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I would like to thank the Productivity Commission for the opportunity to put forward a submission a second time to the inquiry into Caring for Older Australians

I thought it might be useful to the Commission if I were to reiterate (since my last submission) "where I am coming from".

My experience stems from being a young person (age 42) with severe disabilities who is a regular respite resident and has had respite in several aged care facilities within a certain region of NSW; and from information given me from many of my paid part-time carers (past and present) and casual agency carers (past and present) all of whom have worked or still work as nurses in aged care facilities (all different aged care facilities in different locations around Sydney, NSW). As well as from having an informal carer (my husband, who is my primary carer).

The draft report is very thorough, interesting and impressive.

I had considered listing everything that I thought was good about this draft report but given my time constraints (I have to go into an aged care facility for respite soon and the return date for submissions is before I come home again), I thought it might be more useful to the Productivity Commission if I made suggestions on how the draft report (and mainly the draft recommendations) can (and sometimes, should) be improved.

So here we go...

Aged care facilities are largely "waiting rooms for heaven " where society likes to shove old people out of sight (you know this is true. We live in a society that worships youth - sad but true).

Many people do not want to be placed in an aged care facility.

Given that the Commission recommends that older Australians should be allowed to have choice and control over their lives and be treated with respect and dignity (draft recommendation 4.1), allow them the choice of selling off their home of 40 or so years & having to sell most of their treasured possessions (as there is nowhere to store them in an aged care facility} - a highly traumatic and stressful experience to put anyone through - , and leaving their home-mates & spouses homeless with little prospect of finding a new home (to buy or rent) of the size (and in or near the familiar locale) they have just been pushed out of, going into sterile accommodation that they have to share with strangers, forfeit their personal variable daily schedule for a regimented, regular routine, be cared for by a constantly changing parade of overworked (& sometimes under-skilled) rushed nurses and look forward to months (perhaps a few years) of steadily declining capabilities, increasing loss of dignity, increasing pain, larger and larger

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doses of morphine and eventually dying alone, in pain, in a sterile building with nothing familiar; or remaining in their familiar, comfortable home and dying at a time that they choose (chosen months or years before deteriorating to the point where they can no longer be cared for at home), with their loved ones around them.

EUTHANASIA SHOULD BE LEGALISED

Draft recommendation 4 .1 in part states that - "***the aged care system should aim to: ... be easy to navigate — Australians need to know what care and support is available and how to access those services***", therefore, **the existence of an Australian Seniors Gateway** (Draft recommendation 8.1) (which is a good idea), **needs to be widely advertised (including culturally specific advertising) - there should be a recommendation on the need for, and how to do, this advertising.**

In chapter 5, The Commission proposes to "...focuses on the areas that offer the highest potential gains from reform. .(p.94). Unbelievably it does not appear to mention nursing as being in this category. Surely nursing should be included here

The issues of nurses in aged care facilities being unable "...to provide the **social and emotional support to residents that is important to maintaining the quality of life of residents**", and that **(funding is not provided for social and emotional support"** *p132) do not appear to be addressed in the recommendations.

The inability to provide social and emotional support has two possible reasons:

- 1 not enough time to interact with the resident
- 2 inability to communicate because of a language barrier

Reason one can be addressed by ensuring that all residential facilities are adequately funded to allow them to employ an adequate number of nurses. If the number of nurses is adequate they should have time to interact with residents rather than just attending to the residents' physical needs. **There needs to be a recommendation in this report on what the nurses union's and aged care facilities consider to be an "adequate" number of nurses in an aged care facility to allow for this situation.**

Reason 2 could possibly be addressed through **including in this report a recommendation that the Australian government along with universities, TAFE and service providers that provide training for nurses:**

include electives (in their nursing education courses):

- **teaching other language skills e.g. Italian, Vietnamese etc.**
 - **teaching cultural awareness of different ethnicities e.g. Greek, Chinese**

It would also be a good idea to let volunteer visitors have access to language training and education courses.

There also needs to be a recommendation that the Australian government provide aged care facilities with a subsidy of (amount to be determined by the nurses unions and aged care facilities) per resident, to address social and emotional needs of residents.

I do agree that older Australians in residential care should pay for their accommodation and everyday living expenses and contribute towards their care (with a safety net for those who cannot afford to pay for these things) but I am skeptical about the Australian government's ability to determine the point at which a safety net should cut in without having already caused financial distress to the older Australian (as I have been in correspondence with them for almost a year now about the inadequate number of nurses in residential care facilities and they still do not recognize this as a problem. Over the last few years I have been in contact with various government ministers and officials and can quite confidently say that the Australian government is largely out of touch with reality.)

A concern about older Australians largely funding their aged care is that it will lead to a two tier aged care system - the rich living much better in their old age than those on more limited income. As the rich will be able to "choose whether to purchase additional services or a higher quality of accommodation if that is what they want and can afford to do so." (p XX)

After reading chapter 6 about the disgusting mess that the aged care system is in (mostly due to government inadequacies), I would say that the Australian government needs to get its act together and get the aged care sector running cost effectively and efficiently BEFORE they can start reaching into older Australians pockets to fund aged care (as noted in the draft report, older people are now expecting more e.g. better quality services etc).

Also, if the government is going to expect people to pay for their accommodation and living expenses in a residential aged care facility, there needs to be some legislation that will allow these older people to have some of their own belongings in and/or make minor alterations to their accommodation (in much the same as you can if you rent a property) and an increase in the number of nurses to ensure that people are fed promptly and do not have to wait until their meal goes cold before a nurse is free, and that they do not have to rush while eating their meal

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eg nurses do not stuff food in the face of the resident while they are still chewing, nurses have time to coax residents (who are not eating well) to eat. **There needs to be a recommendation to address these situations.**

It is mentioned in chapter 6 increased co-contributions by care recipients “ [are] unlikely to obviate the need for tax increases and/or a reassessment of government expenditure priorities” p135 however, there is **NOTHING about still needing tax increases and or increased government expenditure (in addition to increased co-contributions by care recipients) in the draft recommendations and these issues are not visible enough in the general report.**

In part, draft recommendation 6.2 states " *The Australian Government should adopt the following principles to guide the funding of aged care: accommodation and everyday living expenses should be the responsibility of individuals, with a safety net for those of limited means*

What about a lifetime limit here?

What happens if they run out of money and can no longer afford to pay for living and accommodation expenses e.g. they live longer than they expected and they are currently living in a single room with an ensuite. If they now become supported residents, does the government require that they relocate to shared accommodation?

And how often is capacity to pay assessed? There should be regular reassessment in case a residents ability to pay changes.

draft recommendation 6.2 continues:

- *individuals should contribute to the cost of their personal care according to their capacity to pay, but should not be exposed to catastrophic costs of care.*

What do you class as catastrophic (very subjective) and who gets to define it?

This situation is better described in the Key Points of Chapter 6 “Individuals should contribute to the more predictable and manageable costs of their care, but not be exposed to excessive costs associated with extended periods of intensive care”, although even here a subjective term is used ie “excessive “. **A more quantifiable description needs to be used here.**

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Draft recommendation 6.4 in part states *"... Accommodation charges and their bond equivalents should be published by the residential aged care facility.*

Published where? This should be made clear in the recommendations.

The following sentence (written by the Commission on page 174 of the draft report MUST be included at the end of the first paragraph in draft recommendation 6.6. "The Pensioner's Bond scheme would only be available to age pensioners who wished to sell their own home." - without it, the general public will endure unnecessary and easily preventable stress.

I read the recommendations and much of this draft report before reading that sentence. I, my husband and my carers (who I have been telling about the contents of this report) have all been very stressed since reading recommendations 6.6.

One just had to look at the news on TV the night after the draft report was released to know that people are under the impression that they HAVE to sell their primary residence to pay for aged care.

Draft Recommendation 6.6 The Australian Government should establish an Australian Pensioners Bond scheme to allow age pensioners to purchase a bond from the Government on the sale of their primary residence.

The bond would be exempt from the age pension assets test and income tests and would be indexed by the consumer price index to maintain its real value. All bonds would be free of entry, exit and management fees.

Age pensioners could flexibly draw upon their bond to fund living expenses and aged care costs.

Regarding draft recommendation 6.6, my concerns here are:

How easy it is to draw on the bonds?

Does the person have to justify what they are going to spend the money on - this could lead to people not getting what they need to get and from buying things that will make their lives a little more pleasant (as they are worried about what the bank manager will think of their spending plans) .

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Will there be a minimum withdrawal amount and if yes, will it deter people from withdrawing when they need to ie because the minimum withdrawal amount is greater than the amount they need or are comfortable with withdrawing?

Also, does a pensioner who has sold their primary residence HAVE to purchase an Australian Pensioners Bond?

Will a pensioner who has not bought an Australian Pensioners Bond be penalised (other than the usual assets tests) e.g. aged care facility choosing to do shopping for residents who have bonds ahead of those who do not?

And is there any other way (e.g. other than selling the primary residence) that older Australians can buy Australian Pensioners Bonds? If not, it is discriminating against those who do not wish to sell their primary residence.

In part, draft recommendation 6.7 states that *“The Australian Government’s contribution for the approved basic standard of residential care accommodation for supported residents should reflect the average cost of providing such accommodation and should be set: on the basis of a two-bed room with shared bathroom”*

The following words need to be added to draft recommendation 6.7 It is crucial “that the accommodation payment made by the Australian Government be sufficient to meet the FULL cost of providing an approved basic standard of accommodation” p 175 from the draft report

No-one should be forced to share a bedroom, it must be by choice only - see draft recommendation 4.1.

It is pushing people into potentially uncomfortable, undignified and embarrassing situations (don’t forget the only thing separating your bed from the rest of the room/residents and visitors, is a curtain) eg when I have had to share a bedroom when staying in an aged care facility for respite, the lights kept getting turned on throughout the night as nurses attended other residents in the bedroom. I ended up suffering from sleep deprivation.

One of the residents in that bedroom kept having very messy, foul smelling bowel accidents – the cleaning up by the nurses took at least 20 minutes, and even though the fans were on & all windows were open, the stench permeated the entire room and the corridor (used by other residents, visitors and staff). Two of the residents in this room were bedridden and had to endure all.

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In one aged care facility I have stayed in it is the practice, when a resident is no longer able to sit to go to the toilet, to give them an enema whilst they are lying on their side (in bed), on a sheet of plastic - no bedpan. Thus they are left to defecate involuntarily and remain laying in this excrement until the nurses return to clean them up (which could easily be a 10 to 20 minute wait). Where is the dignity in this??? And remember, there is only a curtain separating you from anyone else in the room. Farting noises and excrement smells do not recognise curtains as barriers.

Draft recommendation 6.7 needs to be revised to say "on the basis of a single room with shared bathroom (however, the supported resident may request [and be given] accommodation in a twin-share room).

A further concern about being supported by the Australian government is who chooses which aged care facility the supported resident has to go into?

This decision should be up to the supported resident.

However, if it is up to the government there should be some mechanism in place to prevent them from sending the resident into an aged care facility outside of the area where the supported resident's family and friends will comfortably travel to visit them.

Also, who pays for the living expenses of the supported resident? There does not appear to be any mention of this in the draft report.

Draft recommendation 7.1 which proposes the establishment of "*...a government-backed Aged Care Equity Release scheme which would enable individuals to draw down on the equity in their home to contribute to the costs of their aged care and support*"), is a **much more preferable option than selling the primary residence to fund aged care.**

For most people the idea of having to sell their primary residence to fund aged care would be absolutely abhorrent.

It is commonly and historically understood that "a man's home is his castle", with emphasis on the word "his" and no one (not even the Australian government) has the right to tell "him" what to do with his castle!

Furthermore, most people wish to keep the family property in the family from generation to generation.

My concern about the main thrust of this draft report (get older Australians to fund most of their aged care) is voiced in the following quote from p140

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".....public contribution **could drain the resources of middle-income families...**". (OECD 2005, p. 80)

Chapter 9 of this Draft Report (catering for diversity — caring for special needs groups), should include a sub-chapter on people with disabilities

I understand that the The Aged Care Act 1997 does not currently recognize it as a "special needs" group, however, as noted on page 50 of this report , there will be a large percentage increase in the numbers of people living with severe disabilities who are living longer and will require aged care.

There needs to be a recommendation that The Aged Care Act 1997 be amended to recognize people (who have aged with) severe disabilities as a special needs group

Young people with severe disabilities, in general, require much more nursing attention than the average frail person: see the following quote off the Federal government's website:

The type of care required for younger people with complex disability support needs is highly demanding in time and intensity. Often it will require particular sets of skills and a number of different professionals attending to an individual's needs. The skills and experience of staff in aged care facilities generally do not cater adequately to such needs.

<http://www.sport.gov.au/internet/main/publishing.nsf/Content/health-investinginagedcare-report-index.htm~health-investinginagedcare-report-13.htm~health-investinginagedcare-report-13-2.htm>

As the population of young adults ageing with severe disabilities becomes a population of older Australians with severe disabilities (OPWD) (note: these disabilities are additional to those brought about by the longevity effect discussed in Chapter 3 of the Draft Report), requiring aged care and as the Commission notes (p43) " The growth in groups that are likely to have distinctly different needs will affect the relative demand for different types of services."

Accordingly, there needs to be a recommendation that higher numbers of appropriately skilled nurses need to be employed (in addition to the usually employed number of nurses for the size of the aged care facility accommodating the old person/s who have aged with disabilities), in aged care facilities that accommodate 1 or more people who have aged with disabilities.

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Funding for such extra nurses could perhaps come from the National Disability Insurance Scheme (currently under investigation by the Productivity Commission).

There is a need to make provision in recommendation 9.2 to allow for extra cost involved in caring for people who have aged with severe disabilities.

Draft recommendation 9.2” *The proposed Australian Aged Care Regulation Commission (draft recommendation 12.1), in transparently recommending the scheduled set of prices for care services, should take into account costs associated with catering for diversity, including:...*”

Comments on chapter 11

There does not appear to be any connection made between the entirely inadequate number of nurses, poor working conditions, high turnover & early retirement of nurses in the industry and the main reason for this which is because of inadequate government subsidies!

Given that the Commission states " The Australian Government recently announced it will support the establishment of teaching nursing homes over four years (Australian Government 2010c). The Commission supports the direction of this commitment but considers the non-ongoing nature and the relatively small level of funding to be inadequate to address current and future workforce shortages in the sector." P370

Why isn't there a draft recommendation to address this situation?

Why is this not highlighted or boxed? Currently, the amount of attention this issue is given is pitiful - considering the importance of this issue - it could easily get overlooked.

In chapter 11 in the Key Points the Commission states "The formal aged care system currently faces difficulties in attracting and retaining workers. These difficulties are expected to intensify due to increasing competition for workers as the overall labour market tightens in response to population ageing." but there **admission that there is currently a shortage does not state that the shortage is extreme and does not highlight the issue and this makes it appear to be inconsequential.**

As I pointed out in my first submission, this inquiry cannot address what needs to be done in the future decades for the aged care workforce if it do not admit that there is a severe crisis now.

I am extremely concerned that the Australian government will get the wrong impression and nothing will be done to address this situation now! This will only make the crisis (extremely inadequate number of nurses in aged care facilities) even worse in the coming decades

According to the Commission "Improving the attractiveness of aged care and the quality of care....Improving the attractiveness of aged care and developing a sustainable workforce to meet future demand will require an integrated approach in a number of areas, particularly remunerating staff competitively, fostering a rewarding working environment (including better management), providing further opportunities for skill development (including increasing scopes of practice) and exploring the scope to source care workers internationally. p363

I realize that your list is not exhaustive however I do think that in the short-term (before the new funding arrangements in this report are implemented) a massive increase in government subsidies provided to aged care facilities in order to employ sufficient, adequately skilled nurses, ranks highly in how to improve the attractiveness of aged care and the quality of care and as such should be included in your "integrated approach" to improve the attractiveness of the aged care and the quality of care.

I still firmly believe that the story and poem of the "Grumpy Old Man" (see below) should be included in the curriculum of every nurse's (Assistants in Nursing, Enrolled Nurses and Registered Nurses) initial education/training.

The story and poem should also be clearly on display in the staff room of every aged care provider and residential aged care facility.

It is good to see that much better support of informal carers is embodied in the recommendations ie draft recommendation *11.1 should also assess the capacity of informal carers to provide ongoing support. Where appropriate, this may lead to approving entitlements to services and/or assisted referral for:*

- *carer education and training*
- *planned and emergency respite*
- *carer counselling and peer group support*
- *advocacy services.*

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Carer Support Centres should be developed from the existing National Carelink and Respite Centres to provide a broad range of carer support services."

However, I would like to point out one more anomaly in the support services for carers that needs addressing. The Commonwealth Carer Respite Centres count the 63 days respite (that carers are entitled to) as being in a FINANCIAL YEAR. Centrelink counts this in CALENDAR YEARS. This becomes problematic e.g. Centrelink recently regarded that my husband had 5 respite days left. The Carer Respite Centre said my husband had NO respite days left! He had to cancel one week off the next respite stay (as mentioned earlier, I will be going into an aged care facility in a few days)

This anomaly is particularly ridiculous as these are both Commonwealth Government departments.

There needs to be a recommendation Centrelink and Commonwealth Carer Respite Centres be made to count respite years in the same manner.

Also, informal carers who do not have assistance, in their caring role, from family or friends should be entitled to more than 63 days respite.

There needs to be a recommendation sole informal carers (carers who do not have assistance from family or friends) in their caring role should be entitled to 77 days respite per year.

draft recommendation 12.6 in part states " *The Australian Aged Care Regulation Commission (AACRC) should explore the case for embracing technological advances in receiving and transmitting information from and to providers in line with SBR. This could be facilitated by imposing a requirement that all providers submit key reports electronically to AACRC.*"

My concern with making all providers submit reports electronically is it could be problematic where:

- This causes financial hardship (e.g. the provider does not have the equipment to submit reports electronically and has to buy it) and this may cause other undesirable consequences e.g. the provider cannot afford to provide some services because they have had to spend the money on the equipment to submit their reports electronically.
- Staff may not have the skills required to submit reports electronically (causing much mental distress) and perhaps having to take time away from providing services to clients who need aged care in order to go and learn the skills required to submit reports electronically.

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(In previous employment [CSTDA MDS Worker for the Inner-West] I assisted disability service providers learn and undertake a new electronic system of reporting (HADS) to Dept of Ageing Disability and Home Care)

draft recommendation 12 7 "The Australian Government should amend the residential aged care prudential standards to allow residential aged care providers to disclose (to care recipients or prospective care recipients) on request, rather than automatically:

a statement about whether the provider complied with the prudential standards in the financial year an audit opinion on whether the provider has complied with the prudential standards in the relevant financial year the provider's most recent audited accounts."

This is good in that it gets rid of unnecessarily time wastage and resource e.g. paper and ink, use, however, it may engender a bad feeling between care provider and care receiver when a care recipient requests documented proof of the care agency's financial status.

Regarding the question of how much individuals should contribute to the cost of their aged care -

To achieve what the Commission suggests is the answer, "...the balance between private and public responsibilities should be based on what is sustainable, considered equitable and 'fair' by older people and the community more generally, as well as what represents value for taxpayers' money. (p154), **the following words should be added to the second bullet point in draft recommendation 14.1 "for example: addressing the question of how much individuals should contribute to the cost of their aged care"**

The first 2 bullet points of draft recommendation 14.1 "***In implementing reform, the Australian Government should:***

- ***announce a timetable for changes...***
- ***consult with providers, consumers, carers and government agencies on issues expected to arise from the implementation of the new system"***

I believe that draft recommendation 14,1 which also states (in part) that "***in implementing reform, the Australian government should:***

- ***establish an Aged Care Implementation Taskforce to oversee the implementation of the reforms and to liaise with stakeholders.*** should refer the reader to the relevant page in the final report that lists the Commission's suggestions on which government departments should be included in the Taskforce (p 451 in this draft report).

In conclusion, I would like to remind The Commission that although my submission talks mainly about what can or should be improved in this draft report

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(and this may sound like I did not like any of the report), I was actually happy with much of the report. And as mentioned earlier found it to be very thorough and interesting.

It must be remembered though that even if the recommendations in this report are acted upon by the Australian government and this whole new system is up and running successfully within a few years, this system will not work in a few generations time if it is to rely on the equity in or sale of a person's primary residence as many people who are currently in their 20s and 30s are renting as they cannot afford to buy into the housing market.

Lastly, I honestly believe that the term "aged care facility" must be changed.

The term "facility" is cold, impersonal, uninviting and sounds militarily.

Even the Department of Health and Ageing refers to "aged care facilities" mainly as "aged care services" or "aged care homes" (which is a much warmer, friendlier, less imposing and more inviting term than "aged care facility"!)

<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-rescare-index.htm>

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THE CRABBY OLD MAN

When an old man died in the geriatric ward of a nursing home in North Platte , Nebraska, it was believed that he had nothing left of any value.

Later, when the nurses were going through his meager possessions, they found this poem. Its quality and content so impressed the staff that copies were made and distributed to every nurse in the hospital.

One nurse took her copy to Missouri .

The old man's sole bequest to posterity has since appeared in the Christmas edition of the News Magazine of the St. Louis Association for Mental Health. A slide presentation has also been made based on his simple, but eloquent, poem.

And this little old man, with nothing left to give to the world, is now the author of this 'anonymous' poem winging across the Internet.

Crabby Old Man

What do you see nurses? What do you see?
What are you thinking when you're looking at me?
A crabby old man not very wise,
Uncertain of habit with faraway eyes?
Who dribbles his 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 sock or shoe?
Who, resisting 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 not looking at me.
I'll tell you who I am. As I sit here so still,
As I do 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 boy of Sixteen with wings on his feet.
Dreaming that soon now a lover he'll meet.
A groom 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 guide And a secure happy home.
A man of Thirty My young now grown fast,
Bound to each other With ties that should last.
At Forty, my young sons have grown and are gone,
But my woman'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 wife is now dead.

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I look at the future 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 now an old man and nature is cruel.

Tis jest to make old age look like a fool.

The body, it crumbles grace and vigor, depart.

There is now a stone where I once had a heart.

But inside this old carcass a young guy 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 open your eyes, people open and see.

Not a crabby old man Look closer see ME!!