I am a Social Worker who has been in the field for over 25 years, employed for the last 8 years plus at Caulfield Hospital, in Baringa, the Aged Psychiatry Inpatient Unit and also in the Cognitive, Dementia and Memory Service (CDAMS). I have been advised that the Commission visited our hospital when I was on leave. Having missed that opportunity, but viewing Social Work as having a strong advocacy role and feeling a strong responsibility to contribute my views and ideas to the Commission, I now submit as concisely as I can some of my views and ideas in writing.

I am in a position to be acutely aware of the already critical situation in aged care and of the fact that with our rapidly aging population and increasing longevity, the critical situation grows daily. I would hope, probably naively but idealistically, that the decision makers, in developing policy, think about what they would like for themselves or a relative if services were required or entry into residential care was chosen or became a necessity and let that thought guide their decisions. That way needs will be met appropriately and relevantly, with quality services.

I will focus in particular on residential care issues, but also give my thoughts on supports for and assistance to the aged in the community.

# RESIDENTIAL CARE:

Entry into residential care is often a distressing and painful process, for the person entering and often for families too. Even for those who actively make the choice, it means giving up a home for a room, giving up the majority of one's possessions and accepting a fairly regimented life where shower and meal times are largely inflexible and one has little choice over what one eats. For those who enter residential care against their wills, it is much more traumatic, with disorientation an extra feature. The problems for all requiring residential care are significantly magnified by the shortage of beds generally and in particular of suitable beds, of accessible beds, of affordable beds, as well as by the issues of inadequate staffing levels, poor staff training and the lack of specialist skills. Three groups in particular are affected.

1) Individuals on pensions requiring concessional beds.

2) The CALD ( Culturally and Linguistically Diverse) communities

3) Individuals with dementia

## INDIVIDUALS ON PENSIONS:

- Most residential aged care facilities are run by private companies for profit.
- Government legislation requires a certain percentage of beds be designated "concessional" ( accessible to people of limited means,

largely pensioners), but this percentage does not meet the demand for such beds and definitely not in most areas close to the CBD.

The need for and lack of such concessional beds is a huge problem when I and my colleagues in Medical Social Work are seeking placements for someone who lives in our region. Given the cost of land, new facilities are being built further out, but placement in these areas is totally inappropriate where there is an elderly spouse, elderly siblings and/or other family remaining in our region, because this mitigates against ongoing frequent contact and maintaining relationships. I am sure this is the experience of Social Workers in other regions too.

- In the past people requiring nursing home care were not so disadvantaged as nursing homes could not charge bonds, though individuals who could only pay low fees at times had to accept shared rooms. Now facilities being built in our and other like regions are "Extra Service" facilities, with existing facilities converting too. This allows them to only offer bonded beds at both Low Level (hostel) and nursing home (high level), i.e. they do not have to have any concessional beds. In the past people requiring nursing home care were not so disadvantaged as nursing homes could not charge bonds. The demand for concessional beds is growing, and will continue to grow but the number available is falling, with certain regions already now almost "no-go" regions for concessional beds.
- With 84% of the pension going on facility fees, individuals who have multiple medical comorbidities, requiring a large number of different medications, have a significant amount of their personal funds (16% of the pension) drained, even with PBS. If they are in this category and smoke, then monies for clothing, personal care (skin care, the luxury of a cheap perfume etc), an outing are scarce. Individuals with a mental illness quite often have a long history of heavy smoking and on top of their psychotropic drugs, often require medications for varying numbers of physical ailments, are especially disadvantaged. Begging is not an unknown, and other risky behaviours may also occur in order to fund cigarettes. One might say they shouldn't smoke, as one might say individuals with limited funds also can't afford to and so shouldn't drink, but with many of such individuals entering care against their wishes, can we humanely deprive them of one of the few personal pleasures they might have.

Even for those who can afford bonds, there is a problem for many in terms of adequate means for personal needs on an ongoing basis as many often have no other income after selling their homes except the pension, of which 84% goes to the facility. They have to pay for medications, personal needs, cigarettes if they smoke etc out of the residual. The government does require an individual to be left with $37,500 after they pay a bond, supposedly so they do have some monies available for extras on an ongoing basis via small amounts of interest or by direct drawing down. Centrelink determines the asset level of the individual and then a facility needs to be sought which accomodates the bond the person can afford. Bonds have gone sky high in some facilities, so it is really only the "elite" who can access these The problem is that Centrelink doesn't, in determining a person's assets, take into consideration in assessing assets for a bond two major factors:

a) the home is usually the main asset for a single person ( if it is a married couple, with one remaining in the home, it is not an asset at all) and there are costs in realising the asset to pay the bond, namely agent commission, and advertising and legal costs.

b) Government legislation allows facilities to charge 8.16% interest ( this is adjusted upwards at least twice a year I understand) on a bond until it is fully paid. This can amount to a substantial sum.

Looking at a fictional example, an individual has his assets assessed at $537,500. The facility sets the bond at $500,000, leaving him exactly $37,500 as per legislative requirement. The property sells for $540,000, with advertising costing $6000, conveyancing $1000.00 and commission at 2% is $10,800. Of his $37,500 he now retains $19,700. If it takes three months (say 90 days ) to sell and settle the property, he is up for $10060 in interest. So what he is actually left with is not $37,500, but only $9640.00.

## THE CALD COMMUNITIES:

Few CALD communities have invested in aged care, particularly residential care. Whilst we are stated to have the second largest congregation of Greeks after Athens, Fronditha, the Greek organisation providing aged care services, only has about 270 residential care beds, with a few other facilities not under their auspices catering at least in part to Greek speakers. The Italian community is serviced by about 325 beds, of which 22 are in Supported Residential Service. The Chinese community has almost 200 beds. The beds for these 3 major communities include hostel, nursing home and dementia specific. The communities that seem best prepared are the Dutch and Jewish communities. In these latter two communities, language barriers are likely to be significantly less than for the former 3 groups, apart from Russian Jewish migrants who may have little or no English. This problem is overcome by virtue of many Russian speaking staff being employed. Many people from CALD backgrounds who are now needing residential care or will in the foreseeable future have no or minimal English, making the need for ethnospecific , culturally sensitive facilities greater.

These and other CALD communities who are poorly serviced by suitable ethnospecific facilities therefore face additional trauma in care due to language barriers, loss of cultural environment, cultural insensitivity and unfamiliar and unacceptable diet. Even where a bed is secured in a matching ethnospecific facility, given the limited choices, distance often mitigates against ongoing family contact, particularly by isolated spouses.

I organised a one day conference in 2007 on perspectives on and understanding of dementia in CALD communities, which underscored the lack of knowledge about the condition, the blocks to service seeking and access etc  The Alzheimer's Association is doing great work in this area, but with very limited funding and, I believe, only one staff member specifically dedicated to this area.  I believe more funding is needed, but the government also needs to be taking some direct responsibility for education, surveying need and planning appropriate services, community and residential. Amongst topics attenders said they would like for future conferences was practical information about managing CALD residents appropriately in non-ethnospecific facilities.

## THE DEMENTIA POPULATIONS:

Whilst health practitioners, academics, government and even some members of the public are aware of the ever growing numbers of people with dementia, many of whom will require residential care at some stage of their illness, preparation is minimal and in my view it is not just a crisis that is looming, it is Armageddon as far as adequate dementia care is concerned.

Many facilities claim they are dementia-specific or provide dementia care simply because they are secure (key-padded.)  Common features of dementia such as wandering and intrusiveness are poorly tolerated in many such facilities and families, having struggled to find what they are lead to believe will be a very appropriate placement, are then decimated emotionally by the news the facility declares itself unsuitable to meet their loved ones needs.

Generally the amount of staff adequately trained to manage behaviours associated with dementias is scarily low.  I am not stating they should be able to manage all behaviours - a significant number of our admissions are of individuals with dementia with associated extremely challenging behaviours and other BPSDs ( behavioural and psychological symptoms of dementia, for example acute psychotic states, including very distressing hallucinations) -but they generally can only manage a very limited number of features associated with dementia.  In part the lack of skills is due to the lack of appropriate training available ( given my personal experiences with people with dementia, I do not consider the online modules available through government funding allow for gaining adequate knowledge and skills).  What is available tends to be very expensive.  Facilities run for profit are unlikely to fund and send staff off to such courses, or even give them paid time off to attend if they self-fund. Given the very poor pay of PCAs, who provide a significant proportion of dementia care, one could not realistically expect them to devote their own time and money to training.  For nurses, dementia care doesn't tend to be a drawing card, given the nature of the work, including the risks of regular verbal and physical abuse to themselves and other residents, property damage, risk of patient harm through them moving/climbing on furniture, handling inappropriate voiding and faecal smearing etc  Whilst some very dedicated individuals might chose the field, to draw good staff, pay rates need to be looked at. A shift in a dementia unit can be very draining, including night shift, because many residents may be unsettled and wandering.

Adequate funds need also to be devoted to suitable activities , with legislation to secure a minimum amount of hours a week , with qualified people (diversional therapists) involved. An individual with dementia, even advanced, must not be treated as if they are brain dead.

The most difficult to manage, even after a period of treatment in an acute psychiatry ward, require psychogeriatric placement for a period (length of stay varies greatly), though this facility is not just for individuals with dementia with BPSDs. We at Caulfield are very lucky to have a psychogeriatric nursing home on site but, with only 30 beds, this may become totally unable to meet demand in the future. However there is no psychogeriatric hostel in our region and largely we use a facility in Seaford when we need a psychogeriatric hostel bed, clearly a problem where there is family involved. Other areas may have the hostel, but not the nursing home. In the future, both will be needed in all areas and with an increased number of beds.

We are seeing more and more early onset dementia sufferers, from late thirties onwards. Placing these individuals with feeble 85 year olds creates risk and is cruel both for the individual themselves and for their families. To add to the trauma of a teenager seeing his mother decline further and further in functioning and cognition having to visit her in a facility where individuals have mobility problems, incontinence etc additional to their dementias is not acceptable.

Place in the above scenario an individual from a CALD background and the problems and risks tend to magnify.

I want to highlight the fact that we are not generally appropriately accommodating younger individuals requiring residential care. I was approached outside work by an individual whose mother had motor neurone disease as I recall - at times the muscles in her throat would "collapse" and she wouldn't be able to breathe. The son fought against residential care, despite the risks of her continuing in the community, because he knew that for her to be placed in a nursing home where people could regularly be dying would be like death for her.

Even when someone enters care, family members may continue to take an active carer role, coming in to feed, toilet, occupy their family member. This reduces the workload for staff, but can be an ongoing stress for the family members. In terms of access to counselling, support, respite services, such individuals are no longer formally classified as carers and therefore cannot access services. I believe there needs to be some flexibility in the system where, on the recommendation of a doctor, social worker etc certain individuals could still be able to access relevant carer services.

To finish this section, I add something sent to me by email, which hopefully, as the current reality stands,  does not reflect our values, and which raises food for thought i.e. how do we treat prisoners vis a vis the aged and what does this reflect ?

## Let's put the seniors in jail, and the criminals in a nursing home.

### Seniors in Jail

This way the seniors would have access to showers, hobbies and walks. They'd receive unlimited free prescriptions, dental and medical treatment , wheel chairs etc. and they'd receive money instead of paying it out.

They would have constant video monitoring, so they could be helped instantly if they fell or needed assistance.

Bedding would be washed twice a week, and all clothing would be Ironed and returned to them.

A guard would check on them every 20 minutes, and bring their meals and snacks to their cell. They would have family visits in a suite built for that purpose.

They would have access to a library, weight room, spiritual counselling, pool and education.

Simple clothing , shoes, slippers, P.J.'s and legal aid would be free, on request.

Private, secure rooms for all, with an exercise outdoor yard ,with gardens.

Each senior could have a P.C., a T.V. radio, and daily phone calls.

There would be a board of directors to hear complaints, and the guards would have a code of conduct that would be strictly adhered to.

### Criminals in a Nursing Home

The "criminals" would get cold food, be left all alone, and unsupervised.
Lights off at 8pm, and showers once a week.

Live in a tiny room , and pay most of their funds for the privilege and have no hope of ever getting out.   Justice for all.

## COMMUNITY CARE:

Whilst there are services and supports available to allow the elderly to continue living in the community, though clearly insufficient, with long waiting lists for many services often confronted, a very large part of the care burden rests with family members, for those who have families, or on privately paid for carers for those who have the funds, a small proportion of the population given the costs. Whilst it is known that family care significantly reduces costs to government, it is false economy very often and will become more so in the future. Carers burn out, become physically and psychologically unwell, have to take days off work, drop out of work etc because of the demands of care, adding costs to the health and welfare systems and impacting on productivity. With our population aging, with individuals living longer at the same time, the ability of the elderly to rely on their children to assist with their care in the community will reduce as their children will be elderly and quite possibly have care needs of their own. In terms of carer support, residential respite care is often not easy to access unless well-planned in advance, though the need often tends to arise suddenly ( e.g. the carer suddenly becomes unwell), due to the limited number of beds set aside for respite purposes. In terms of community respite, demand way outstrips supply and waiting lists tend to be extensive. Whilst carers wait for relief, via residential or community respite, the risks of them burning out increases.

To keep people at home, we have HACC, CACPs, Linkages, EACH and EACH Dementia, respite services, day centres. In terms of assistance with things like showering, shopping, cooking, getting to appointments, social activity and engagement, a few hours respite for the carer, the system currently is pretty inflexible. On a CACP you can get 4 1/2 hours a week, on an EACH or EACH Dementia I believe it is about 14 . Clearly there are people who need more than 4 1/2 hours, but quite a lot less than 14. Linkages focuses on filling the gap to some degree, but isn't a full solution and waiting lists for Linkages can be months long. It isn't easy to find exact information on the web in my experience and as I can only refer for HACC, not CACP or EACH (which require a referral to ACAS when the individual concerned is in the community), I have to admit I have limited knowledge of finer details. Waiting lists for packages exist, often quite significant ones, and at times this applies too to HACC through councils, including for cleaning and personal care. Services are often most vital upon discharge from hospital and Post Acute Care and the Transitional Care Programs are aimed at filling the void, but TCP in particular can have a significant waiting list, keeping people unnecessarily longer in hospital, which can then lead to increasing deconditioning, making their ability to cope in the community harder when they go home and so increasing the risk of placement being required. In our acute psychiatry ward, once someone is ready for discharge, delays to discharge can negatively impact and put pressure on their recovery.

For CALD communities there are many constraints to accessing support services in the community - as with residential care, language barriers, dietary issues, cultural environments apply to in home services and or day centres and senior citizens clubs. There can be resistiveness to accepting outside help because it is viewed as shameful or an intrusion of privacy, or because of fears of confidentiality (others in their community learning they need help.) and for cultural and religious reasons, the nationality or sex of personnel sent to assist can be very significant, as can their dress. This area is a very underdeveloped one, urgently requiring attention, particularly because individuals and families, finding they cannot access ethnospecific facilities in the short-term ( or over tome that will likely become the long term) may well do everything to keep their family member at home, whilst not utilising, finding access difficult or not finding services they can effectively use, which may put many elderly ( both the person requiring direct care/assistance and their spouse/carer) at risk. Much of the research done by the Alzheimer's Association regarding the issues and problems for CALD community members requiring community supports equally apply to the English-speaking populations too.

The benefits of people remaining in their own homes and familiar local environments as long as possible, balancing benefits with risks, are widely accepted. I understand it also involves lesser costs to the government than residential care . But behind the belief there must be a commitment to adequately service needs in an appropriate, sensitive and timely fashion, with equal access for special needs groups.

To finish, I again add something, not my direct contribution, which underscores my statements about problems with community services and raises further problems and obstacles to maintaining people in the community. This is from the minutes of the Port Phillip Aged Services Network (21/7/2010).

**Themes- Community Aged Care Packages and Linkages. continued**

· General
· If clients are on a CACP and move areas-cannot keep same provider
1 Often HACC provide same amount of hours as CACP
2 Need to sometimes ‘sell’ idea of packages
3 Harder to encourage pick up of CACPs if fees are not negotiable
4 Ongoing challenges of costs shifting across 3 different level of govt as well as the private and NFP sectors.
5 Transition to CACP can be jeopardised due to reluctance to lose their HACC worker
6 CoPP not currently able to provide their staff for CACP work
7 Emphasis is on importance of a client advocate for acceptance of a package-need to co-ordinate services involved.

o ACAS- (Aged Care Assessment Service, Caulfield Hospital)

· Some providers have their own carers compared to others that use agency staff which can be challenging when recipients compare each others services and ask staff why the variation

1 Fees and amount of care can significantly vary across providers once person is on a package
2 ACAS come mainly from intake and referral perspective
3 Range of referral sources and reasons for requesting an ACAS assessment so also different outcomes which may include recommendation for CACP or EACH

4 Lots of different points of assessment
5 Intake will be allocated to a worker-if possible the person who has seen the client previously to ensure continuity

6 Assessment incorporates medical history, activities of daily living, chronic disease, personal care issues, skin care, cognition, domestic situation, family situation, nutrition.

7 Complete an aged care client record
8 Also complete a priority tool and list on a centralised waiting list-Providers can then see what level of urgency people have been listed eg high, medium and low.

9 EACH & esp. EACH Dementia have extra assessment outcomes-for eg. when person with dementia shadows their carers, other challenging behaviours

10 Waiting list can present range of challenges as there can be a significant waiting time
11 Councils tend to provide a comparative type of care compared to CACP so ACAS worker tries to also distinguish what extra the CACP will bring in terms of hours, case management

12 If clients have cultural specific needs-not currently stipulated on centralised waiting list so providers need to check this further

13 Approx. 18-20 providers in this region-many with a specific focus. You are able to specify particular providers on the centralised waiting list including only listing one preferred provider however this would add to length of possible wait.

14 Quite a variance to turnover/ waiting times –it is possible to check with providers directly to gauge likely waiting time but negotiating someone being picked up by provider disadvantages those already waiting.

15 There are many more funded CACPs than EACH and EACH Dementia packages so possibly longer list for an EACH as well as greater demand.

16 Tricky to understand how some people get picked up more quickly than others staying on list already. Some even still waiting near the 12 month mark and require their papers to be updated.

17 Increasing complexity and requiring of ACAS assessments a minimum one hour to carry out compared to previous could do in 30 minutes

I am not naïve and understand that there are not endless funds available, but if we don't start making provisions now, the costs will be much greater, both financially and in terms of human pain and suffering, and the ability to pay much less.

I hope at least some part of this submission is helpful.

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