Submission:

Senate Community Affairs References Committee
Inquiry Into Aged Care
Terms Of Reference

On 23 June 2004 the Senate referred the following matters to the Senate Community Affairs References Committee for inquiry and report by 30 September 2004:

(a) the adequacy of current proposals, including those in the 2004 Budget, in overcoming aged care workforce shortages and training;

(b) the performance and effectiveness of the Aged Care Standards and Accreditation Agency in:

- (i) assessing and monitoring care, health and safety,
- (ii) identifying best practice and providing information, education and training to aged care facilities, and
- (iii) implementing and monitoring accreditation in a manner which reduces the administrative and paperwork demands on staff;

(c) the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements;

(d) the adequacy of Home and Community Care programs in meeting the current and projected needs of the elderly; and

(e) the effectiveness of current arrangements for the transition of the elderly from acute hospital settings to aged care settings or back to the community.

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1 INTRODUCTION

The following submission is based on my personal experiences and observation of the health care system in Victoria, with particular emphasis on the treatment of elderly patients within the system.

The areas I wish to comment on are specifically:

(e) **the effectiveness of current arrangements for the transition of the elderly from acute hospital settings to aged care settings or back to the community.**

2 SUMMARY

The main purpose of this submission, is to illustrate that the public health system is failing the needs of the elderly and frail, particularly in an acute setting.

My father suffered a stroke and was admitted to a major Melbourne based public hospital, (in 2003). Whilst in their care, he developed septicaemia.

Whilst in hospital for 3.5 months, my father survived his stroke (with severe right side paralysis), pneumonia, bronchitis; stomach peg feed operation (due to loss of ability to swallow; and also suffered loss of speech), yet his steep decline in health was not attributable to any of these medical conditions. It was due to an ulcerated bedsore[1] that went through to his bones, and infected his blood supply (septicemia) which unfortunately, resulted in his death.

Due to his condition, my father was categorised as requiring high level nursing home care. My family was then placed under considerable pressure by the Hospital Social Worker to locate a suitable nursing home placement (ie, 'high-level' care).

As a result of these experiences, I observed many weaknesses in the public health system, as well as experiencing the difficulty of locating suitable nursing home placement.

Fourteen weeks after entering hospital with a stroke, my father died of sepsis.

There was not one, isolated incident which we felt was at fault, it was a number of factors.

It appears that when people become elderly and frail, they become an inconvenience to the public health system and society. This submission includes a series of events that we felt impacted on the level of care to our father that contributed to his decline in health, as well as the impact of some staff attitudes towards elderly and frail in the hospital setting. There was enormous pressure from the hospital to move my father to a nursing home, thus freeing up a hospital bed.

I could not believe that any hospital would think that this level of care is acceptable.

For these reasons, I make the following submission.

Death is never easy, especially that our family is very close. However, our grief is exacerbated by the treatment of our father and family whilst in the hospital setting.

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[1] **Alternative Names: Decubitus Ulcers, Pressure Ulcers, Pressure Sores, Bed Sores, Dermal Ulcers, Pressure Wounds**

A bedsore is an area of skin and tissue that becomes injured or broken down. Generally, bedsores occur when a person is in a sitting or lying position for too long without shifting his or her weight. The constant pressure against the skin causes a decreased blood supply to that area. Without a blood supply, the area cannot survive and the affected tissue dies. Pressure ulcers are extremely difficult to heal. The resulting wound can be painful, destroy tissue, fat, muscle and can lead to death.

3 TRANSITION FROM HOSPITAL TO NURSING HOME

After the hospital had declared that our father was not a candidate for rehabilitation (no longer classified as requiring acute care), we were told he should move to a nursing home.

The social worker assigned to us provided us with a list of nursing homes around Melbourne (including in the proximity of our local area).

We were asked to choose six from this list, and, if in a fortnight no beds became available, then we would have to select more nursing homes, repeating this selection process until a bed became available. **Anywhere.**

We visited and contacted many of the nursing home facilities, only to find:

a) they were not accepting any new residents (some facilities had lists that were closed for **two years**)

b) few beds were available for men – the beds were "allocated" to either male or female, and there simply were not enough "allocations" for men.

c) other facilities we asked were told that the waiting lists were "indeterminate" (unable to give us a timeframe – basically it is dependent upon death on a current resident, and there were many other on these waiting lists ahead of us). *We realise that it would be difficult to 'calculate' when a bed became available, but we would have reasonably expected that a facility could provide an idea, or approximate any indication at all, on how many were on their waiting lists.*

d) The waiting lists, (we were told were "long") – but we were shocked to realise just how bad it was. After our father died, I rang the facilities we had applications with, to inform them that we no longer required a bed. Despite this - we received a phone call **seven months after** our father died, to inform us that a bed had become available for dad at one facility. *We are coping the best we can without dad, and it is moments like this, which bring back the painful memories, prolonging our grief.*

e) We queried why the lists supplied by the hospital to us included details of nursing homes which had closed lists – (some up to **2 years**). We were informed that it was "**not hospital policy**" to advise families that lists were closed.

f) we were not confident that they could provide the level of care my father was assessed as requiring (high-level care)

g) the environment in some nursing homes was so depressing that we could not consider placing our father in the facility. We observed the resident's program of activities and noted that the number of staff that were 'on duty' at the facility at the times of visiting. There were simply not enough staff and resources to sustain my father's medical requirements.

h) some facilities were geographically located at considerable distance from homes of the family members, particularly our mother, who herself is elderly and frail and would have found it impossible to visit her husband on a regular basis by herself (they had never been separated in their 55 years of marriage)

i) additionally, our father's long-term physician would have been unable to treat him if he was located outside his "jurisdiction". (by the same token, the nursing home might also require that the physician is close to their facility for emergency treatment).

j) despite the **two week** time frame (hospital policy imposed) to locate the "list" of nursing homes, several of those contacted, were unable to provide me with an inspection appointment for up to ***three weeks***.

3.1 REVIEW IN SUMMARY

Due to the lack of success to locate a suitable facility, we referred our (limited) choices back to the hospital social worker, who by this time was exerting relentless pressure upon myself and family, to locate a nursing home.

Instead of supporting and counselling our family, with what was a very difficult and traumatic time, the hospital social worker's relentless dedication in adhering to hospital policies was a priority.

> We felt vulnerable and helpless. Our interpretation of the social worker's attitude was that "your dad is in the way – get him out of the way".

We were told bluntly that we should consider accepting "the first available bed", and that we could move dad again, even if we did not think the first choice was suitable. The message was very loud, persistent and clear – locate a nursing home – any nursing home.

We explored the idea of the 'hospital in the nursing home' programme, but this was we felt too difficult at this point. *Based on information provided by local council, we could expect around 4 hours 'help' per week – that would not even be enough time to attend to basic hygiene needs as a minimum.*

3.2 PUBLICATIONS AND INFORMATION

The theory and stated intentions of aged care publications (particularly with government related publications) could not have been more contradictory. Despite the best intentions, that are well documented in aged care publications, when it comes to practice, lip service is paid to the practice side.

For example:

a) Government publications available on the Australian Government Department of Health and Ageing web site, list "additional services" for high level residents - which **should** be supplied by nursing homes – for example water and air mattresses, and wheelchairs.

   This information we found was incorrect. Most facilities when visited, responded that the patient's relatives paid for the hire/supply of these items. (equipment was acquired by the facility after relatives residents had died, they donated the equipment they purchased back to the facility).

b) We were told by the hospital that there was a "standard application form" that we could fill in once, and when applying to the facilities, to simply photocopy, sign and send to each aged care home we had applied to – **despite being told this was the case, most of the facilities insisted on additionally filling out their own application forms.**

3.3 QUALITY CARE OF ELDERLY AND FRAIL IN THE HOSPITAL SETTING

The purpose of outlining the problems we experienced in this section, is to highlight the pressures, problems, and quality care for frail and elderly patients in an acute hospital setting.

Sadly, we found that we were not alone. Talking to other people who were in a similar situation, confirmed to us the pressures and problems in the hospital system for patients awaiting nursing home placement or similar, and were not receiving the level of care they should have received.

After initial treatment of stroke, my father was placed in a general ward (several wards and then transferred to and fro for the duration of 3.5 months). The family was informed that he was not a candidate for rehabilitation, and there was little they could do. Their assessment was that he required high-level nursing home care.

Our observations with the level of care whilst in hospital included:

Staffing, Resources and Equipment:

- Staff resources were stretched to the limit, and we noticed a heavy reliance on agency nurses. Having nurses unfamiliar with the basic work routines of the ward and the general layout of the hospital proved problematic. Agency staff often had to constantly seek assistance from the permanent nurses thus adding to the intensification of the latter's workload.
    - If staff had time - dad would be ‘lifted’ out of bed and placed in an unsuitable vinyl chair (no proper side supports, older patients would often “slip” or find it near impossible to be comfortable) sitting for a large length of time (anything up to approx. 4-6 hours at a time – again, dependent upon staff and lifting machine availability).
    - There were blocks of days which we felt dad should have been moved (out of bed), but wasn’t, due to lack of resources and equipment – we offered to help, but, for the hospital’s policies, we were unable to. He spent days on end in bed, which resulted in bed sores. Some days dad was still laying in his own waste in bed near mid-day – there was simply not enough staff to cope with a geriatric ward full of elderly and frail patients.
    - Rotating staff were unaware of the importance that the (third) orthotic device be fitted at all times on dad’s foot (neither were we at this stage), and as a result, our father suffered ongoing pain due to friction whilst bed bound. An A4 sign was belatedly placed sticky-taped above his bed on the wall for rotating staff to note.
    - (the same bed mechanism had spasmodic ‘maintenance’ problems).
    - Occupational therapy, speech pathology, or any services which might assist in some small way for high-level care patients (elderly) were very limited. We made our own arrangements with external providers to visit dad and provide gentle physio therapy to combat the lengthy periods of bed-bound care, as well as to provide some post-stroke relief, also to help avoid spasticity[2].
    - (due to limited resources, patients not considered for rehabilitation were simply ‘overlooked’ for any type of stimulation or treatment.)
- Sub-standard equipment (for example, air bed) had spasmodic ‘maintenance’ problems.
- One of the wards dad was moved to was a transitional ward where elderly and frail are looked after prior to entering nursing home transferral. This was probably one of the most under-resourced, and depressing wards I have visited.

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2 **Spasticity** is a condition in which certain muscles are continuously contracted. This contraction causes stiffness or tightness of the muscles and may interfere with movement, speech, and manner of walking. Spasticity is usually caused by damage to the portion of the brain or spinal cord that controls voluntary movement.

- The daily routine would be to get each resident up in the morning (limited staff and resources meant that sometimes it was close to lunch time before dad was even changed in the mornings) – the staff would take turns in who they would get up first, especially on weekends as the ward would have many high level patients, depending upon the mix, they were also required to use a lifter and two staff to get each patient out of bed. It was not an easy or quick job for them.
  - Each patient was then wheeled into a common area (if there were enough wheel chairs), where they would stay for most of the day. Most of these (older and frail) patients had both eye and ear deficiencies, could not see or hear the television (which was turned down so as not to disturb the nurses station nearby), and the food trays were usually given to the patients (not enough staff to feed the patients), which, some of them would have difficulties feeding themselves – end up with more food on their clothes/bib/wheelchair, than in their mouths. Some were simply wandering around scared, or delirious. Some were sitting in the common area going to the toilet (sitting on a chair at the table).

General Observations:

- Until the family complained, dad was not referred to the "wound specialist" for treatment of his bed sore. Staff on the ward referred me between different staff – with one doctor commenting "it's not my job – speak to the nurse" – which I already had done.
- Lack of communication with the family – difficulty locating doctors to talk to us, even leaving messages to phone us for up to five days with no response (visiting every day).
  - A meeting was organised after complaining to hospital administration. Five days later, the meeting was conducted only after dad was moved to a new ward and building, with new staff, who admitted to not understanding why they were asked to attend the meeting. *In fact one of the medical staff was particularly hostile that the meeting was even initiated.*
- We were not informed of when the Aged Care Assessment Team (ACAT) were to assess dad – we were only told *after* it had occurred. As dad had lost the ability to speak, we know that he had a right to have his family attend – and would have wanted his family present for the ACAT assessment.
- Staff confusion over dad's impending transfer to a nursing home – we were told by one doctor that dad's condition had worsened, and that he needed to stay in hospital for at least another 10 days. Upon visiting the next morning, all of dad's belongings were stacked in big brown paper bags next to his bed, with some staff telling us that dad was going to be transferred to a nursing home that day.
- Insensitivity by some staff discussing the transferral of dad to a nursing home, when we explicitly requested (repeatedly) staff not to do this, as well as discussing his prognosis in front of him. *As a close knit family, we wanted dad to hear the news from us and not hospital staff. Although he had lost the ability to speak, he understood us and responded well to our visits.*
- Until our physician was involved with assisting to advocate for dad, we felt that too little, too late was achieved – particularly with palliative care. Dad was still in a normal hospital ward the same week that he died (restrained as well). In the end, we insisted (with the help of our physician) on bringing our dad home for the remaining 2 days of his life.
- After we got dad home, we checked dad's bed-sore, and were shocked to see that he had several – we had only been told that he had one bed sore. (the area was covered and bandaged the entire time so that we never saw the damage that was done until we brought him home. *Every time the dressings were being 'changed', we were asked to leave.*
- Agency staff who had worked at various hospitals in the Melbourne central area, had commented to us that treatment of bed sores was questionable at this particular hospital

Pain Management:

- Non-existent. Especially on weekends when there was limited access to a doctor, and we had to beg the nurse (I have never felt so humiliated when, on several occasions, had to beg staff "please could someone come and see my father"), for a doctor to come and check on dad's condition. This felt very wrong.
  - Little, or inconsistent pain control meant that when dad was in pain, he would be restless, his breathing was laboured, and we found him restrained, thrashing around and moaning and groaning in pain (he had lost the ability to speak, and was paralysed on his right side of the body). This was very upsetting for us – we would often not let mum visit dad at these times as it would have caused her great distress (as it did us) to see him in this state. It was not uncommon under these circumstances to restrain dad's remaining unparalysed side of the body. *We thought that if adequate pain control was administered, this might have reduced the need for restraints.*

4 GOOD, BETTER, BEST PRACTICE

- A central database/registry that contains a list on vacancies/beds available at nursing home/hostel facilities
- Hospitals not to apply unrealistic and inappropriate timeframes given to relatives – or forcing patient's relatives to make inappropriate decisions.
- Improve staffing and resources in acute/hospital settings be reviewed to enable proper and quality care for elderly and frail patients.
- Improve staffing resources within residential aged care settings – these facilities were also stretched – some places we had to wait for up to **3 weeks** for a viewing appointment only. [consider that the time allowed was 2 weeks to locate a facility]
- Improve the level of training in geriatric care for medical staff.
- Practice what is preached – ie, what is published, should at least be adhered to in reality. It appears that what is written in publications, is not adhered to in the "real world".
- Any patient (especially elderly and frail) who presented with similar medical conditions to dad, should have undergone a risk assessment earlier – also, skin care and pressure relieving interventions and devices could have been implemented much earlier.

5 REFERENCES: PUBLICATIONS

This section highlights articles and their related links, with regards to topics outlined in this submission.

Title:	**A family's perception of a public hospital**
Source:	Contemporary Nurse - Vol 11, no. 2/3, Dec 2001 http://www.contemporarynurse.com/11-2p243.htm
Author:	Dianne Cullen, Lecturer in Education, Australian Catholic University, Melbourne
Brief:	"…this article tells of one family's recent perceptions of a major public hospital. Their story is a personal one that revolves around the illness of a family member. Visiting their loved one every day meant they gained a heightened awareness of the day-to-day running of the hospital. As the patient had to stay in hospital longer than originally anticipated the family members begin to observe details of contemporary hospital life not noticed on occasional visits. What they perceive leads them to question those often heard, and taken-for-granted, values of efficiency, accountability and competitiveness…."
Title:	**Beneath the bottom line**
Source:	http://www.users.bigpond.com/smartboard/decline/jobs/bttmline.htm
Author:	Deborah Hope [Senior Writer -The Australian Magazine, 6-7th May, 2000]
Brief:	…the hospital setting provided a veneer of hope, but this vanished when the hospital's specialist in the field declared Dad was not a candidate for rehabilitation. No longer classified as needing acute care, we were told he should move to a nursing home. Impatient now to be rid of him, the hospital began to pressure my emotionally and physically exhausted mother to find him a bed elsewhere. ....
Title:	**Analysis of complaints lodged by patients attending Victorian hospitals, 1997-2001**
Source:	http://www.mja.com.au/public/issues/181_01_050704/tay10038_fm.html Medical Journal of Australia
Author:	David McD Taylor, Rory S Wolfe and Peter A Cameron
Brief:	"description of complaints made by patients attending 67 hospitals (meto and rural) in Victoria, and lodged with the Victorian Health Complaint Information Program (Jan 1997 – Dec 2001)……… aged-care departments had a significantly higher rate of complaints…."
Title:	**Attitudes to the elderly**
Source:	http://www.clininfo.health.nsw.gov.au/hospolic/stvincents/1993/a06.html
Author:	Alison Parsons [Alison Parsons is the Nursing Unit Manager on St. Clare's Ward (Geriatric Assessment Unit), St. Vincent's Hospital, Sydney]
Brief:	This paper highlights the perceptions and attitudes of health workers that may be detrimental to the care of elderly people. The literature suggests a widespread negative attitude to older people, based upon negative myths and stereotypes and perpetuated by the media's lack of understanding of anything of the ageing process or the potential of older people.
Title:	**Nursing homes: "The system let my father down," says daughter**
Source:	http://www.aboutseniors.com.au/Aged-Care-Housing-QA.html
Author:	Christine Innocenzi
Brief:	"…nearly 12 months after her father's death, Christine Innocenzi is still aggrieved at the fact that the family's search for a "good" nursing home did not pay off. Writes Christine: "My dad died in hospital last July, and he had been there since February. After tireless work in searching for a good nursing home he never made it into one! We obviously have a big problem (with the system)…"
Title:	**American Pain Foundation**
Source:	http://www.painfoundation.org/
Title:	**Preventing pressure ulcers**
Source:	http://www.mja.com.au/public/issues/180_07_050404/sta10029_fm.html Medical Journal of Australia
Author:	Michael C Stacey
Brief:	"…adequate staffing and devices to implement active strategies are the key. Pressure ulcers significantly reduce the quality of life of patients and increase the costs of patient care, as well as length of hospital stay. The most notable feature of pressure ulcers is that most are preventable..."

6 REFERENCES: ARTICLES

The following is not a comprehensive listing of media articles that have been published that relate to this submission, it is simply a very small "sampling" of recent events.

Title: Rehab strains in RHH strife [The Sunday Tasmanian]

Date: Sunday, 25 July 2004

Abstract: "PATIENTS at the Royal Hobart Hospital are missing out on vital rehabilitation because of a lack of staff and resources. And the head of the hospital's geriatric services, Dr Velandai Srikanth, fears the situation will get worse because of a lack of forward planning to cope with an increasing ageing population. "Our main concern is the significant lack of resources and staff to provide a good service for older people in the hospital," Dr Srikanth said. "

Title: State's terminally ill fiasco [by Margaretta Pos - The Mercury]

Date: Wednesday, 21 July 2004

Abstract: DESPITE an urgent need for palliative care services, palliative-care beds in the North-West are empty -- with patients sent to hospitals instead.

Title: overload stresses patients [The Mercury - Lovibond]

Date: Wednesday, 7 July 2004

Abstract: "The hospital still has 45 elderly patients awaiting nursing home placement despite some contract beds being secured at New Norfolk and St John's Park."

Title: Hope for more aged care places [ABC]

Date: Monday, 14 June 2004

Abstract: "A private aged care provider says dozens of beds in Bundaberg's hospitals are occupied by people waiting for a bed to become available in an aged care facility."

Title: Patients still waiting for policy that works [The Age]

Date: Thursday, 10 June 2004

Abstract: "When a third of emergency patients wait eight hours or more for a bed, excuses wear thin. One in three patients in Victorian hospital emergency departments waits more than eight hours for a bed. That statistic, derived from an unhappy one-day snapshot of Australian hospitals in which only NSW fared worse than Victoria, is no aberration."

Title: Elderly forced to wait as aged care crisis worsens [Sydney Morning Herald - Adele Horin]

Date: Tuesday, 1 June 2004

Abstract: …"More than 20,000 elderly people are on waiting lists for nursing homes and aged care hostels in NSW and the ACT, a survey shows. They are waiting longer for a vacancy than they did in 2001. The survey of 208 residential care services was conducted in December 2003 by the Aged and Community Services Association of NSW and ACT, the peak body for non-profit providers. It shows people wait on average 24 weeks for a vacancy in a nursing home and 36 weeks for a hostel, at least four weeks longer than they did when the last survey was carried out…"

Title: Coroner rings deadly alarm bell [The Advertiser - Craig Bildstien]

Date: Saturday, 1 May 2004

Abstract: "STATE Coroner Wayne Chivell is seeking wide-ranging powers to monitor the state's annual death toll, revealing 70 per cent of deaths are not scrutinised. Mr Chivell said just 3671 of the state's 12,161 deaths were reported to his office in the previous financial year. "Now that leaves 8490 cases where a doctor has concluded that he or she has sufficient evidence to write a death certificate," he said. "That certificate goes straight to the Registrar of Births, Deaths and Marriages and is not scrutinised by the Coroner, or anyone else. "The registry does not exercise any qualitative analysis of information it receives and does not do any research into the database."

Title: Aged care crisis requires national response [The Canberra Times [have your say] - Annette Matheson]

Date: Friday, 19 March 2004

Abstract: "IT IS WITH anger and heartache that I read a 78-year-old waits for someone to die to make room for her (Canberra Times, March 17 p3). The difficulty for people in finding respite care or a nursing home bed does not seem to be just an ACT problem. Rather, it's a nationwide epidemic, and represents a crisis in policy. **Five years ago** in Sydney I went through the same problem of trying to find an aged-care place for my father who suffered with dementia. **My father had spent many months being shunted through a hospital system that could not cater for his needs. My father died in hospital the same day a suitable bed became available."**

7 A POEM

This poem was found among the possessions of an elderly lady who died in the geriatric ward of a hospital. (*No information is available concerning her -- who she was or when she died.)*

What do you see, nurses, what do you see?

Are you thinking, when you look at me --

A crabby old woman, not very wise,
Uncertain of habit, with far-away eyes,
Who dribbles her food and makes no reply,
When you say in a loud voice -- "I do wish you'd try."

Who seems not to notice the things that you do,
And forever is losing a stocking or shoe,
Who unresisting or not, lets you do as you will,
With bathing and feeding, the long day to fill.

Is that what you're thinking, is that what you see?
Then open your eyes, nurse, you're looking at ME...

I'll tell you who I am, as I sit here so still;
As I rise at your bidding, as I eat at your will.

I'm a small child of ten with a father and mother,
Brothers and sisters, who love one another,
A young girl of sixteen with wings on her feet.
Dreaming that soon now a lover she'll meet;

A bride soon at twenty -- my heart gives a leap,
Remembering the vows that I promised to keep;
At twenty-five now I have young of my own,
Who need me to build a secure, happy home;

A woman of thirty, my young now grow fast,
Bound to each other with ties that should last;

At forty, my young sons have grown and are gone,
But my man's beside me to see I don't mourn;

At fifty once more babies play 'round my knee,
Again we know children, my loved one and me.

Dark days are upon me, my husband is dead,
I look at the future, I shudder with dread,
For my young are all rearing young of their own,
And I think of the years and the love that I've known;

I'm an old woman now and nature is cruel --
'Tis her jest to make old age look like a fool.

The body is crumbled, grace and vigor depart,
There is now a stone where once I had a heart,
But inside this old carcass a young girl still dwells,
And now and again my battered heart swells.

I remember the joys, I remember the pain,
And I'm loving and living life over again,
I think of the years, all too few -- gone too fast,
And accept the stark fact that nothing can last --

So I open your eyes, nurses, open and see,
Not a crabby old woman, look closer, nurses -- See ME!

End of document.■