10 Carrodus Street

Fraser ACT 2615

Email: string@hotkey.net.au

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Committee Secretary

Senate Standing Committee on Community Affairs

PO Box 6100

Parliament House

Canberra ACT 26100

Dear Committee Secretary

Please find attached a submission from me regarding the Committee's Inquiry into Palliative Care in Australia. I am prepared to discuss my submission before the Committee if required, or to provide further information or answers to questions.

Yours sincerely

Denis Strangman

Submission by Denis Strangman to the Senate Inquiry into Palliative Care

Background: This is a personal submission by an individual who has had extensive involvement in the palliative care community over the past ten years, including membership of the Quality Committee at Clare Holland House (ACT Hospice), membership of the Federal Government's Palliative Care Medications Working Group 2006-2010, and membership of various oversight and palliative care and cancer-related planning committees in the ACT.

The author's wife received home-based palliative care and community nursing services in the ACT when she developed a malignant primary brain tumour in 2000 until she passed away in 2001. The author helped establish the national brain tumour advocacy and support group and is currently secretary (2008 -) of Brain Tumour Alliance Australia (www.btaa.org.au) and Chair (2005 -) of the International Brain Tumour Alliance (www.theibta.org), although this submission is not made on their behalf. He is in almost daily contact with brain tumour patients and their families who are high users of palliative care because of the often lethal nature of their disease. About 1400 Australians per year die from a brain tumour.

Executive Summary

- Palliative care is not just about older people
- I have never seen an estimate of total Federal, State and non-Government palliative care expenditure
- An example of inefficient workforce practices
- There is a component of historically-based delivery of palliative care services in Australia by religiously-oriented organisations
- Advance care planning should be accompanied by recent discussions between the patient and their carers and loved ones
- Experience inside a palliative care research grants selection committee
- Concept of the "consumer" in palliative care
- Example of an uncaring and insensitive question for patients
- An example of insensitive media reporting about "affordable cancer care"
- The Federal Government's Palliative Care Medications Working Group
- More extensive data about the palliative care experiences of former carers should be collected
- There is widespread misunderstanding about palliative care in the community
- There is "opioid myopia" and fear about pain
- Death in an institution is sometimes unavoidable
- There is misunderstanding about the principle of "double effect" and the non-curative approach
- Evidence of depression and anxiety disorders in the dying need to be identified and responded to.

Palliative Care in Australia

Terms of Reference

The provision of palliative care in Australia, including:
...
(v) children and adolescents;

Children and adolescents: The statistics will show that most palliative care clients are older people and most (about 70%) have cancer but among the small number of children and adolescents a significant number are brain tumour patients because malignant brain tumours now compete with leukaemia as the greatest cancer killer of children aged 0-15. Indeed, brain tumours are the greatest cancer killer for both men and women under 39 years of age. People in these age categories often have different needs to older people, particularly young adults who might have a young family. It is a mistake to present palliative care as being something for "older people". I attended the recent opening of a palliative care day respite facility for carers and was surprised that the facility has an age minimum of sixty years for its palliative patients. When I questioned this and pointed out that some palliative care patients are younger than sixty the organisers said they were obligated to institute this age restriction because of the terms of the (non-government) funding source.

(b) the funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent;

My impression is that funding can be uncertain and it is often a case of seeking funding for particular projects from the nearest available source. I have yet to see an adequate calculation of the total funds expended by Federal, State and the non-Government sector, on palliative care in Australia.

In a letter to me on 7 July 2011 the Minister (Hon Mark Butler) talked only in broad terms about funding allocations. He wrote: "In 2008-09, the Australian Government provided an additional $500 million to the states and territories for subacute care including palliative care. This funding is being used to expand service provision over the period 2009-10 to 2012-13. From 1 July 2010, the Commonwealth is providing a further $1.63 billion to fully fund the delivery of an additional 1,316 new subacute places, including palliative care places, by 2013-14." From that general statement it is very difficult to identify the funds specifically intended for palliative care.

(c) the efficient use of palliative, health and aged care resources;

...

(ii) the adequacy of workforce education and training arrangements;

Workforce - efficient use: If I could give this example of **in**efficiency. In recent years we had a highly regarded palliative care Doctor in the ACT who had been recruited from the USA. The relevant Royal College suddenly declared that his qualifications and experience were insufficient. He could not extend his working arrangements. I spoke with a senior member of the ACT Health Directorate about the matter who told me he could do nothing because the "societies were a law unto themselves". I helped to obtain media publicity for the situation and soon after the relevant qualification-approving body reversed its decision, however, in the meantime the palliative care specialist had signed a one-year contract with a US hospice service and returned to the USA. He has subsequently served that contract and has returned to the ACT and is once again working in his former position. What a waste of time and resources. This episode indicates an absence of understanding of the needs of the palliative care sector within the medical sector and the need to be more flexible.

(e) the composition of the palliative care workforce

My impression is that there is a significant component of historically-based delivery of palliative care services in Australia by religiously-oriented organisations. In the ACT Clare Holland House (the ACT Hospice) is run by the Little Company of Mary Health Care (LCMHC), which is owned by the Little Company of Mary (LCM), which is a Catholic religious Order. Funding is provided by the Territory Government. I believe that this management arrangement results in a clear understanding that the principles governing the work of employees at the Hospice will be guided by the values of LCMHC.

In recent times I have served as a volunteer carer peer support worker in the Mental Health Ward (2N) at Calvary Public Hospital and on numerous occasions consumers and their carers remark to me how they find the "atmosphere" different at the LCHMC-owned Calvary Hospital (i.e. better), compared with the public institutions. The input by members of religious orders to the conduct of the Hospital is now only superficial because of dwindling numbers but the influence of the founding principles and tradition is still strong and I believe this is connected to what is perceived as the different "atmosphere".

I believe this atmosphere also permeates the operations of the Hospice. While its workforce might include people of different Faiths and none they, and the people who enter the Hospice for their last days, are aware that the Hospice operates within the true principles of palliative care, particularly in regard to not hastening the death of anyone nor unnecessarily prolonging the life of someone whose life is drawing to a close. In fact, I understand that staff are required to agree to these principles as part of their employment conditions.

There is a certainty about how you will be treated at the Hospice (and I assume in similar institutions around Australia) that creates comfort for a majority of the community. I once spent a day as a former committee member of the ACT Palliative Care Society discussing a risk analysis program for volunteers and staff at the Hospice and it seemed to me that the greatest potential risk was posed not by someone who accidentally slipped on water left on the floor but by a staff member who might go outside of the principles of palliative care and deliberately and illegally hastened someone's death. That action would immediately negate the accumulated high reputation in the community for the work of the Hospice.

I acknowledge that some people might have real or imagined difficulties with a palliative care facility operated under this set of values but in my experience there is often a degree of exaggeration and misrepresentation of the true situation. Some people talk about unwelcome and intrusive religious "iconography" at the Hospice but if you visit it all you will notice as something different are photographs of an elderly woman, the Venerable Mary Potter, who founded the LCM and who died 99 years ago next month. The photos are not threatening at all. There is a Chapel or a "quiet place" but it is non-denominational. Ministers of all religious are freely allowed access and encouraged to attend to the spiritual needs of patients.

I have experienced a less open and friendly approach when on a tour of a Government hospice in an (unnamed) Asian country which has delicate inter-racial, cultural, religious, and ethnic challenges. In an endeavour to convey an impression of strict secularism the Government had decreed that no Ministers for any religious faith should be based at the hospice and therefore have easy access to patients and so the onus had been placed on the patient to request that a Minister for their Faith be summoned and permitted access.

The attitude by that particular government ignores the evidence of the heightened relevance of spiritual and existential concerns at the end of life. 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 Versus 65% physicians) and to pray (85% patients Versus 55% physicians). Interestingly, coming to peace with God and pain control were nearly identical in importance for patients and bereaved family members.

However, the Hospice I am familiar with is welcoming of people of all Faiths, viewpoints and none. Indeed, I served for 10 years as a volunteer guide at Old Parliament House and for many years a fellow guide on my shift was the local secretary of a pro-euthanasia group and we would have interesting discussions in between conducting tours for the visitors. I was not particularly surprised to find that when she was dying she or her relatives chose for her to be looked after at the Hospice because I am sure they were aware of the impeccable medical treatment she would receive.

(g) advance care planning, including:

(i) avenues for individuals and carers to communicate with health care professionals about end-of-life care,
(ii) national consistency in law and policy supporting advance care plans, and
(iii) scope for including advance care plans in personal electronic health records; and

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Advance care planning: Advance care planning has its relevance but if it is confined to written documents then it will suffer from not being informed by the context and recent discussions between the person and their loved ones. A person might stipulate in a written document that they do not wish to receive any "heroic" medical assistance and they want to "let nature take its course" but in some cases they might also have recently told their family that they wish to continue with a therapy (e.g. a chemotherapy) that gives them hope, even though they are officially categorised as a palliative care patient. This should be permitted but is often frowned on.

Similarly, a person might have a terminal illness and know that they will die soon but may wish to try and remain alive until an important family member arrives from overseas, or until a student grandson graduates. I am not saying that the medical staff should be permitted to manipulate a person's time of death but I believe that a degree of flexibility should be adopted and attempts made to consult the family or loved ones about what the person may really desire in the current situation.

If I could use an analogy - you as Senators will be aware of the concept of "extrinsic aids to interpretation" i.e. documents and speeches (Second Reading speeches on a Bill) that can be used to flesh out the intention of a written law. In a similar way, the recalled previous discussions of family with a dying person, about that person's wishes, can help to provide a context and interpretation for the written text of an advance care document.

On the other hand, I acknowledge that a written document might help to guard against occasions of abuse of a person's rights. In Canada, for example, there have been a number of recent examples of "elder abuse" where greedy potential beneficiaries have exerted undue pressure on elderly and ill relatives. There has also been a case involving a $15m estate in Queensland where they have the "Elder Abuse Prevention Unit" whose spokesperson said they have had cases involving $3m reported just through their helpline. While concentrated on the question of access to a person's assets, such developments could flow into the area of patient care.

But my general impression is that in the headlong rush to promote written advance care directives the relevance of conversations about the dying person's wishes are under-emphasised and I have been present at forums where palliative care nurses themselves have asked for a wider framework, embracing both conversations and documents, to be adopted.

(h) the availability and funding of research, information and data about palliative care needs in Australia.

Research (1): In 2007 I was appointed as a consumer member of the Palliative Care Research Working Committee of the National Health and Medical Research Council (NHMRC) Palliative Care Research Program, Round 3, to evaluate applications for grants under the Program.

I understand that the program existed for five years from 2006-2010 (See: http://www.nhmrc.gov.au/grants/types-funding/-z-list-funding-types/program-grants/palliative-care-research-program) and $4.205 m was allocated. It might be useful for the Committee to ask if the program was evaluated and if its objectives have been subsumed in some other program.

Although I signed a confidentiality agreement about the information made available to us as members of the Committee I believe I can refer to an interesting aspect of the Committee's proceedings without breaching that agreement, namely the creative ways in which applicants sought to align their applications with a requirement for consumer consultation in preparing their submissions.

Consultation with consumers is an established requirement in many cancer and other health programs involving Government funding (see for example the schemes administered by Cancer Australia) but it obviously proved challenging to some of the applicants under this scheme.

As a Committee we were required to rate the applications according to their adherence to the required criteria. Some applications scored well in meeting other criteria but rated poorly in the area of consultation with consumers. Some believed that simply referring their project for consideration by fellow staff (as proxy consumers) satisfied this criteria but it does not. This experience revealed to me examples of ignorance and disinterest in true consumer consultation on the part of some palliative care staff seeking funds for research projects.

Concept of consumer in palliative care

It is true that the concept of a "consumer" in palliative care is not well developed. The most obvious "consumer" is the patient but, unlike say, cancer patients who go into remission, palliative care patients do not generally go into remission and therefore they are not available to act as advocates after their experience of palliative care. However, the concept of a "cancer consumer" also includes someone who has had contact with the cancer experience through a family member or loved one and that is how it should be applied in the palliative care area.

This definition differentiates between people who might have a connection with cancer by virtue of their career (e.g. research scientists or hospital staff), as opposed to those who have been involved by family links or friendship. In the palliative care area the definition would (and does) apply to people such as myself who are widows or widowers, or bereaved parents or siblings, or former carers for someone who experienced palliative care.

After their experience of the nature and delivery of palliative care services some of these people become involved in the palliative care voluntary sector as companions to the dying, working in hospices or palliative care wards as volunteers, or in bereavement or grief organisations. I believe there needs to be an active identification of people from the palliative care consumer ranks who can go one step further and become consumer representatives and advocates.

In the 2007 instance mentioned above I believe I was selected as a consumer representative via the Consumer Health Forum selection process but there have been very few recent opportunities of a similar nature and I believe that may reflect a disinclination by official bodies to seek out a non-health worker or non-researcher input to the development of programs and the selection of grant recipients in palliative care.

Some institutions will no doubt say that input by the community sector is adequately accommodated by the requirement for evaluation of research projects by institutional health research ethics committees which include community representation but usually that representative has had no direct connection or experience with palliative care.

A true palliative care consumer representative may have a significantly different approach to a project or the administration of a hospice or palliative care service and, as advocates for the patient, they might very well identify features that are not readily apparent to staff or government officials.

NHMRC document and ethics

To illustrate the likely differences in approach and perspective from where health officials are coming, could I draw the Committee's attention to a publication issued in September 2011 by the National Health and Medical Research Council, entitled "Living well with an advanced chronic or terminal condition: How ethics helps".

The introduction states: "This guide explains the key ethical principles relevant to palliative care and identifies some questions to be explored by those involved (whether patients, their own doctors or nurses or a specialist service) and at any stage in the management of the condition (and particularly towards the end of life)."

The document contains a series of questions for people (patients) to ask themselves and questions for family and carers. Under the section on Justice there is a question framed in a most uncaring, insensitive, and inappropriate way. It is the first question under the heading "Some key questions for people to ask themselves to ensure justice in health care" (page 4) and is: **"1. Do I think that the demands of my care are becoming a burden to others and how do I feel about that?"**

Presumably this is a document to be widely distributed to medical staff for their on-forwarding to palliative care patients and their loved ones, perhaps as part of a helpful kit when they first enter palliative care.

I believe it is a thoroughly inappropriate question to direct to a person who has entered the end of life stage and it displays an insensitivity and uncaring attitude on the part of those responsible for its drafting and approval. I have been told that there was a thorough consultation process associated with its drafting. All I can say is that those responsible for its approval were "asleep at the wheel".

The episode illustrates the need for committed palliative care advocates to be involved more directly in these processes so that they can bring to bear a perspective that is more firmly grounded in the caring and supportive nature of palliative care and not tainted by the nihilistic thoughts of some economic rationalists and health bureaucrats who have lost contact with the real scenario in the palliative care ward, hospice, aged care home, or hospital.

Affordable cancer care

Another example which illustrates the careless approach of some commentators and a pre-disposition to not consider the effect on people currently receiving cancer care or palliative care, concerns the September 2011 report of the (UK) **Lancet Oncology Commission on delivering affordable cancer care in high-income countries** (See: http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045%2811%2970141-3/abstract)

This report generated more than 4,000 on-line media reports (see: http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045%2811%2970380-1/fulltext), many of which were sensationalist, such as the UK Daily Mail's headline "Don't give out cancer drugs if it's just to extend life: Treatment costs can't be justified, say experts". Some of these interpretations filtered into the Australian media.

When I read such media reports I went back to the original document to identify what exactly had been said and I could find no precise statement supporting such a claim but I did find sufficient loose and ambiguous wording by the Report's authors to understand why the media might have drafted such headings. I assumed that the authors would have gone straight to the media with a major statement correcting these cases of misinterpretation but as far as I am aware, they did not. Instead, four months later - after the damage had been done - the principal author wrote a learned article analysing media reporting of the Commission's Report (see above URL) and bemoaning how they had been misquoted.

My point is that had the authors been alert to the situation of people who were desperate to cling to life and who might have been benefiting from an extension of their life, they would have been more careful with their language and would have immediately issued a correction. Perhaps they were not unhappy that this misinterpretation had been allowed to run uncorrected?

Again, it is a case of relying predominantly on an economist's or an accountant's approach and overlooking the viewpoint of the palliative care patient and their carer. There is a place for a debate about the costs of cancer care and new treatments but not to the point where it makes patients and their families feel guilty and a "burden" to society.

Research (2): During 2006-2010 I served as a consumer representative on the Federal Government's **Palliative Care Medications Working Group**. The role of the Committee was to promote the collection of evidence of efficacy and relevance for palliative care use, for drugs that had been developed for other non-palliative care indications. Ultimately, these drugs would then attract subsidisation under the Pharmaceutical Benefits Scheme (PBS).

I believe the Committee was undertaking a useful purpose and was one of the few opportunities where representatives from a wide variety of components of the palliative care sector could come together. In late 2010 I received a letter from the Department of Health and Ageing saying that the Committee had been disbanded. I realise that there had been occasional discussions about whether the committee should continue to exist but I had understood the consensus was that it should continue. I remain puzzled as to why it was disbanded and whether or not the perceived need for which it was established is being adequately looked after today.

Data: I believe there is room to extend the gathering of data from those who have had a recent involvement with palliative care as carers, with a view to embarking on a process of continuous improvement. I understand that most palliative care providers do undertake satisfaction surveys, particularly if they are part of a major health institution and seek to have this evidence available for health facility accreditation purposes.

I have occasionally heard indirect references to these surveys but have never been asked for my view on the questions that are being asked, or to comment on the results. In a recent community consultation in the ACT as part of the development of our future palliative care plan in the Territory I mentioned the potential usefulness of examining the frequent favourable references in funeral notices to the care provide by our local Hospice, the palliative care service, or particular Doctors but a member of the audience pointed out that this type of information was unreliable because of the emotional situation of the person who had been recently bereaved.

I acknowledge the partial relevance of this point but repeated (not once-off) in-depth interviews should be introduced at a later time in a period of emotional stability so as to gather any relevant feedback. Consumers should be welcomed onto the committees evaluating this information and be invited to monitor the implementation of any remedial actions arising from particular experiences.

Information

Generally I believe there is widespread misunderstanding in the community of the availability and true nature and practices of palliative care. There is still much work to be done in achieving Goal 2 of the National Palliative Care Strategy 2010 viz "To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to, palliative care services".

In a pamphlet produced by the National Breast and Ovarian Cancer Centre for people whose cancer has progressed the authors write: "Some women say they had no idea what palliative care could offer until they experienced it, and then wished they had asked for help earlier". One comes across this statement time and time again, not just from people with breast cancer but from those suffering from different cancers. Indeed, there is a recent study showing that the early introduction of lung cancer patients to palliative care actually led to an extension of life and a better quality of life on the part of these patients.

There is also a degree of "opioid myopia" in the community in which some people have a fearful attitude towards the use of morphine in the terminal stage. It might be useful to institute some observations, and then measurements, of the use of strong opioid analgesics in end of life care in Australia, to identify if this is a problem.

There is also an element of fear about pain at the end of life which, in my view, is misused by some people to support the introduction of euthanasia and physician-assisted suicide, both of which are inimical to the true principles of palliative care, which are based on a desire not to hasten a person's death nor to unnecessarily prolong a person's life when they are in the end of life stage (see World Health Organisation definition).

There is continuing work being undertaken internationally on better pain control, e.g. researchers at the University of Michigan have engineered a herpes virus to deliver the gene that encodes for a natural pain killer. This virus migrates to the nerves and makes the nerve cells produce the pain killer for a month to six weeks. (See: http://www.guardian.co.uk/world/2011/nov/13/drugs-therapy-cancer-painkillers?newsfeed+true). Are Australian researchers involved in research for better pain control in the end of life stage? Are they being supported by the Australian Government? What support is given to the cross-fertilization of ideas between pain management experts in the different areas of medicine?

Dying at home

Unlike former times when a dying person was nursed at home and members of the wider family had a close experience of the dying process, this does not often happen today. Even though surveys might repeatedly show that most people prefer to die at home, the reality of the patient's care needs often require transfer of the dying person to hospice, hospital, or a palliative care facility. In the brain tumour journey, which I have personally experienced with my late wife, some patients have occasional seizures and might collapse to the floor. It can then become very difficult to physically cope with the required mechanics of looking after the person at home. Hoists and bed poles can be of great help but it can be a challenge if there is only one carer and the patient's capacity to engage in self-care is diminishing.

Misunderstandings

I find that misunderstanding of the true nature of palliative care often manifests itself in an attitude of "wink-wink, nudge-nudge, you might say that the Doctors don't overdose but we know what really goes on".

The principle of "double effect", which is practised in palliative care, is not well understood in the general community. The principle usually involves the administration of a therapy or drug for palliative care purposes, including pain control, where an incidental and unintended effect might be the hastening of the person's death. In the brain tumour journey this principle is relevant to the withdrawal of dexamethasone when it is no longer performing a useful purpose in reducing brain swelling. The drug is withdrawn because it is no longer useful but it may generate a "rebound effect" which incidentally hastens the patient's death.

There is also misunderstanding in the community about the non-application of curative or extraordinary medical procedures, such as CPR, when a person is in the end stages. (Although see my comment earlier that so-called curative therapies should be continued during palliative care if the person retains a hope that they might be successful).

I believe that much pain or distress that one might experience at the end stages can be relieved or ameliorated by experienced palliative care specialists. In the brain tumour end of life experience many patients have a very peaceful death, except perhaps if their tumour has metastasised to the spine and they might require palliative radiation therapy. I acknowledge that this is not always the case with people dying from other causes but the pain control knowledge of most palliative care specialists is not often understood or recognised.

If I could give this example of a friend who had oesophageal cancer. He was being treated by an oncologist and a GP but they could not control the pain he was experiencing. Even though he was not technically a palliative care patient I managed to convince a palliative care specialist to see him and he was able to quickly introduce medications that controlled his pain.

It might be useful for the Committee to explore the understanding and continuous education of non-palliative care Doctors about the latest developments of pain control. The images in Letters to the Editor of people dying in situations of unbearable and unrelieved pain are often found, on further examination, to date back many years, or to be the result of incompetence or poor pain control knowledge by the treating staff in the relevant situation. Stories of this nature are often produced as evidence of a so-called "need" for access to physician-assisted suicide.

Another poorly understood area is the frequency of depression and anxiety disorders among those who have been diagnosed with a terminal condition. Brain tumours are the only cancer to directly affect both the mind and physical situation of the patient and the patients we support and advocate for are particularly susceptible to developing these conditions. Through my contact with Dr Ally Rooney, an oncologist at Edinburgh, and by learning of his research in this area, our brain tumour group was able to partner with the anti-depression group Beyond Blue and produce a Fact Sheet alerting patients and their families to this susceptibility. Our material has subsequently been reproduced by a UK brain tumour patient group.

But depression, anxiety and ideation about suicide, can also affect all patients who are in a terminal stage and I often wonder if some medical staff are sufficiently knowledgeable and alert about this possibility so as to introduce appropriate therapies at the relevant time.