

SUBMISSION TO THE HOUSE OF REPRESENTATIVES
COMMITTEE ON AGEING

A plea for recognition, respect and restitution of dignity for aged
Australians in residential care, particularly those with dementia.

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In the first week of May 2000, a distinguished Australian, A, was admitted to the Accident and Emergency Department of a major teaching hospital in Sydney. For some days he was close to death, treated with antibiotics for a major bowel infection from which he recovered. He was then taken to the hospital's geriatric ward where he stayed for another eight days, during which he was quite confused. Cognitive function tests and a brain scan showed frontal lobe deterioration. Dementia – but not Alzheimer's Disease – was diagnosed.

Ten days after admission to hospital he was moved to a nursing home in Surry Hills. He died there in December 2001, never returning home.

In the year before going to hospital, A had enjoyed a daily walk in a harbour-side park near his home. He had gone to films, concerts, art exhibitions and other social events, seeing the friends and colleagues from a lifetime of business, government and community service for which he had been awarded an Order of Australia. While he was at times confused, he was functioning as a community member.

A's involuntary move to the nursing home distressed him terribly. He was not consulted about it and believed he had been betrayed by people he trusted absolutely. He was bewildered to find himself, without warning, in a totally alien place, his previously comfortable home exchanged for a small spartan bedroom shared with a stranger who was a stroke victim.

The swiftness and finality of the move suggested a degree of unhealthy collusion between a Catholic hospital and a Catholic nursing home in emptying one and filling another bed.

For the next 19 months, by arrangement with his family, I visited A every day for several hours and the following comments are based on extensive notes I took about how he was treated and how others were treated.

I believe that Australia will, in time, come to the realisation that the incarceration of aged people in inadequately equipped and staffed nursing homes is a scandal similar to the current concern on the confinement of asylum seekers in detention centres.

A Room With No View

The room to which A was taken contained two beds separated by hospital curtains, two bedside cabinets and a built-in wardrobe, leaving barely room for one chair next to each bed. There was one window overlooking a light-well near the other resident's bed and two wall fans, one of which, near A's bed, did not function for 12 of the 19 months he was there. A's bed was situated next to their shared bathroom and opposite the men's lavatory across the corridor.

This cramped, ill-lit and poorly ventilated room enlivened only by his radio and family photos, apart from flowers and cards from friends, was A's home for the next 19 months. Initially shared with a gentleman who had suffered a massive stroke and could not communicate other than in moans, for the last 12 months of A's life his room-mate was a gently demented nonagenarian Christian Brother who prayed constantly and loudly for the forgiveness of his sins.

First, Do No Harm

A was so unhappy at his enforced incarceration that he made his feelings of abandonment and betrayal clear to staff, trying desperately to find his way out of this Special Unit for dementia sufferers which could be accessed only by using a press button security code.

His new treating doctor, recommended by the Home, had not previously met A who was sedated because of his distress. There was some discussion about whether he should have any visitors for a few days while he settled down, but this was vetoed.

Inadequate case notes from the teaching hospital provided information only on A's bowel condition and recently diagnosed dementia. The new doctor was not made aware of A's previous history of angina and a platelet disorder, nor of the fact that his GP had prescribed a popular anti-depressant, Prozac, which had disagreed with him in the last year.

A's new medication, Xyprexa, reduced him in stature and demeanour to a sad, drooling, hunched peasant figure barely able to walk, until my protests saw the Olanzapine reduced, but it was never properly monitored over the next 19 months.

It is perhaps worth noting that this drug, an anti-psychotic medication whose prescribing is supposed to adhere strictly to guidelines set out by the Pharmaceutical Benefits Scheme, is one of the main drugs reported as being responsible for a significant blow-out in the cost of the PBS for the last year. Its cavalier prescribing for the aged needs to be reined in, in the interests of patients, since it appears to be chosen as a drug of first choice for convenient behaviour modification of residents in aged care facilities.

A later example of drug intolerance saw A, in a matter of days, reduced to an almost catatonic state, quite unable to walk. It transpired that he had been placed on an anti Parkinson's drug, Congentin, presumably for a barely discernable hand tremor; this time the nurses and doctor actually noticed his condition and it was decided to take him off this drug, with dramatic improvements and restoration of the ability to walk.

These instances, for one person, highlight the need for careful clinical care, for an awareness of the interrelatedness of drugs prescribed for different conditions and the absolute need for all side effects to be documented and reported. Behaviour considered to be a natural consequence of the progression of dementia may rather be a natural consequence of taking particular drugs. Who is to decide what is a tolerable side effect? Who is to decide whether its impact is not devastating to the individual?

A recently announced move by the Therapeutic Goods Administration to enable doctors to report any side effects through voluntarily using a software package currently being prepared is a long overdue step in monitoring side effects of drugs used in treating dementia. Its use will be dependant upon nursing staff being educated observers capable of describing the more obvious side effects to doctors who in turn should pass them on to the TGA.

An allied concern is the potential for aged people to be unknowingly entered into clinical drug trials. A report in The Sydney Morning Herald on 16 July 2002 suggested that the medical profession felt that the elderly should have more opportunity to take part in clinical trials if they are capable of informed consent. It went on to say that consent could be given either at the time of the trial or in advance, when providing for a future when the person might have lost their mental faculties.

An Elder Law professor said: "People are able to say now that at the end of their lives extraordinary measures should not be taken to keep them alive. They should also be able to say that at the end of their lives, they are happy to be part of medical experiments".

This begs the question of how many are currently effectively taking part in non-formal drug trials, since new anti-psychotics and their side effects are still being worked through, patients having no say at all.

At a practical level, the daily dispensing of medication appeared, at this nursing home, to be the main reason for having Registered Nurses employed. But since so many were agency staff, unfamiliar with the residents, their dispensing of drugs was rarely accompanied by any registration of effects and tolerance because they didn't see residents from one day to the next, often not even once a week. The nightly drudge of dispensing, always with laxatives for most residents – presumed necessary because of poor nutrition and lack of exercise – spoiled the evening meal for many. Depending on the RN on duty, the drugs trolley might come round at 3.45 pm or 4.45 pm or 5.45 pm or later, regardless of whether medication was prescribed to be taken before, during or after meals. Since some residents might be given 9 or more pills the nightly effort to get them down was disruptive in the extreme.

Another disturbing aspect of clinical care was the treatment of wounds resulting from falls. cursory cleanings, poor bandaging and inadequate monitoring led to unnecessary infections and in the case of diabetes sufferers, of avoidable ulceration.

In A's case I observed a blood filled plastic patch on his elbow one evening in which blood was pooled like an egg. Hardly satisfactory for someone with a platelet/clotting disorder. The dressing had not been monitored all day since a morning fall. When reported, an appalled RN carefully sluiced, cleaned and rebound it, obviously unhappy at what had happened. Similarly, I saw ulcerated legs unattended, people in wheelchairs pushed through doors without opening them properly, clearly bruising them in the process, rough handling when transferring from chairs to toilet and chairs to bed, often seeing bruising around shoulders consistent with being shaken. But regular visitors and family felt constrained from complaining because they didn't want to be seen as trouble makers, so they did not contact the Commonwealth Aged Care Complaints Unit.

One caring RN, who has since left, confided that far too many people in the home were getting inadequate pain relief for cancer. Many were starving because there were not enough staff to assist them to eat, but ironically, they were still given laxatives.

My own monitoring of A's skin led to the first awareness by staff that he was developing a pressure area on an ankle and, later, that he had additional pressure areas which needed daily attention but whose effective treatment depended on which harried staff were on duty.

There was no discernible regular observation of temperature, pulse and respiration, the old nursing mainstays. Relatives of residents with respiratory problems were frequently reduced to frustration by the lack of attention paid to such problems and the inadequate administration of equipment designed to ease their distress.

A source of constant amazement was the fact that, while residents had been given flu vaccinations, no staff had been required to have them. As a consequence, staff absences from flu, flu-like illnesses and colds were frequent and more often than not they were sneezing and coughing over the frail aged in their care. When residents developed

coughs and colds, little was done to ease their discomfort. No efforts were made routinely to keep temperatures down, to provide any soothing medicaments for sore throats and to ease coughing, so reinfection of each other was common. A lack of fresh air and sunshine didn't help, and nor did the virtual absence of fresh fruit from their diets.

Recent studies of nursing home residents reveal the vast majority to be suffering from Vitamin D deficiency from lack of sunshine. A study by Professor Caryl Nowson of Deakin University reported in the Medical Journal of Australia on 5 August 2002 revealed that 76 percent of nursing home residents have a vitamin D deficiency.

I always had a supply of fresh, varied, seasonal fruit for A, which was shared by others, provided permission was given by staff, to their clear delight and appreciation.

Naming Rights

The State requires our names to be registered as soon as possible after birth. Most of us are used to determining what we will be called. We keep, modify, change by marriage or divorce or deed poll, our names throughout our lives. We are known as Mr or Mrs, Miss or Ms, sometimes Doctor. We are often proud of our family names, sometimes unhappy with our given names, amused or embarrassed by diminutives or nicknames, but we know who we are. Until entering a nursing home, that is.

In the case of this particular home, which had large numbers of aged religious, Sisters and Brothers were accorded the dignity of their professed names, but everyone else was presumed to be content to be addressed by his or her first given name. Individual status and sense of self was thereby reduced to that of a familiarly addressed child, with a few honourable exceptions.

Only when accreditation was imminent did residents' names appear on their bedroom doors, the first reminder many had of who they were or had been before they arrived. An excellent booklet, "In Their Shoes" prepared by Megan Stoyles and Patrick Flanagan for Aged and Community Services Australia addresses this vexed issue.

A Sense of Self

For a fastidious person, awareness of self is tied to what he or she sees in the mirror, in the first instance. If the person who stares back is unfamiliar, there can be a gradual loss of perceived identity, exacerbated by the company one keeps.

Too often residents in the Special Unit were victim to the daily corner cutting in essential grooming, as opposed to showering, which accompanies the problem of insufficient staff in any nursing home. Frequent shift changes and the use of casual agency staff meant that insufficient attention was paid to the way residents looked, day after day. Little or no notice was taken of whether residents were appropriately dressed for the climate and whether they were equipped with the spectacles, hearing aids or dentures that enabled them to see, hear or eat properly. No obvious notice was available for new staff to check on what individuals needed to get through their day.

Nearly every time I arrived for my daily afternoon visit to A, I would notice that another resident who depended on glasses was not wearing them despite being seated in front of the TV set. I would retrieve them from his bedside drawer, put them on him and be rewarded with a smile. Others might be without hearing aids or loud whistling would proclaim them to be wrongly adjusted. Sometimes residents lacked dentures which meant they had probably not eaten properly thus far that day, walking frames were abandoned all over the place, shoes and slippers were often ill fitting and the potential for falls easily fulfilled.

Frequently there were days when none of the men had been shaved or had their hair washed. To look into the mirror and see a stubbled face and to look around the dining table and see others the same is not only disorienting, it is a way of others saying that you don't matter any more.

In A's case, I preferred to shave him myself, with his electric razor, kept in his bedside drawer, because the alternative was genuinely hazardous to his health. Too often a cursory shave by staff using a disposable razor resulted in quite savage gashes. Apart from looking awful, an existing platelet disorder meant clotting took a long time and he

could bleed for quite a long time as a result. He always felt better after being shaved and certainly looked like the A he knew himself to be.

For others, the haphazard choice of clothing by staff in the morning meant that residents could too easily look like Orphan Annie all day and be treated accordingly. Too many clothes in hot weather and too few in cold was another problem, while failure to provide proper serviettes at meal times, meant that food found its way down too many fronts, the occasional use of cloth bibs doing little to alleviate this, an air of dishevelment resulting. When incontinence was a problem, residents might be left in soiled and wet clothing for quite a long time, to their own obvious discomfiture and to that of others around them. Inadequate supplies of incontinence pads due to administration cost cutting led to some staff hiding supplies to look after individuals in their care but when there were not enough to go round, residents suffered ongoing indignity and embarrassment because of this.

The Company of Strangers

While acknowledging that dementia is no respecter of persons, the total alienation experienced by A at the time of his admission to the home is understandable.

This gentle, courteous, distinguished Australian spent his last 19 months with a group of people properly honoured in their own right as good Australians, but quite unfamiliar to him and linked to each other only by dementia.

They included a great South Sydney supporter who had been a proud maker of Akubra hats; a furniture upholsterer; a triple certificated nurse who had worked with and terrified Fred Hollows the eye surgeon; another old nurse who had come from the country; a former fashion consultant and three Christian Brothers, one of whom prayed constantly for forgiveness, another repeating number sequences ceaselessly, all day, every day.

He had chaired companies with Australian and international connections and accepted key Federal and State appointments in the arts, education, science and communications. He was interested in policy and governance. He encouraged and mentored women and

young people. He set in train the first Australian guidelines for returning Aboriginal remains to their true custodians. He was well regarded by both sides of politics.

A had enjoyed classical music, films, the theatre and reading, especially history, his first love. He delighted in the outdoors, bushwalking in Sydney's National parks and harbour side gardens. He was endlessly curious. He cared about where Australia was going. In the Home, it was assumed that he would be content to sit in front of the TV all day, like everyone else.

A was visited in the nursing home by a former Prime Minister, anxious to pay his respects, by former and serving Commonwealth and State Ministers, by former Heads of Commonwealth Departments for the Arts, Heritage, Environment and Immigration and by people he had mentored in business, science and the arts. He was touched to receive a personal letter from a High Court Judge and others from journalists and writers he had known for a long time. He treasured regular cards he received from friends of the last twenty, more public, years of his life. He was always pleased to see visitors, but many older friends had been given to understand that there was no point in coming to see him because he would not recognise them and so they stayed away until it was time to attend his funeral. Similar misunderstanding affected others.

Because I was in the fortunate position of being unemployed and having no dependants, I could visit A every day and take him for the walk he treasured so much in his new inner suburban neighbourhood. He was able to enjoy the freedom of being outside, away from the cries and moans and endless TV, delighting in fresh air and sunshine, visiting local parks and cafes and restaurants for good food to supplement his institutional diet, as well as interacting with people in the real world who were endlessly kind to him. His fellow residents had little such relief and clearly envied the alacrity with which A headed for the door, leaving the others to vegetate in front of the television.

Activities

Integral to the preparation of any personal care plan, required for each resident in a nursing home, must surely be some understanding of who the person is, where he has

come from in his life journey, what his occupation might have been, what interests or hobbies he might have enjoyed, what he might still be capable of doing.

There are nursing homes incorporating dementia units which manage such things well, but no such understanding was apparent in the place where A found himself.

The one constant was the television set, turned on all day every day, usually to a commercial station, chairs arranged some distance away. Then a small fish tank was added to the room to the bemusement of most residents since the fish that did not die off were too small to see.

For the most part, special unit residents sat near the TV because there was nothing else to do. It was too much trouble for staff to take them down to the activity room to watch a movie on a large screen and no craft activities catered to them. A young man came once a week with a portable keyboard which he played valiantly but not well, the songs always from WWI to suit the eldest resident who was supremely uninterested in the event.

In A's case, it seemed to be appropriate to provide him with the familiar tools of his working life to help give some shape to his mornings, at least. Since he had been a businessman and chair of several companies and public institutions, used to regular meetings, with minutes, diaries and reports to read, I set him up with a leather portfolio, manila folders, notebooks, paper and pens. He also had his diary and letters and cards from friends of the last 20 years of public life, anxious to keep him feeling attached to the outside world. Every day he worked at his papers, continuing the routines of an ordered life, rarely losing or misplacing any papers, clinging to what he knew. He also looked at the Sydney Morning Herald for which his family provided a subscription and this also provided a diversion for other residents.

But for most of them there was no simple reminder of life before the Home, nothing to cater for their individual interests or talents, save the odd photo or photo album brought in by relatives, themselves uncertain and bewildered about what they could do to help. Little guidance or intervention was ever proffered by staff who seemed incapable of imagining what those lost lives might have been like.

The constantly distressing plea: "I want to go home! Take me home!" was always answered by: "But you are home. This is your home now." No matter how demented they were, residents know that this place was not their home, just somewhere to sleep and watch TV.

You Are What You Eat

Nutrition was a constant worry. Until I was informed by another resident's carer of the problem, I had not remained in attendance for the evening meal, having been told by staff it was better to go before it was served.

It was apparent to me, as it was to other people's relatives in the habit of remaining for this meal, that it was a time to be got through quickly rather than an occasion for enjoying a meal. While the midday meal was well prepared and appetising, the evening meal was often quite gruesome, being unattractive in presentation, inadequate in amount and always lacking in nutritional value. A series of photos of this meal, which I took for a week, serves as a reminder that I did not imagine this.

The same helpings were provided to men over 6 feet in height and still walking unaided, as were given to frail old ladies confined to bucket chairs and unable to move. Repeated protests made no difference. Staff urged relatives to complain, because the administration took no notice of their own protests as to the paucity of food provided night after night.

A typical run of evening meals was fish fingers and mashed potato, baked beans and mashed potato, party pie and mashed potato, baked pasta and mashed potato, a finger of asparagus mornay and mashed potato, sausage roll and mashed potato and minced meat and mashed potato. Salads and soup, which were much more appetising, were available but had to be requested; sometimes carrots were added to the hot meal but greens were rare. The most bizarre meal was probably the ham and cheese croissant with Brussels sprouts which featured occasionally.

Accompanying these meals was bread and butter which was used to fill people up since it was a long time between 5.00 p.m. and 8.00 a.m. next morning. Despite this, weight fell off people, particularly the men; the easy explanation that they lost it because of the progress of the dementia was hardly convincing. The simple truth is that they were virtually starving because what kept a frail old lady alive was insufficient to keep an active man functioning. In addition, those whose dementia led them to an increasing difficulty in using cutlery properly, were hard pressed to find assistance with eating and often ate nothing, because they could not manage it. Offers to help were usually refused, because of the Home's duty of care to residents. One might be forgiven for believing that a duty of care extended to preventing starvation, under the circumstances. My provision of fresh seasonal fruit, vegemite, jam, pate and cheese to go with the sought after bread and butter was appreciated by A and other residents whose relatives were happy to see them share this bounty but it seemed little enough to augment their meagre evening fare. After I had drawn attention to the paucity and lack of nutrition evident in the evening meal, when talking to the accreditation team, there was a big improvement but it did not last long. Given the nature of the meal it is hardly surprising that everyone was on laxative pills.

For those with swallowing difficulties, the pureeing of their food became another exercise in revolting gag-inducing splodge. Anyone who had ever enjoyed food was unlikely to be encouraged to eat by being offered a plate of dark brown sludge, beige sludge and pale brown putty sludge. Green or yellow sludge would have helped enliven the palette, at least, but it was an encouragement to stop eating completely.

When raised with management at a relatives' meeting the CEO informed us that the food was unparalleled in the industry.

Death by Dementia or Medical Misadventure?

It is a truism that many people fear going into a nursing home now because they see it as a last step into God's waiting room. Whereas people once put their names down for rest homes to accommodate them in their twilight years, few now imagine that their nursing home years will be long lived. Families usually make the decision, based on

geriatric assessment, but those entrusting relatives to the Special Unit in A's nursing home could have had no intimation, however, that their stays there would be so short.

The special unit has six single rooms and two twin rooms. In a little over twelve months from November 2000 to December 2001 some eight residents who had been in the Unit died. Their common condition was dementia, complicated in two cases by strokes and another with diabetes. Mismanagement of a choking episode saw one lady admitted, probably too late, to hospital, only to be returned to the Home to die. Consistent mismanagement of a resident's respiratory condition led to his admission to hospital, only to be returned to ongoing mismanagement of the condition and removal by his son to another home, but he died in hospital soon after. Carelessness in monitoring leg ulceration in a gentleman with diabetes led to his hospitalisation and return with a more painful end than necessary. Falls were common, often followed by hospital and a return to the Unit. Hospitals don't cope well with elderly people, let alone those with dementia.

Whatever the actual cause of death, the absence of adequate palliative care was notable. In A's case, it became evident that he was seriously ill when he was no longer able to walk unaided, having enjoyed a daily walk in the neighbourhood on the previous seventeen months. Confined to a bucket chair too small and unable to be adjusted to his long, lean, frame, he was clearly uncomfortable and cramped. Requests to secure a more appropriate chair were ignored. It was my vigilance, and not that of the staff, that saw his first and subsequent pressure areas recorded. The care of these areas was variable, depending on the professional standards of the staff. Since so many were agency staff, unaware of the particularity of his condition, this also required constant watching. Even after a fortuitous random visit by Health Department staff checking on care of pressure areas in residents, the regular turning required for appropriate relief was not always observed.

As A became more frail and spent more time in bed, comfort was paramount. Soon after his admission to the Home I had provided good pillows for him to replace the hot, scratchy, plastic-covered ones made available to each resident. I now supplemented them with smaller pillows, cushions and sheepskins for his bed, none of which were volunteered by the Home, but all of which made a great difference to A. The best and

most caring staff lifted him gently, positioned these carefully and thoughtfully; the worst jolted and jarred him and chose not to use them.

Repeated requests to monitor and deal with massive temperature rises were ignored by registered nurses who seemed unwilling even to take A's temperature, let alone do anything to relieve it. Told that there was nothing I could do about it, given their refusal to give even Panadol to reduce it, I resorted to old fashioned, common sense remedies which seemed to have been forgotten: making sure the fan was on, opening the window next to the opposite bed, giving tepid sponge baths, laying a cool flannel on his forehead, ensuring he drank as much as possible. The good nurses were more caring and administered Panadol at regular intervals to reduce the debilitating temperature; even so, ignored early on, it meant that it could take hours for it to come down and for A to get to sleep. Even if there were an instruction not to treat him, in the interests of hastening his demise, the dreadful discomfort he suffered at these times of raging temperature resulting in dehydration was unforgivable. The purpose of palliative care is to relieve suffering and to ensure, wherever possible, relatively pain free and peaceful passage to the welcome embrace of death. That it is not routinely practised in nursing homes makes a mockery of entrusting the frail aged to their care.

An honourable exception in the provision of comfort was the pastoral care team of visiting nuns whose gentle presence and affectionate laying on of hands relieved anxiety and supported and acknowledged the burden of grief of those caring for the dying.

Accreditation

A few weeks after A's admission to the nursing home, notice was given of a forthcoming meeting of relatives and carers, an occurrence said to be unusual by relatives of long term residents. It was clear to me, given my familiarity with the aged care system, that Commonwealth accreditation must be around the corner, not least because spot painting had started to occur in public areas, curtains were being laundered, and residents' names were suddenly attached to bedroom doors, early signs of the need to present facilities in their best light.

Perhaps twenty people attended the meeting, held on a week night, together with the CEO and Director of Nursing. The agenda allowed for the CEO to brief those present on the accreditation process, and to explain a long standing problem with the telephone system, and to provide a draft copy of an update of a Residents Handbook which had not previously been known to exist by regular visitors to the facility. Repeated questions as to when the accreditation team was coming, and how anyone might meet and comment on issues to them, were fielded by the CEO who reluctantly yielded the dates.

Observations about the handbook draft being a new creation rather than an update were denied. Certainly it contained information about a philosophy of care, a partnership of equals and a provision of service level that seemed quite foreign to many present, but maybe their regular visiting of relatives for up to three years previously had meant they had not had copies given to them.

Discussion of the malfunctioning telephone system revealed that a recent fire alert could have been a catastrophe because staff could not be contacted to check on evacuation preparation but it was said to be in hand.

The CEO's attempts to close the meeting after his agenda items had been dealt with were thwarted by individuals anxious to proceed to any other business. Issues raised included the timing, serving, paucity and lack of nutritional content of the evening meal; the unavailability of fresh fruit and the over use of laxatives; the failure to clean blood and faeces off a bedroom wall despite repeated requests; and the frustration felt by

many relatives at the staff's unwillingness to discuss treatment, medication and side effects, but especially obvious changes of medication, given to residents for no apparent reason. The quick answer to this last was that medication could only be discussed with treating doctors; the rejoinder that nobody ever knew when doctors were coming and that family and work commitments made it difficult to manage even if they did, was dismissed. As for the meals, the CEO stated that he had extensive experience of aged care facilities and that the food served there was second to none in Sydney, which is why residents were happy to be seated at table at 3.45 p.m. every day for the 5.00 p.m. meal, since they looked forward to it as a highlight of their day.

Next day, fresh fruit appeared on the wards, a practice continued until after the accreditation visit, but not for long.

During the visit by the accreditation team some three weeks later, the above version of the meeting contrasted sharply with the minutes provided to the team by the CEO which, among other things, praised the meals provided. The Residents' Handbook was presented as a long term fact of life and concerns about the medication and cleaning issues were skated over. My meeting with one member of the two member accreditation team was held in full view of residents and staff; others preferred to speak to them on the phone, so fearful were they of identification as trouble makers with retribution likely for their relatives, while some were simply unable to make the time allotted to them in the 2-3 day visit of the team, held during working hours. I do not know whether my comments about the lack of stimulation and activity for residents, other than TV; the nutritional standard, quantity and variety of food and timing of meals; the positive failure to encourage residents to walk; the inadequate numbers of staff and apparent failure to educate them on obvious aspects of dementia care and the sudden appearance of both relatives' meetings and Residents Handbooks, allied to quick paint jobs around the place, made any impact on the accreditation report. It is a fact, however, that the facility received a lesser accreditation score than the CEO and staff anticipated and that it shocked them greatly.

The ongoing problem with the accreditation process is that it concentrates on the standard of physical facilities rather than adequately addressing the quality of care provided. Random checks need to be made on all Homes without notifying proprietors,

with particular attention given to weekends, when staff numbers are down. This would give a more accurate assessment of the standard of care in each facility.

Intimidation

A pervasive attitude amongst regular visitors to the facility, whether relatives or friends, was the anxiety not to make a fuss, not to complain, not to enquire, not to be noticed, for fear that it would reflect badly on their resident and lead to some kind of retribution.

The partnership of caring proclaimed in the newly produced Residents' Handbook was regarded as a dishonest and sick joke. No attempt was ever made to harness the experience, love and dedication of regular visitors to the general betterment of life in the place, but in this respect it did not differ from many such facilities where carers were positively discouraged from even bothering to visit, as recorded by the Carers Association of New South Wales in consultations held last year.

An obvious reason for a lack of serious engagement between carers and staff is the very unequal nature of the relationship. Partners of residents are so grateful to have found a place they are fearful of losing it if they complain. Adult children or other relatives of residents are likely to be younger and more questioning but are similarly tied by the difficulty of finding alternative accommodation. Friends can see a great deal but have no status. If they are not next of kin they can be ignored and their concerns, loving and observant, even constructively critical, as they might be, will disappear into the ether.

My grandmother had been admitted to a nursing home in Hobart in 1982 after breaking her hip. While it saddened me immensely to see her there, she was in a small community whose standards of care were witnessed every day by people she knew and who knew and cared for her in turn. Even so, she was wisely wary of some staff. How different it is in the next century, in Sydney where communities are scattered and forgotten, where many residents in nursing homes have nobody to look out for them and where relatives are too frightened to speak out, no matter what.

Two decades of advisory work in health, community services and social security at the Federal level, encompassing veterans and aged care, disability and drugs policy,

medical education and professional standards development, however, did not prepare me for the intimidation I encountered at the hands of the CEO of A's facility.

By early November 2001, A's condition had deteriorated significantly. The daily walks in the neighbourhood we had enjoyed over the last 17 months had ceased and he was now confined to a chair, suffering pressure areas and spiralling temperatures and having trouble swallowing. He still knew me and welcomed my daily visits, but it was clear his days were numbered.

It was in this atmosphere that I received a letter from the CEO, asking me to attend a meeting at which conditions attaching to my continued visiting of A would be discussed, since a number of complaints had been raised about me.

Although tempted to ignore this letter, I arranged a meeting time, but asked a trusted friend, a former Federal and State Health bureaucrat of high standing, to go with me.

On the appointed day, there was an air of unexplained agitation around the foyer, with much coming and going of staff and strangers. It transpired that the place had just been raided by the Immigration Department and a number of staff, believed to be illegals from the Philippines, China, Sri Lanka and maybe East Timor, had been taken into immigration custody and transferred to Villawood Detention Centre.

The CEO and Director of Nursing were somewhat preoccupied, since cleaning, laundry, kitchen and nursing staff were involved and rosters for the next month had been provided to Immigration so checks could be made on other suspect illegals.

My own five year appointment as a Member of the Immigration Review Tribunal from 1994 to 1999 meant that I had first hand knowledge of the illegal immigrants underpinning the operation of many nursing homes, so I had some sympathy with what had occurred but this was not the matter in hand for me.

Over the next half hour I was read a litany of complaints made about me, starting with my propensity to help feed residents other than A at the evening meal. This activity on

my part compromised the home's duty of care to residents; they might choke. My bureaucratic friend suggested that I would not do this again and I agreed.

Some staff had made adverse reports about my visits to A and considered that they were not in A's best interests and should be curtailed. I responded that these visits incorporating a walk had been part of A's daily life for a year prior to his admission and ever since; that they had ensured he had regular exercise in fresh air and sunshine, access to good food and company and retained a sense of being part of the community. To cease visits now could not possibly be in his best interests and this was conceded.

Querying the nature of the adverse reports from staff, I was informed that they were required to report any "incidents" involving visitors and that some found me to be difficult, arrogant even. I responded that I thought I had a good relationship with competent, caring, professional staff who were gentle, caring, competent and respectful in their dealings with A and others but those who did not display these qualities might well find me a little difficult. Indeed I wished to raise a number of incidents involving myself that were unlikely to have been included in reports to management.

While conscious of the need to mind my own business and confine my caring activities to A, there had been several disturbing incidents in the past fortnight while I was sitting beside A's bed.

The first had involved hearing noises of a scuffle in the adjacent community area, agitated cries of clear distress and a loud female voice proclaiming, "Die! Die! Die!" I had immediately intervened in the absence of any staff in the vicinity, and loosened the choking hold the strong woman resident had around the throat of a much smaller, older and frailer resident, a former nurse of gentle confused disposition. At the same time I had shouted for assistance, which had eventually come, but with no thanks for my timely intervention.

The second involved the same woman resident who had taken it upon herself to lead a recently arrived blind resident, without his white cane and against his will, up a corridor away from his room forcing him into the men's lavatory and closing the door on him. Again, no staff had been present, but the same woman was believed to have hit the

gentleman in question when he was asleep in bed one night and the two should have been kept apart. I duly alerted staff to this incident.

On the third occasion I became aware of cries for a nurse from the gentleman in the opposite room, a recently arrived stroke victim confined to a wheelchair, who, it transpired, had slid from his chair to the floor. I alerted staff to this, too.

The CEO and Director of Nursing did not respond directly to these comments but conceded that there were sometimes occasions when there were differences of opinion or personality clashes between staff and carers and these could not be avoided. In addition, staff could not be everywhere at once. I was not thanked for my efforts on behalf of residents other than A, having also pointed to the fact that I had recently drawn the staff's attention to two instances of choking during the evening meal that nobody else had noticed, despite their duty of care.

The final point raised against me was that A's doctor was concerned at the recent rapid deterioration in A's condition and that this might have been due to my interfering with or preventing A from taking his medication.

Given my Catholic upbringing, I was devastated at this suggestion that I might in any way have contributed to A's distress and impending demise. Aware, however, that I had to keep my counsel and avoid any further suggestion that I could no longer see him, I countered simply that I found this suggestion offensive. Indeed, I had alerted staff to the difficulty A was experiencing in swallowing tablets, especially laxatives, some time earlier and, as a result, his regime had been altered to incorporate a natural laxative preparation that was easier to take. More recently, I had pointed out that he could not manage to swallow a large antibiotic tablet unless it was crushed. I had been assisting rather than hindering as was being claimed. When this particular issue was raised with the CEO and doctor after A's death, both denied that any such accusation had been made. The Director of Nursing kept her religious counsel.

The meeting concluded with the agreement that I would not help feed anyone else and that I would continue to visit A on a daily basis. This I did, until his death, some three weeks later.

I have described this encounter in some detail because I believe it to have been an unconscionable attempt to dissuade me from continuing to visit a dying man who depended upon me for comfort and support.

It was an unhappy experience for me, clearly designed to intimidate and to show me who wielded the power in this Commonwealth-funded aged care facility. Fortunately I had taken a trusted friend to the meeting as my witness. Someone with less self-confidence and knowledge of the health system may have been so crushed by the experience that she would have been unable to continue to face the nursing and administration staff each day, knowing that some of them wanted her out of there. As it was, I had grown to hate the daily journey, because I never knew in advance whether I would be greeted by warmth and support from good staff or hostility and resentment from bad staff. But after receiving this letter and attending this meeting, I knew absolutely that I was being watched, in the hope that I would step over some ill-defined line and forfeit the right to visit A at the time he most needed me to be there for him.

The Benefit of Hindsight

The letter to me from the CEO, I now realise, followed a period in October 2001 when A was clearly ill and when my requests to nursing staff to do something about having his condition investigated were brushed aside.

The treating doctor and nursing staff had been instructed not to discuss A's condition with me because I was not next-of-kin. It should not have been beyond their intelligence and imagination, let alone professional competence, to enquire themselves about matters I raised with them, as follows.

On 8 October, A was very hot and distressed, so I reported this to staff, wondering whether he might have a urinary tract infection and whether a urine sample was needed. Nothing was done. For the next few days he was clearly unwell, but no action was taken.

On Sunday 14 October A complained of a painful shoulder and had difficulty angling his arm. He also had two nosebleeds on the weekend. I reported both problems to the registered nurse on duty who noted them and said she would raise them with A's doctor.

On Monday 15 October, I was told that the doctor had been notified and would see A during the day. A waited all day in his room and came out to the dining area for dinner. The doctor arrived during this dinner period and sat at the nurses station for several minutes, aware that A was in view a few feet away from him. He left without even greeting him, let alone examining his shoulder. On Tuesday 16 October A was required to have blood tests at the doctor's request as written up the night before. For the next two days A was very quiet, hot and unwell.

On Thursday 18 October, 10 days after I had alerted staff to the problem, a urine sample was taken and A started a course of antibiotics, specifically, Augmentin, for five days, for a urinary tract infection. He was confined to a chair in which he was obviously uncomfortable because it was too small. He did not walk again after being so confined with his long frame and legs. His temperature continued to spike to high levels after the antibiotic course finished on Tuesday 23 October.

On Thursday 25 October I pleaded with the registered nurse on duty to do something to relieve A's temperature and she said she had advised the doctor. A portable X ray was finally taken of A's shoulder which now had a distinct bruise and pressure area 10 days after he first complained. She told me there was absolutely nothing I could do to reduce A's temperature, so I continued to do the obvious old fashioned basic nursing – tepid sponge, cool flannel, loosened clothes, window open, fan on, cool drinks – none of which were even attempted by staff.

On Friday 26 October A was given some liquid Panadol for his temperature.

On Saturday 27 October A's temperature was again very high and he had developed a number of blisters which I drew to the attention of the registered nurse on duty who was so shocked she called the doctor who was not able to visit that evening.

On Sunday 28 October A's temperature was still high, the blisters had broken on the pressure areas and these were properly dressed by the registered nurse on duty who said the doctor would see A next day.

On Monday 29 October, A was again confined to a chair too small for him, clearly uncomfortable and with a continuing high temperature, even though he was supposed to be having bed rest to relieve his pressure areas. When I mentioned this to the registered nurse on duty, she arranged to have A moved to his bed, and dressed the pressure areas, saying that A's doctor would visit during the afternoon.

In the evening, A's doctor spent 15 minutes, from 2.55 pm to 3.10 pm at the nurses station in the adjacent ward but, as on a previous occasion, did not even see A, let alone examine him,. Once again blood tests were ordered for next day.

When I expressed my disbelief that A's doctor had not bothered to give him even a cursory greeting, given his obvious illness, another registered nurse told me that if I complained, "they will stop you seeing him."

A continued thereafter to be confined to a chair unsuited to his frame, spending hours without moving, his pressure areas unrelieved apart from the sheepskins and pillows I provided, his temperature still spiking with little relief apart from my old fashioned nursing and no prospect of ever walking again.

The letter asking me to justify seeing him again was dated 1 November 2001; it was some three weeks after I had first drawn attention to A's deteriorating condition.

When my grandmother was in her nursing home in Hobart in 1982, her doctor would do her the brief courtesy of dropping by her room or chair, greeting her with "And how are we today, Mrs Parker?" and hurrying on to collect his Medibank benefit without waiting for her reply.

Twenty years later, in Sydney, it seems that doctors are able to prescribe blood tests and change medication for patients without even seeing or greeting them, let alone examining them, before claiming their Medicare benefits.

It is clearly necessary to make it more attractive to medical practitioners to visit patients in nursing homes, but before this happens, there should be a thorough investigation of what Medicare benefits are paid to doctors currently seeing residents in nursing homes. The Health Insurance Commission needs to be satisfied that they are not defrauding the Commonwealth in the same way that some are defrauding the patients they profess to care for.

Situation Vacant

As I intimated to the CEO and Director of Nursing, I felt that I had built up a good relationship with competent and compassionate staff. The tragedy of the place was that so few met this description and that is the essential tragedy in aged care in this country.

A number of parliamentary and other government enquiries have sought to identify and ameliorate the shortage of trained nurses and especially aged care nurses in Australia. My comments will add little to what is already known but they are worth repeating, since the generality of them is underlined by the atmospherics of this Home.

It is a truism that there are not enough registered nurses interested in a career in aged care and that there are insufficiently trained enrolled nurses and assistants in nursing. Lack of adequate remuneration is only part of the answer.

In the case of this Home, I saw good and dedicated staff leave because they felt unvalued, because they were stressed, because they were worked into the ground and because they could no longer tolerate the administration-induced corner cutting that put the health and well-being of residents at risk. They did not want to take the blame for the catastrophe of inadequate care that would claim lives.

The culture of unquestioning obedience to administrative dictates allied to strict adherence to the doctor/handmaid model of professional interaction meant that individual residents were the losers. Staff were not encouraged to think, possibly because thinkers can become whistleblowers.

Registered nurses seemed to be employed only to dispense drugs and write up notes, with virtually no hands-on nursing. Concentrated on the drugs trolley or seated at the nursing station in each ward, they had little opportunity to observe or interact with residents.

The constant use of casual agency nurses made a mockery of any continuity of care because they did not know the residents, having to double check with relatives and other residents that they were dealing with the right patients.

For such nurses to accompany a doctor visiting a resident was worse than useless but was as likely as not to be the case, since doctors often visited after hours, when casuals were more likely to be on duty.

Both registered nurses and nursing assistants were victim to capricious shift changes which meant that they often had no idea from day to day what shifts they were working. Broken shifts and double shifts were equally dangerous in terms of tiredness and stress, but seemed to be used to underline how disposable staff were to the administration.

Enrolled nurses and assistants in nursing varied greatly in their competence and compassion. While technically able to provide the required basic care in showering, toileting etc, they often showed a complete lack of empathy and understanding of residents and were usually run off their feet. Very little in-service training was provided, other than trialling cost-cutting incontinence pads from time to time.

Some staff, notably older women with their own families from countries like the Philippines and Fiji, were practical and gentle and treated residents with the respect accorded aged people in their countries of origin. Visiting young Irish nurses were also cheerful and interested carers, lightening the atmosphere considerably.

Some staff, however, were unsure and uncaring, rough and even abusive in the way they dealt with people, prone to exhausted impatience and taking unsubtle retribution against residents who irritated them. Too many bruises and skin tears were not accidents but due to careless handling of frail aged bodies, especially those of people unable to complain.

Lack of staff in the dementia unit meant that there were often long periods of time when residents were not properly supervised, accidents and falls resulting, as well as residents being left in soiled clothing until they were cold and uncomfortable.

As mentioned earlier, a registered nurse, long gone, expressed concerns about the lack of adequate nursing and pain relief being given to terminal cancer patients and the fact that many, unable to feed themselves, were being allowed to starve to death because there were not enough staff to feed them. Some religious orders had removed residents from the home because of their concern at the inadequate level of nursing care for their elderly nuns.

In A's case, nobody was to blame for his dementia and therefore, in a sense, nobody was to blame for his death.

But in the last week of his life he pleaded to be taken out of this place, as he had pleaded every week he had been there.

And while he was grateful for the care of those nurses who were gentle and affectionate and who treated him with respect, he was frightened of those who handled him roughly and made him feel a nuisance and a failure.

For every nurse who cradled him with compassion and empathy, who sympathised with his carers and who grieved at his impending death, there were others who saw him as less deserving of attention because he was just the next empty bed waiting to happen and there can be no forgiveness for that.

The Best Is Yet To Be

I believe that the great task ahead of us as an Australian community is to destigmatise current notions of ageing and to restore the sense of affectionate respect for old people which once was part of our way of life and remains significant to many in our immigrant communities.

In the nineteenth century, the poet Robert Browning urged his readers to "Grow old along with me! The best is yet to be" How unfashionable in Australia in 2002!

Two noted women writers who had been friends of A for many years responded quite differently to the suggestion that they consider writing to him in the nursing home and thus illustrated the dichotomy in our attitudes to older Australians in aged care.

The first, who had worked beside him in Sydney in the fifties, delighted him with a couple of affectionate letters recalling old times, following these up with a postcard from France while visiting former colleagues, which also gave him real pleasure. The other, a novelist noted for her understanding of the mores of modern Australian society, refused, on the grounds that a letter or card would mean nothing to A and would offend his family.

The first chose to accept and celebrate A's individual and ongoing personality and humanity, despite his circumstances and condition, as did those who visited him. The second adopted an attitude based on what she had been told was his complete disconnectedness to the world outside and her own desire to be seen to be supportive of his family, rather than him.

The contrast shows both how easy it is to comfort an old friend and how easy it is to "disappear" someone with dementia, someone already punished by being placed in care.

Our own image-obsessed society sees millions of dollars spent daily exhorting people to spend millions more in staving off the signs of ageing. Is it any surprise, then, that some are repulsed by the physical manifestations of ageing and find themselves as frightened about being in touch with frail elderly people as their forebears were of touching lepers? Indeed, just as lepers were put away because of fear of contagion and also to absolve citizens of the need to face them, so many older Australians have been put away, out of our sight and in the belief that they are out of their minds.

We need a massive public education campaign, akin to the effort that went into HIV/AIDS awareness and destigmatisation in the early eighties, about both respect for

age and understanding of the conditions that can exacerbate individual isolation and frailty.

Such a campaign has the potential to unburden the weight of caring which falls on the few relatives and friends with time to care for those in need. Only when community empathy for old people translates into empowerment and status for the volunteers and staff who look after them will we achieve any kind of justice in this field.

For, in the end, the care of elderly people in Australia is a justice issue.

One of the tragedies of the nursing home I came to know so well was the number of frail elderly women who had devoted their lives to serving the Australian community as teachers and nurses and who were now in care, for the most part unloved and unvisited. If there was any justice in the world, they should be receiving unparalleled care to thank them for their contribution to our wellbeing. The way to thank them, and people like A, is to value them in their old age.

As a society, we should be putting as much effort into the provision, location and standards of aged care facilities as we have come to expect in child care, and with as much emphasis on variety of care as in that sector. And we should be doing it not because baby boomers demand more for their old age, but because our old people deserve better now for what they have already done for all of us.

At the same time, we should be harnessing the goodwill and energy of the community to contribute to an effective partnership of shared responsibility so that doing unto others becomes a reality.

When we feel comfortable about the prospect of our own ageing, knowing that we will continue to be valued and cared for, no matter what our ailments, we will be a better society. More practically, when we also value our carers, though vastly improved attitude, education, conditions and remuneration for them, we will have made a timely investment in our further peace of mind.

But we may still have a moment of slight hesitation whenever we sing the first discriminating lines of our National Anthem:

Australians all, let us rejoice
For we are young and free.

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30 August 2002

The Committee Secretary
Standing Committee on Ageing
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I would like to thank the House of Representatives Standing Committee on Ageing for the opportunity to make a submission to its enquiry into long-term strategies to address the anticipated ageing of the Australian population.

My submission draws on my daily observations of life in an aged care facility in Sydney over a 19 month period, allied to my career background in policy development in health, community services and social security. I am presently serving as a laywoman member of the NSW Health Department's Health Ethics Committee, but my views are my own and do not reflect that Committee's views or policies.

I am convinced that a vital element in dealing with the anticipated ageing of the Australian population is the need to de-stigmatise age and to engage in extensive public education about conditions such as Alzheimers Disease and dementia, ignorance of which condemns sufferers and their families to a twilight of despair.

Sincerely

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