics, are one with them, in believing that no one should die in pain that can be relieved but we reject the idea that the medical staff or the patient themselves should deliberately hasten their death as an acceptable means of dealing with this problem.

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There is a major task facing us in the community to explain the principles of palliative care, including the principal of double effect, and to point out that while a complete absence of pain in the terminal stage cannot be guaranteed, there are excellent methods available to alleviate pain and there is continuing work being undertaken to develop new palliative medicines.

In fact, one of the advisory committees I serve on is the Australian Federal Government’s **Palliative Medications Working Group** and it is tasked with identifying and supporting projects that will enable wider access to medicines suitable for palliative care. This includes clinical trials of drugs that might be approved for other purposes but have not been examined and approved for use as palliative care medications. Often there is no incentive for the manufacturer to embark on expensive clinical trials to achieve approval (and in our health system, subsidisation by the Government) for their use in what is a small commercial market area. This Working Group seeks to remove these barriers and facilitate the process of approval.

All these medications are intended to either ease the distress of the dying process or to provide greater comfort. I am sure there are similar initiatives in other countries.

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As a visitor I do not wish to be critical but I did notice that in the study undertaken recently by the **Economist Intelligence Unit** and commissioned by the Singapore-based Lien Foundation, Singapore ranked 18 out of 40 countries in its “Quality of Death” index, just behind Luxembourg but outranked by Hungary, Taiwan and Poland. It could be that a discussion needs to take place about the adequacy of services in Singapore and that improvements might be possible.

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One of the most difficult questions you are likely to encounter from those who are troubled by spiritual and existential matters is: “Why must I suffer like this?”

To be honest with you, I have yet to find an appropriate response to this question that is not grounded in a religious context and that, of course, will not meet the needs of the growing numbers of unbelievers.

At this stage could I introduce you to **Dainere**, a twelve year-old girl from Canberra, the city where I live.

Dainere has a medulloblastoma brain tumour and has suffered just about every possible bad side effect from the treatment regimen intended to cure her. She has difficulty walking and is now deaf in one ear. Her pain is inadequately controlled and that disturbs her sleep. She is a gifted writer and has chronicled her day to day journey on a blogspot on the Internet, which has been published in a book.

When I recently travelled to the United States and Europe I took a copy of Dainere’s book with me and showed it to the clinicians and patient advocates I met. They were all very impressed.

In her diary entry for 1 March this year she writes of an evaluation by her neurologist – the coordination on her right side is worse, her balance is unlikely to improve, her eye flickering and drooping is likely to remain, and she has permanent nerve damage in her hands and feet. She comments “This was not news I wanted to hear”.

In January she had written: “Some days I feel like my old self and other days I find I just want to sit down and cry and wish I would wake up from this nightmare and I still question why this had to happen to me.”

The family are Catholics and one day following a visit to a local Church she writes “As I sat in Church and looked up at Jesus on the Cross I thought how he suffered and then I thought about my own journey so far and I truly think that I have suffered as much as he did, in a different way but both of us were not terrible people and had to try to be brave and determined on our journey.”

Dainere has developed an understanding of her suffering which provides an aim and a context which may help her to come to terms with this challenge. For other people the answer might be different.

I want to refer to the wise advice of another brain tumour survivor I have been fortunate to meet, Cheryl Broyles, who I met at an American brain tumour patients’ conference in Oregon last year.

Cheryl is a ten year survivor of a glioblastoma brain tumour, which is a very rare and remarkable achievement.

In May a fellow brain tumour patient asked her on one of the email discussion lists how she coped and this was Cheryl's response, which she has given me permission to quote to you:

"I've been on this list for years and years. I try to never "preach" to others about my Lord. But my heart goes out to you. I know your fear. I feel it too. And I know the only thing that deeply gives me peace and hope for the future is leaning on God for the peace and strength to handle the challenge. So I've got to be honest and tell you. For myself, I've been in prayer often today, fighting the fear. Wondering now if I have brain cancer and liver cancer too. I just got 9 blood tests today looking into my liver, seeing if the "tumor" in my liver is cancer. Waiting to hear the results is hard. The only answer I have for you on "how do you do it?", the only advice I have for you, is the first thing you said yourself, "leave everything in GOD's hands." Every time you look away from God and get caught up in fear, look back to God in prayer. You can be filled with peace that surpasses understanding."

I can endorse that advice.

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But while there might be a need for some patients to undertake prayer as a means of coping with their illness, the same can apply to the loved ones who are also travelling this journey. Here is a photo of myself and colleagues when we visited the **Jogyo shrine** for cancer patients in Kamakura, Japan last year. I am the one with the Penguin-looking feet! The shrine is a popular location for patients and their loved ones and here is a photo of 1000 Origami folded paper cranes hanging from the ceiling of the temple. They are called **Senbazuru** and are often made by friends to give to someone who has cancer, in the hope they will be cured by this intervention.

In the cancer journey there are **two very strong natural desires** that arise, in my opinion. One is to try and identify **a cause** for the cancer and in relation to brain tumours that is why we read so much discussion about mobile phones being a cause of brain tumours.

The second is **a desire by loved ones to intervene** and to help the patient to become better and even be cured. That can take different forms – creating a *Senbazuru*, as described above, recommending complementary and alternative medicines or supplements that the patient should take or, in the case of Christian and other religions, engaging in intercessory prayer to God or to Saints asking that the person be cured or to experience a peaceful passing.

In the Catholic tradition that can take the form of special novenas or prayers to Saints such as St Jude, prayers to Our Lady of Lourdes, and so on.

I believe there is an obligation on the part of nurses and Doctors who care for the dying to recognise this need on the part of families and loved ones and even to facilitate it by providing a Chapel or a prayer room where it can take place.

The strength of this desire was illustrated to me when I created a website which was a record of my wife's journey with her brain tumour. The website, which started off as a means of keeping family and friends updated on her progress attracted attention from many people around the world who were in a similar situation. I started keeping a record of the number of visitors and gave up after it passed the 100,000 mark

A number of these visitors sought prayers for their loved one and to handle their requests I developed an on-line “prayer request” form which automatically received their requests. I then forwarded them to a friend in Sydney, Australia, who undertook to place these requests on the altar during a Healing Mass for the Sick which was held once a week. Hundreds of requests were forwarded.

I am reasonably familiar with the literature relating to the effect or non-effect of intercessory prayer and it was fascinating to read just last month about new research that indicated in regard to *proximal* intercessory prayer (compared with *distant* intercessory prayer) that it may have had a beneficial effect with patients who had aural and visual medical problems. And just recently at the World Cancer Congress in Shenzhen Professor Ian Olver, who is the CEO of the Cancer Council of Australia, presented findings to be published soon indicating that in a blinded study group of oncology patients numbering just short of 1,000, the spiritual wellbeing for the intervention group who had been the subject of intercessory prayer had shown improvement. The jury is still out.

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May I conclude by quoting to you a prayer given to my late wife and I by the Catholic Chaplain at Canberra Hospital. It is non-denominational, perhaps even non-Diety specific, but it has been picked up and used by people around the world and has provided great comfort to many.

On one occasion after my wife had a *grand mal* seizure and was lying helpless on the floor of our dining room she asked me “Am I dying now?” I said she was not and we read this prayer together, which brought great calm.

It reads:

A PRAYER FOR TODAY

Every day I need you Lord, but this day specially. I need some extra strength to face whatever is to be ... This day more than any day I need to feel You near - to fortify my courage and to overcome my fear.

By myself I cannot meet the challenge of the hour. There are times when human creatures need a higher Power - to help them bear what must be borne. And so, dear Lord, I pray - hold on to my trembling hand and be with me today

Source references

International Brain Tumour Alliance – www.theibta.org **Denis Strangman Email address:** chair@theibta.org An edited version of this presentation, the PowerPoint slides and these source references can be downloaded from: <http://www.ozbraintumour.org/StrangmanEdited.doc>
<http://www.ozbraintumour.org/StrangmanSingaporePresentation.ppt>
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