* (Hanna)

Good morning, Senators, Staff and Members of the Public.

Thank you for the opportunity to speak and, hopefully, be heard.

I suffer from oromandibular dystonia, which causes the muscles of my face to go into spasm, making speech difficult for me, so please bear with me, and I hope you will indulge me if I go a minute or two over my allocated time.

My husband and I have travelled 800km to be here today. It's a long and expensive exercise, but I believe so strongly that this new Aged Care Bill will be extremely detrimental to the elderly citizens of Australia, that I was determined to attend in person.

I wanted to be able to see you face to face as I stand before you bereft. Bereft, because I fear for our future as we progress into old age. Under the current Act, although not perfect, it gave us a sense of security, knowing we would have the services necessary to enable us to continue living in our own homes.

1. First and foremost, the Aged Care Act was designed to give the elderly more rights and the ability to stay in their own homes rather than going into a nursing home. Under the new Act, this will be impossible. Our rights will be eroded! The new Bill appears to give providers more rights than the consumer. They even have the right to step in and petition the Guardianship Board to be allowed to take over the full care and financial management of a person over and above family members! They do this when they don't like complaints from family – complaints about mistreatment! Providers then have the power to ban family from visiting.

2. We need consumer choice and control!

   I asked members of the forums I belong to let me know what their main concern about the new Bill was, and overwhelmingly, their responses were one hour of cleaning per week is totally insufficient (it will actually be 2 hours per fortnight as the govt mandated we must employ support workers in 2-hour blocks!) and 18 hours per **year** of gardening is totally inadequate. There were over 100 responses. The other major concern was co-payments.

3. We will be living in squalor. Our houses will become progressively dirtier, our gardens more and more overgrown and unsafe.

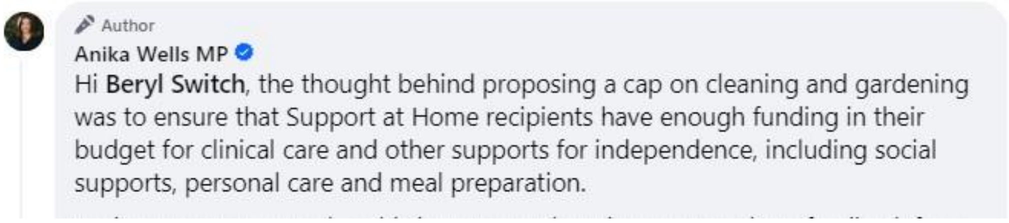
   As mentioned, gardening will be limited to 18 hours **per year!** Can you imagine the state of our gardens with so little help? In the northern parts of Australia, grass becomes overgrown in a week! At least in South Australia, it takes two weeks

4. The elderly will become more isolated - who would invite visitors into a dirty house?

5. There should not be any cap on any service! Everyone is an individual and has different needs.

6. Let the person who needs care determine what care they need. We need more autonomy, not less.

   Minister Wells said in a reply to a comment on her Facebook page (and I quote): …

   Anika Wells MP

   Hi **Beryl Switch**, the thought behind proposing a cap on cleaning and gardening was to ensure that Support at Home recipients have enough funding in their budget for clinical care and other supports for independence, including social supports, personal care and meal preparation.

   But most don't need clinical support! We can shower ourselves, most can prepare meals, and many can still manage their washing. What we can't do is gardening and heavy cleaning. Therefore, we need gardening and cleaning support! We need our windows cleaned, and 'spring cleaning'.

   I self-manage three packages: my husband's, mine and that of a friend who has dementia. Every month, our Provider, Trilogy Care, sends out a statement, so I know exactly what funds are available. They even have a portal where I can see funds and invoices in real time! How dare the Minister say she is trying to ensure we have sufficient funds for clinical care.

7. Every recipient of a Home Care Package has a Care Partner (I work with three). The Care Partner's role is to work with recipients or their advocates to manage the funds. Together, we work out a Care Plan and work out what services we need and what will fit within our budget. For the Minister to try to tell us how to suck eggs is disingenuous.

8. For every item we need, we are forced to get a clinical justification from an Occupational Therapist. Need a $30 shower chair, get a $600 OT report? Need a $20 walking stick or a pick-up-stick? A tipping kettle? Get a $600 OT report! We need autonomy and funding to be able to go and buy those items without interference from a provider or government. OT reports are bleeding our funds dry. If a provider doesn't deal directly with a supplier (such as Bunnings) we need to find the money ourselves to purchase the items – this sometimes means recipients are not able to get the items.

9. In the past we have been able to save funds in our package in order to buy high priced items. This will change under the new Act. Instead, there will be a loans system, so we won't be able to have new equipment. Instead, will be forced to have old equipment that has been used – possibly urinated and defecated on by previous users. The items may not be fit for purpose, we are individuals, different heights, weights etc.

10. The allowance of being able to carry over only $1000 per quarter is insufficient. What if there is a crisis and extra support is required at short notice?

11. Co-payments: how are the elderly supposed to fund co-payments of 17.5% for cleaning and gardening out of their Aged Pensions, which are already below the poverty line? We will be expected to contribute 5% towards the cost of having a shower! We are now being charged approximately $65 per hour for cleaning and gardening. Some pay more! Some other services are charged at around $120 or more per hour.
    Seventeen and a half per cent of $65 is $11.37. For two hours, $22.74. What pensioner can afford this, when we can barely afford to put food on the table? Have you heard there is a cost-of-living crisis? By the time we pay for electricity, water, council rates, rent, and insurance, there is nothing left. This is disgusting!

    I would love to sit down with the person or people who came up with these ideas!

12. Where was the consultation for this Bill? I attended a workshop facilitated by Craig Gear of OPAN, numerous webinars and read many documents: not once was there any indication that pensioners would have to pay! It was said the ‘wealthy’ would have to pay more. Are pensioners now considered wealthy?!

13. Many elderly have no family to assist them. Where will these unfair and inhumane caps leave them?

14. What about carers? How will someone looking after a loved one with dementia cope? A friend has a wife who is often incontinent – faeces and urine all over the bed 2 or 3 times a week, faeces and urine all down the hallway when they fail to make the toilet in time. All the extra load will fall on carers who are already at burn out and breaking points. Just when should they maintain their gardens and clean house?

15. So many changes have already been implemented, although Minister Wells constantly denies this. We are no longer able to claim for essential supplements from our packages: For instance, we used to be allowed to claim for vitamin supplements – they are expensive, but can be life-changing and life-saving. The Minister ruled they were no longer allowable. Lymphatic drainage and remedial massage are no longer permitted. Lymphatic fluid build-up leads to falls and considerable pain, but it's not covered if administered by a qualified masseuse – it has to be a physiotherapist or doctor! In rural areas, this is often impossible. Please ask me about these changes!

16. Are Senators aware that many providers are now requiring support workers, including cleaners and gardeners to provide 'Shift Notes'? These Shift Notes are to report to providers on the medical status of recipients: are they well? Have they deteriorated since last seeing them? Do you think they are coping? And so forth. These are gardeners and cleaners! People with zero medical training! This is an invasion of privacy and could be dangerous. Providers say this is a requirement of government.

17. We are told anything and everything we require in the way of items or service must be age-related or we cannot have it – this includes physio. My physio thought I was joking and burst out laughing when I told him. He wants to know, just when does old-age kick in?

18. We are not allowed to truly self-manage. We are infantilised and treated as though we all have dementia. It is demeaning and frustrating. We need to be allowed to truly self-manage our packages.

19. There should be the ability for family members to be employed (at reasonable, fair rates) to assist in the home. This is especially important in rural and remote areas where it is sometimes impossible to find support workers.

20. We virtually need permission just to live a reasonable existence!

21. These changes will lead to more pressure on hospitals and mental health services as the elderly fall into depression, become suicidal and injure themselves trying to do tasks that should be done by support workers

22. Suicide has already been mentioned on a number of forums I belong to. It's frightening and sad people are already losing the will to live – we don't want to be forced into substandard nursing homes (who can find $750,000 for the RAD – the refundable accommodation deposit that's no longer so refundable?!). We want to remain in our own homes. The new act will prevent this.

23. Will this be Labor's Robodebt in another form? Have we learnt nothing in recent years?

24. The new Bill regarding the RAD is a death tax by stealth! Allowing providers to keep 2% per annum of the RAD is anathema to those who spent their lives toiling to have something to leave their children. Aged Care should be funded by a Levy so that every citizen can look forward to being cared for appropriately in old age.

25. There is no provision for dental care: if a person is in a Residential Care Facility, the govt takes 85% of their pension. The remaining 15% is to cover medications (often many), clothing, toiletries etc. Where is it possible to find the money for dental treatment? We know poor dental health contributes to adverse overall health outcomes, including heart disease.

26. If you take nothing else away from my submission today, please force an amendment to remove the caps on services such as gardening and cleaning and remove the co-payment for pensioners.

27. The general consensus among the elderly is the new Bill amounts to elder abuse by the government

In summary, these are the points I would ask you to take away from this hearing:

1. **The new act is ageist and discriminatory**
2. **Recipients need autonomy in managing their own packages**
3. **They need funds available for purchases that need to be paid for upfront**
4. **They should be able to have as many hours of cleaning and gardening and other support as they need in order to stay in their own homes**
5. **Pensioners cannot afford and should not be expected to pay towards services that will help them stay in their own homes – after all, isn't this what HCPs were designed for?**
6. **The alternative is a tsunami of elderly needing nursing home beds – something none of us want!**

I implore the Senate – I **beg** you! – not to let this Bill pass into legislation! At the very least, please ensure there are amendments in place that will enable the elderly to have as much cleaning, gardening and social support/maintenance as they need and that we are not forced to contribute from our already insufficient pensions.

Thank you for hearing my submission today.

NOTES

The restrictions on hours of cleaning and gardening. It is not clear if these restrictions will also apply to social support and maintenance. Will there also be caps on those services?

The Bill caps cleaning at 52 hours per year. **That is one hour per week**! I don't know about you, but even in the fittest days of my youth – and I was extremely fit! – there was no way I could clean my house in one hour.

And then there are the **Copayments!** Again, I ask, is the Senate aware there is a **cost-of-living crisis?! We will be expected to contribute 17.5% out of our below-poverty line Aged Pensions for cleaning and gardening. We will be expected to contribute 5% towards the cost of having a shower! This is outrageous. It is unjust, unfair and disgusting.**

Minister for Aged Care, Anika Wells keeps saying people have to pay from their savings. What savings? They also have to maintain their homes at the same time. People run out of money. Many people, especially women, do not have the luxury of super.

Professor Kathy Eager stated this:
Fact: 80% of people who die aged 60+ have no superannuation left 4 years before death.

Fact: By age 85, only 20% of superannuants have balances of $50,000 or more.

So many women of this generation received next to no superannuation because it had not started or because it was denied them.

Most pensioners live from fortnight to fortnight. Like tens of thousands of other elderly people, we have little or no savings. We don't drink alcohol, smoke or gamble – although we do buy the occasional cross lotto ticket – we live in hope! We haven't had a holiday for about ten years – and that was one week in Victoria using Travel Auction deals.

By the time we pay for electricity (I'm still waiting for the $450 reduction in prices promised by Tony Abbott!), water, council rates, fuel, insurance and car maintenance and food, there is very little left.

The Minister, although denying it, has slowly but surely started eroding what we can have included in our packages. For instance, we used to be allowed to claim for vitamin supplements – they are expensive, but can be life-changing and life-saving. The Minister ruled they were no longer allowable. Her answer to me in response to questioning why was 'non-PBS medicines have never been claimable on the HCP'. I know that! We all know that. That was not my question. Politicians are very good at answering the question they wished they were asked, rather than answering the actual question they WERE asked

I need a range of supplements called 'The Protocol' to treat my cardiac medication, Perhexaline-induced peripheral neuropathy. The Protocol even gets a mention on the Mayo Clinic support pages. The Protocol has proven that although it cannot cure neuropathy, it can mean the difference between living in severe, chronic pain and being unable to walk, to not needing pain killers or terrible drugs such as Lyrica or narcotics and being able to function in everyday life. My doctor, an emeritus professor, no less, highly recommends The Protocol. Sadly, I can't afford it, so my condition continues to deteriorate and I will, sadly, end up in a wheelchair.

I am not permitted to pay for these supplements (a cost of about $150-$200 per month), from my HCP. However, the government will happily, on Medicare, at huge cost, amputate my legs, starting with my big toes, progressing upwards, amputate my feet and possibly up to my knees. What sort of care will I require then? A simple allowance to be able to pay for The Protocol supplements from my Aged Care Package would help prevent this! Sounds so simple and reasonable, doesn't it?

Lymphoedema and Lipoedema:
People who suffer terribly with painful fluid build-up because of Lymphoedema and Lipoedema are no longer covered because it's deemed as 'remedial massage'. A dear friend of mine and fellow Alumna from UTAS, who is here in the Gallery today, tells me lymphatic drainage makes such a difference – it prevents falls and makes walking less painful because the fluid builds up unevenly. It also builds up around her heart and in her lungs – lymphatic drainage is the only way to remove the fluid from her body. One treatment costs her $100 – she cannot afford that out of her pension, so, because she cannot pay for the treatment from her HCP, she can no longer have this vitally important treatment.

There was no consultation about these changes and the many more that were made during the past 18 months by Minister Wells