

Why are Home Care Recipients so Angry?

27th February 2023 Sydney NSW
Helen Bonyng

There has been a lot of anger in the home age care community recently, but what are they angry about?



They are ignored by Anthony Albanese MP, Anika Wells MP and Mark Butler MP. Letters and emails go unanswered and on social media comments are removed and they are blocked.

They want to be included in the new age care reforms due June 2024. They want to be part of consultations and listened to.

Nothing about us without us

A recent manual for Home Care Package (HCP) providers, January 2023 names certain exclusions.

A link to this manual is in the following article. [https://www.theguardian.com/australia-news/2023/feb/14/new-home-care-package-rules-limit-claims-but-labor-government-denies-they-amount-to-cuts?](https://www.theguardian.com/australia-news/2023/feb/14/new-home-care-package-rules-limit-claims-but-labor-government-denies-they-amount-to-cuts?CMP=Share_iOSApp_Other&fbclid=IwAR1e1DtF_1G4JGtWcp411OjW4DUdGGwG7WqExLycVuFAQhNnqJndnWopnHQ)

[CMP=Share iOSApp Other&fbclid=IwAR1e1DtF_1G4JGtWcp411OjW4DUdGGwG7WqExLycVuFAQhNnqJndnWopnHQ](https://www.theguardian.com/australia-news/2023/feb/14/new-home-care-package-rules-limit-claims-but-labor-government-denies-they-amount-to-cuts?CMP=Share_iOSApp_Other&fbclid=IwAR1e1DtF_1G4JGtWcp411OjW4DUdGGwG7WqExLycVuFAQhNnqJndnWopnHQ)

Anika Wells on numerous occasions has said that these are not new but are to make things clearer for providers. However we would like to give examples of these and why they are so important to us and should still be included.

1. HCP recipients would like to be able to claim maintenance and servicing of heating and cooling. Many receiving HCP have conditions which do not allow their bodies to regulate temperature. Eg SCI, MS, Parkinson's and MND plus ageing in general. https://www.theguardian.com/australia-news/2023/feb/24/inability-to-cool-homes-in-summer-heat-making-almost-90-of-centrelink-recipients-ill-survey-finds?CMP=share_btn_link

"Great leaders make it clear that they welcome challenges, criticism, and viewpoints other than their own. They know that an environment where people are afraid to speak up, offer insight, and ask good questions is destined for failure "

Travis Bradberry

2. They would like to retain the ability to claim vitamins, minerals, nutritional supplements and non PBS medications, many of which are recommended by medical practitioners to ensure better health and less likelihood of a hospital stay which would cost the government more money.

3. They would like to have help to make home gardens more accessible like raised garden beds. Mental and physical health is proven to be so much better when they can enjoy the outdoors.

4. They would like to get a swimming pool cleaned. This would save money on the transport and a physio to go to a public pool. Better value from their meagre funds, to say nothing of the health and wellbeing it would provide.

5. They love their pets, which give them great comfort, so would like to be able to claim for pet care which they can no longer do themselves. It is good for a person's mental health and wellbeing.

6. They would like to claim for a hairdresser and a manicure every few weeks, to enable them to get a haircut and keep nails healthy. This is all part of personal health and hygiene.

7. Lastly but by no way least there should not be a situation where recipients have to choose between care and equipment. This is the situation now as package funds are eaten away by the means test, fees and the constant reports required to say what you can and can't have. Every request needs a report for even the simplest items, often costing more than the item.

They ask that all the above items be funded by the HCP which is essential to keep older people in need of support at home, in relative comfort, thus avoiding entering residential care and saving the government a big chunk of the age care budget. Some may argue that such goods and services should be covered as everyday living expenses but many older people live from week to week and HCP recipients are already means tested for their contribution.

So is it too much to ask that as Australians get older they can still enjoy their lives? Everyone ages, it is a shock ahead for every living soul if this is how Australia treats its elderly. It is time to show respect and empathy and allow them to contribute to the decisions that affect their lives

You should be angry too.

For more information please visit <https://agedcarein-home.com/>

**Examples of the ‘lived experience’ of DoHAC’s January 2023 exclusions
for items and services for older Australians receiving Home Care Packages**

The Federal government through DoHAC issued updated guidelines on inclusions and exclusions for older Australians receiving Home Care Packages (HCPs) with effect from 1st January 2023. The intention of a HCP is for older Australians who are assessed with a serious medical condition, to remain at home longer rather than enter a residential aged care facility. In the long run HCPs save the government and taxpayer money.

These updated guidelines resulted in home care providers denying requests from HCP recipients and carers for necessary health-related items and services that previously had been approved. Most requests from recipients were accompanied by supporting evidence that the items/services were health-related and needed to maintain a reasonable quality of life while living at home with a medical condition and disability. Yet, the requests that were once approved, are now denied.

The Minister for Aged Care and Sport Anika Wells stated that “*the update was done after extensive consultation with industry*”, yet seeming to contradict this, also stated that the “*rules had not changed*”. The providers, supported the changes and through an industry spokesperson, blamed older Australians for ripping off their HCPs by spending on unnecessary items. However, prior to 1st January 2023 these same items were approved under previous guidelines by the providers as being necessary for older Australians, and presumably, the providers were audited by DoHAC for compliance with those guidelines. What a mess!

Forgotten in this administrative chaos, mismanagement and the word-games of press releases are older Australians living at home with serious medical conditions and disabilities. We receive a HCP to supplement our age pensions and help cover our health-related expenses, while trying to maintain a reasonable quality of life. In the Final Report of the Royal Commission into Aged Care Quality and Safety, Commissioner Pagone stated that “**there is no threshold under which the community should tolerate substandard aged care**”.

Here are stories of the **lived experiences of these “changes” to HCP guidelines and the substandard care** that is currently being imposed on older Australians. These lived experiences are from members of a self-managing HCP recipients forum (approx.1500 members) who wrote about the impact of these decisions on their lives since 1st January 2023. I’m sure that there are many others with similar lived experiences who have not yet voiced their concerns:

- **Excluded from HCPs: Heating and cooling eg Air-conditioning**

HT wrote: As a recipient of a level 4 aged care package, I wish to express my concern about one of the exclusions listed on page 68 of the recently released report 'Home Care Packages Program: Operational manual'.

The exclusion I am particularly concerned about is the one relating to heating/cooling. While this will be of concern to many older people for other reasons, this is of particular concern to me because I have Parkinson's disease and it is known that people living with Parkinson's disease (PLWP) are unable to control their body temperature because of their neurological disease.

**From members of Self-managed HCP internet forum
22nd February 2023**

In NSW, where I reside, the State govt. recognises this, as do many other Australian state governments, so they provide a rebate on the electricity bills for people with 'autonomic system dysfunction (medical conditions in which the autonomic system has been damaged, such as severe spinal cord injury, stroke, brain injury and neurodegenerative disorders).' They also provide electricity rebates for a person who 'has been diagnosed as unable to self-regulate body temperature when exposed to extreme hot or cold environmental temperatures.' They require a certificate from a doctor to confirm that someone has this condition. These rebates allow the use of the extra electricity needed to keep housing at a consistent.

This is the link where this information can be found:

<https://www.energy.nsw.gov.au/sites/default/files/2022-09/medical-energy-rebate-application-form-retail-customers.pdf>

For me personally this is of particular concern as I have no heating in my bathroom at present, and I had real problems with showering last winter when the outside temperatures where I live dropped to single digit levels. Not only am I unable to regulate my body temperature but I have rigidity and akinesia predominant Parkinson's disease and my Parkinson's disease is aggravated by the cold. This means when I get cold, I sort of seize up and am unable to move or my movement becomes very slow. I also live alone. I don't think it's rorting the system to say I need help to get heating in my bathroom before the next winter.

I had approval from my provider to get some heating in my bathroom last year, but I delayed doing this as I needed to save money from my package to get other equipment and use the money in my package for other things which I needed more urgently.

These other things I need to do are:

- Pay for an electric adjustable bed so I can elevate the head of the bed. As I also have gastroesophageal reflux disease (GORD). I have scarring in my lungs due to aspiration to which the GORD is contributing and it is important that I manage the GORD in a way that will prevent further aspiration.
- Improve disabled access to my backyard. I have fallen several times over the last six months and have been advised by OTs that to avoid further falls I need to use a walking frame most of the time. At present I cannot go into the backyard of my house as I need to use a walking frame and am presently unable to take a walking frame into the backyard, because the steps at the back of my house make the backyard inaccessible for me. I have delayed having this fixed for five months because several builders quoted prices of more than \$9000 to do this work and I have had to save money in my package over a period of time.

I was hoping to pay for these expenses first and then to have enough in my package for heating the bathroom by about April and have been delaying getting bathroom heating until then. Now it is an exclusion, and unless I can find money in my personal savings, I won't be able to get it done. I am concerned about my personal hygiene during winter, as I think showering will be very difficult for me unless the winter is very mild. Am I wrong to feel aggrieved by this?

I would like to ask that you consider allowing exceptions, to this exclusion for people who are unable to control their body temperature.

I am sure there are others who like me will have difficulties because of this particular exclusion.

**From members of Self-managed HCP internet forum
22nd February 2023**

MK wrote: I am so sorry that you are all going through this. I am also heat sensitive as a result of heart, lung, and blood issues and I couldn't get approval for the air-conditioner to be cleaned. I have had heart failure for ten years and have had numerous cardiac emergencies as a result. I have air-conditioning, but it's full of dead flies and grey crap comes out when I turn it on. The first time I turned it on, it spewed out a heap of black ash type crap that went all over everything. Result was an infection in the lung.

Given that they won't approve a professional air-conditioning clean I can't risk it, so I sometimes lay on the tiled floor and drink iced water to drop my body temperature. And they think that is OK for a 68-year-old woman!

The Minister says that restrictions will avoid inappropriate claims like air-conditioning and heating. Overheating for high-risk cardiac patients, as well as respiratory and haematology patients can be very dangerous if they don't have access to suitable cooling, i.e., air-conditioning!

LD wrote: Only someone medically trained should be making these serious decisions about health issues. A letter from a treating healthcare professional should be enough evidence that it is a life-saving issue. I have a letter from a specialist and it would have been approved last year if I was able to attend to it. Tried in January, now case manager is saying no, I cannot have it.

HB wrote: I have a spinal cord injury and I cannot regulate my body temperature so require heating and cooling all year round. I am not on NDIS as I was 6 weeks too old when it rolled out in my area. Therefore, I am on My Aged Care, which is woefully inadequate for someone with a disability. In fact, woefully inadequate for anyone. People had access to items like servicing air-conditioning before, and now they are taken away.

SO wrote: An OT report had reverse cycling air-conditioning marked extremely URGENT for my mother who is on a Level 4 Package. My mother's provider refused to do anything about it. 2¹/₂ years of absolute hell. My mother was forced to continually have OT reports undertaken which she was happy to do considering the provider hadn't done one from the inception of her contract in 2016. We are now in to 2023. Each OT report was marked as a major priority and the provider continued to refuse to acknowledge. I threatened legal action as she has a large sum in her Contingency Package they refused to allow her to use. Finally, after 3 years she has an entire house full of reverse cycle air-conditioning. I've just had my mother's air-conditioning cleaned and I paid for it. \$160 for one air-conditioner. Packages are no longer worth it.

Also took over 4 years to fight for a moving bed. At the end of 2022 we sacked the provider as the stress was too traumatic after they'd been deemed negligent. Levelled package elderly clients should never be neglected when an OT report has items marked extremely urgent. My mother is going blind, and the items identified four years ago and every year since have never ever been purchased. To this day the sight aides have never been implemented. It's absolutely appalling.

CW wrote: I have multiple sclerosis and it is currently 35 degrees C. As a result, I have to sit in my lounge room all day, where there is air-conditioning. I cannot do my daily bed exercises as the bedroom is too hot. Going to the bathroom is also difficult due to the heat. Once I get too hot, I have difficulty assisting my husband when he helps me transfer from the lounge chair to my mobility scooter, so he takes most of my weight. This situation occurs when the temperature is

**From members of Self-managed HCP internet forum
22nd February 2023**

over about 23 degrees C. I am going to have to ask for more air-conditioning to manage this problem. I never thought in a million years that heat would have such a huge impact on my life.

VP wrote: I have osteoarthritis throughout my whole body causing nerve damage to my spine and feet, which was made worse by cancer treatment. Radiation and Chemotherapy were followed by 1 year of Immunotherapy and on days 24 degrees C and over I am in terrible pain. My hands and feet feel like they are being held over hot flames. I am already on the highest amount of nerve pain relief and air-conditioning is the only other way to relieve the pain. I am lucky at the moment as I live with my sister, so I am not paying the bill, but she has to be careful of the usage with electricity being so expensive now. I dread when I move as I won't be able to afford air-conditioning.

DH wrote: I have peripheral neuropathy (non-diabetic) and osteoarthritis through my entire body. The neuropathic pain in my hands and feet is indescribable for a good part of most days and multiple times worse at night as I try and sleep. I rely upon a mixture of Gabapentin, Tramadol, plus CBD oil and the daily maximum of Panadol. I have to ration out these drugs so that I get maximum benefit from the least amount of drugs. I will presumably only have a couple more years to live and I need to be able to think into the future where I'm not a total zombie from medication. CBD oil is not covered by our packages or health insurance, and it is massively expensive. I have reached the stage where I have little choice anymore if I want even a few hours of sleep. I am fortunate that I was able to pay for installation of air-conditioning in my living room by extending a mortgage 12 years ago. Ditto when I had a very expensive repair done to it a year or so ago. How I pay for its replacement soon, I do not know. How I pay for maintenance, I do not know. Without the air-conditioning I would either be spending my days in a hospital to keep cool via their air-conditioning and refusing to move on from there because I become symptomatic of heat stress early in any heat exposure situation. I do not believe that the law-makers of this land have an even vague clue as to what it feels like to live in extreme pain, feeling like you are simply unable to think rationally due to pain and the sweat dropping off you, or the need to keep hydrated and the need to keep cool with ice blocks draped off you in bed at night where a fan is not adequate. Couple this with the distress of heat-related stupor and the need to rationally deliver serious drugs to oneself and it starts to look like a problem area where people will make medication errors. I wonder how many of those have occurred to add to deaths by heat in this land???? I was informed that my package level could not be raised as pain was not a disability covered by Aged Care. If not Aged Care, then by who??? Especially when some of the required medications are not PBS items.

SE wrote: My Dad's concerns are home maintenance and heating and cooling, as they relate to the whammy combination of dementia, end-stage kidney failure and extreme dual incontinence.

1. Your treating GP, OT, and/or Geriatrician should have a say and be able to override an exclusion on medical or functional safety grounds.

The care manager Dad had, 2 care managers before current one, said it had to be a specialist, (which is fine but can take 4 months to get appointment), but even a letter from Dad's treating Geriatrician was ignored.

2. Without a blanket exclusion ruling out something, a risk assessment approach should be taken. Is an incident risk or health issue worsened by this item or service NOT being provided? Was the service or goods being asked for caused by the client's condition e.g., in the case of dementia and breaking a light switch that needs replacing?

Regarding incontinence e.g., is the carpet a biohazard? i.e. urine soaked through to the foam underneath and cannot be cleaned.

Care workers will rightly refuse to work in such an environment, yet the exclusion manual makes NO allowances for damage caused by dual incontinence or home maintenance that needs to be completed and is unsafe due to dementia (ie damaged light fixture). - there are many safety examples here.

SW wrote: I have MS and cannot tolerate heat at all. It was 27 degrees today, too hot and humid for me to leave the lounge room or the house. Going to the bathroom or bedroom is difficult due to the hot rooms. It's not just getting hot for a few minutes, if you get hot then it takes quite a while to cool down on the inside, so to speak. When overheated my husband has to lift me up to transfer from chair to toilet and to bed, with me being unable to assist as I lose any strength I have. If he has to go out for an hour or so, I usually lie on the bed, but this is not possible in a bedroom with no air-conditioning. It will be awful over the next few days with temperatures over 30 degrees. OT has approved air-conditioning, but I have not applied it yet through provider. I am just hoping it will be approved.

- **Excluded from HCPs: Vitamins, supplements, non-PBS items**

DH wrote: Regarding magnesium. I have taken it for over 20 years for my cardiac health. The one time I stopped taking it for a bit I ended up in hospital with a pulse of 40 and so tired! Without any discussion, the minute I told the hospital staff that I had stopped taking magnesium, they inserted IV line with a dose of magnesium. It took exactly 25 minutes for me to say that I was ready to go home! It was like a miracle. The nurse lectured me on the need to keep taking my magnesium supplements.

My cardiologist agrees that for me and my strange heart issues, magnesium is critical. But even with his support I will not be able to get around this exclusion. For me this is a life-threatening situation and I'm really cranky about it.

KA wrote: My nan has multiple health issues including dementia, dual incontinence, a heart condition, mobility issues, and cramping in muscles.

She takes magnesium tablets to stop her from getting cramps and help her heart health. Is there a way for her to continue getting the magnesium that she needs directly for her health? Or, has the government put our loved one's health at risk with these new guidelines?

Previously, I was able to get most reasonable requests approved. I even have vitamins on an invoice that I submitted to the provider this week and I'm expecting it to be declined with either my Nan or myself having to foot the bill of almost \$200.

Magnesium and multivitamin tablets seem to have helped keep her health in good condition.

There must be a way for her to continue to take them.

PS wrote: While many things on the exclusions/inclusions lists are open to interpretation, because it is such a poorly thought-out document, non-PBS medications are clearly not allowed. I, like many others, take a medication which is essential to my health. It has been prescribed by a specialist doctor who has told me it is required, and without it I am in massive pain. It is essential to any kind of quality of life that I have at home. This is a small but important example of the absolutely incompetently written inclusions/exclusions, and there are many more examples from others. The provider has no more idea than I do about prescribing essential medications, yet they are the deciders of what is acceptable and what is not. As with many other providers, they say no for fear of having to cover the cost if their decision is wrong, and we are left struggling physically and mentally if we can't afford to pay for it ourself.

• **Excluded from HCPs: Other services/items**

MK wrote: I have severe arthritis in three of the five fingers on my right hand. I have had injections into the knuckles for it but to no avail. I need a food mixer because it's getting more painful to just hand mix something in a bowl. I have spoken to my provider who tells me she has doubts that it's now approvable under the package. I am not needing anything like an expensive model, just something that will do the job for me.

My doctor supports it, but the provider says it's unlikely. I have the funds in my HCP and it's less than \$100.00. These costs add up. It reminds you of where you're at when you can't do a simple kitchen task.

KF wrote: I have severe osteoarthritis and have had cancer treatment and spinal surgery There are so many things now that are excluded. It's taken me 3 months to get an OT report and if it was completed before the end of December 2022, I would now have vegetable pod for a garden which would help my mental and physical health.

ZL wrote: My husband is spending 3 weeks in respite, in a large well-known facility while I recover from an operation. After seeing conditions and staffing in this profit-driven place, I am convinced even more of the need for us to stay in our own home.

But it is very difficult, without willing family living nearby.

We don't like going, cap in hand, to beg for assistance. Then spend time and precious energy constantly justifying the request. But under the current "guidelines" this is what we are condemned to.

Minister Wells, would you subject your mother to this?

WH & CC wrote: last year I asked the Complaints commission about carpet cleaning and I was told it was a perfectly normal thing to have done, to maintain the health and life of the carpet. Not to mention my need due to chronic asthma and Bronchiectasis. That came from the commission and now it's denied. Please explain Minister Wells.

Update. Got a call today from the **Aged Care parliamentary team** who read from the "exclusions" section for carpet cleaning saying that as this is a professional qualified service and not covered due to its nature i.e. being carried out by a professional. Seems to me that you now need a Certificate or university degree to clean carpets. Totally laughable.

**From members of Self-managed HCP internet forum
22nd February 2023**

BSU @ SO wrote: A gardener charged \$1500 to my HCP for just 1½ hours work mowing the lawn without edge-cutting, without collecting green waste and throwing all weeds from the lawn onto existing raised garden beds.

My mother's package was hit almost \$4000 for bark put on garden by a contractor. Absolute day light robbery. When the provider was challenged about this, they did ABSOLUTELY NOTHING. The Aged Care Commission too did ABSOLUTELY NOTHING, when I reported the provider.

MO wrote: These are guidelines, they're not rules, they're not legislation!

We've read the legislation and highlighted to the department the flaws and the misinterpretations. A former Director of the DoHAC branch that looks after in-home care made a few changes to inclusions and exclusions in the guidelines following our representations, eg. including some nutritional and health supplements instead of just enteral feeding. However, she is now part of the Minister's advisory team.

She also accepted that gardening is not just about mowing and realised that it is part of our mental well-being. My herb and vegetable garden and orchids give me great pleasure, and help with my mental health and purpose to live at home. Things I cannot do anymore, but I can still give my support worker direction on how to do it, while I watch from my special chair.

Other home maintenance items such as dripping gutters and the damage they cause that can become a safety risk. Heating and cooling, refrigerator repairs or replacement to keep medication safe and prepared meals (what's the point of approving these frozen delivered meals, if they can't be kept frozen) or a microwave to heat those meals, washing machines for hygiene upkeep! And the list goes on and on!

Sure, some will argue that some of these requests are part of the normal home maintenance expenses, but most if not all of us are on a very limited pensioner budget which renders such essential purchases, unaffordable.

BC wrote: Many of us have serious medical conditions and/or disabilities which means that excluding many of these items and services presents a serious risk for us remaining at home, where the alternative is to enter a residential care facility. Isn't the intention of a HCP to keep us at home longer rather than going into an aged care facility? What an administrative mess!

LD wrote: I can barely walk. The physiotherapist and doctors say that I need to exercise in my pool, which I cannot use at present due to repair issues. I need repairs done on pool and the response from my case manager is: "The Government has recently made changes to the home care package guidelines and pool maintenance is on the excluded items list. Unfortunately, you will not be able to claim for maintenance or repairs".

SO wrote: My elderly mother's oven and stove no longer work. They are over 30 years old. Originally, she had approval to replace it from her HCP then the provider refused to come to the party. Frozen dinners in a microwave are NOT a healthy option. An utter disgrace. One way to kill off an elderly client is from malnutrition. All her vitamins and iron are extremely low, yet she cannot buy supplements under her HCP. Any reasonable person would think that this would be an extreme necessity for health and survival, and she has a sum of money sitting in her Contingency Package that they refuse to let her use.

- **Excluded from HCPs: General comments about exclusions since January 2023**

DC wrote: How are bureaucrats and politicians allowed to make decisions about what constitutes necessary equipment to enable vulnerable people to remain in their own homes? We jump thru so many hoops with medical and allied health professionals to have needs assessed, surely, professional advice should be the primary driver for how funds are spent. I'd be much more interested in examining the fact that the cost of goods and services doubles or triples when they are being funded by a HCP. This can't be considered as value for money...one of the key considerations for spending public funds. Older people deserve better.

MO wrote: denying someone in dire need of essential medical supplements, devices to help control their fluctuations of temperatures due to their health conditions, fixing a leaking toilet for essential human functions to happen, providing functional refrigeration to store not only lifesaving medication, but also the meals that are approved to be delivered frozen and are devoid of taste and often adequate nutrition as well, microwaves to heat those meals (or do you suggest they get consumed frozen or just cold and thawed on the kitchen bench, with bacteria multiplying in them), functional washing machines to keep up with hygiene when bedding gets soiled multiple times a day, and a dryer for when running out of sheets to give a bit more time for the carer to make up the bed again or see to more urgent matters such as helping with showering, toileting and grooming, rather than having hair remain scruffy, internet access subscriptions to be able to communicate with DoHAC and providers, raised garden beds that were used as an example by the My Aged Care website as something of value to include but is now excluded, and Minister, you say there are no changes?

Daily Telegraph 15/02/2023

Northern beaches couple Dot Waterhouse, 70, and her husband Chris, 72, said the changes had made it much harder to live at their home.

Mr Waterhouse, who has severe Parkinson's disease, needs several non-PBS medications such as Acidophilus, which is \$30 a bottle. The couple will now have to pay over \$800 a year on medications that used to be free.

Ms Waterhouse said any assistance to access the supplements stopped immediately, without warning. "It was absolutely overnight," she said. "People with Parkinson's have huge problems with their gut health, it can be life and death.

"The whole thing is just ridiculous, these are not people rorting the system, these are people who are elderly and sick trying to stay in their homes."

Compiled with permission by

Brian Corless

A self-managing HCP recipient

Email bcorless@shoalhaven.net.au

Home Care Packages and substandard care: A story of two Federal governments.

“The true measure of any society can be found in how it treats its most vulnerable members”

Mahatma Gandhi

For many years, through DoHAC, aged care in-home care providers were allowed to accumulate unspent taxpayer funds from Home Care Packages (HCPs), invest those funds and gain a direct return on that investment.

For example, members of a HCP internet forum reported recently that they had over a number of years accumulated sums of unspent funds from their Level 4 HCPs which was held in an account by providers, and some of these funds were used to purchase a few necessary services and items. Their requests were accompanied by supporting medical evidence and allowed them to have a reasonable quality of life while living at home with a severe disability. The providers presumably had access to the remaining unspent funds for investment purposes.

In 2021 the Coalition government through DoHAC estimated that **“Home care providers currently hold more than \$1.5 billion of care recipients’ Home Care Package funds”** and decided to shift the responsibility for managing the monthly balance of these unspent funds from providers to Services Australia. This would have been a significant reduction in the earning capacity of providers who no longer had access to large sums of taxpayer funds for investment opportunities and profits. In my opinion, this was a fair and reasonable decision, provided that HCP recipients were not disadvantaged and retained access to unspent funds for larger more expensive aged care items so that they could remain at home longer, rather than enter a residential aged care facility, and continue to have reasonable quality of life.

In January 2023, after “extensive consultation” with businesses, the Federal Labor government, through DoHAC, updated the HCP guidelines on “inclusions” and “exclusions” for funding, resulting in providers declining HCP recipients’ requests for items and services, more often. Minister for Aged Care and Sport, Anika Wells in media releases stated that *“this update was done after extensive consultation with the industry, which found that the existing manual was too vague and ambiguous”*. It also allowed providers to retain more unspent HCP funds in business accounts on a monthly basis for investment purposes, perhaps offsetting the loss of access to those large amounts of unspent funds that were previously available.

There was no mention by Minister Wells of “extensive consultation” with older Australians living at home and receiving HCPs because this did not happen. DoHAC conducted some token attempts at consultation, featuring bureaucratese and webinars for “consumers” during 2022, but the true effect of these “changes” was unknown and unexpected for most HCP recipients. Not surprisingly, many of us who self-manage our HCPs were shocked when in January 2023 providers began declining reasonable requests for necessary health-related items and services, that previously they had approved.

Yet, seeming to contradict herself, Minister Wells also stated that despite the guidelines update, *“the rules have not changed”*. In any English dictionary “update” is defined as “change” (a synonym is “revised”, meaning “to change or alter”). And certainly, HCP recipients are bearing the brunt of those DoHAC-inspired “changes” in reduced access to much needed items and services since January 2023, despite providing supporting evidence that many of these items and services are health-related.

The intention of a HCP is to help older Australians stay at home longer, rather than enter a residential aged care facility. A HCP saves taxpayers and the government money in the longer term. This aspect has been lost in these punitive changes and the semantics of media releases.

The provider lobbyists were pleased with the decision of the Labor government and DoHAC. Lorraine Poulos, an industry spokesperson said on 15 January 2023, **“The updated home care packages program guidelines give much more clarity to providers about what can and can’t be purchased”**.

However, rather than bite the government-hand that feeds it, the provider industry took the moral high ground and chose to demonise and blame older Australians for previously rorting their HCP claims. Ms Poulos continued **“Some clients viewed their home care packages program as a bank account to purchase goods and equipment rather than support for care.”**

Furthermore, laying the blame squarely on older Australians, Ms Poulos added, **“I think taxpayers would query some of the previous purchases that have been allowed through a home care packages program, particularly with people with much higher acuity levels wanting to stay at home.”** A strange choice of words by an industry spokesperson, given that acuity refers to **“the ability to hear, see or think accurately and clearly”**. These are leadership qualities and are clearly missing from the provider industry, DoHAC and the Federal government.

Bearing in mind its previous ready access to large amounts of taxpayer funds, this statement comes from an industry about which the Royal Commission on Aged Care and Safety commented **“there has also been a rapid expansion in home care providers, with limited scrutiny applied to their suitability”**. Could it be that the profit motive rather than the care needs of older Australians is foremost in the behaviour of government and industry? Some have even said that the in-home care provider industry has had its snout in the lucrative aged care trough for many years, and it now wants to attribute blame for ripping off HCPs to those older Australians who are most vulnerable and most in need.

Commissioners Briggs and Pagone noted in the 2021 Final Report of the Royal Commission into Aged Care Quality and Safety, **“at least 1 in 3 people accessing residential aged care and home care services—or over 30%—have experienced substandard care”, and that **“there is no threshold under which the community should tolerate substandard aged care”**.**

While the in-home care provider industry continues to blame older Australians, many with severe disabilities, we continue to experience **substandard care** as requests for necessary items and services are denied by these providers, empowered by government and DoHAC. Meanwhile, the government through Minister Wells and DoHAC, sits on their hands. These punitive measures will have serious and potentially life-threatening consequences for the health of many older Australians.

Since January 2023, more of us are becoming more anxious and fearful about what these “changes” to HCPs mean for us, our carers and our families. If you have a chronic and complex medical condition, the last thing you need is the stress and worry of wondering whether you can continue to stay at home, or to start looking now for an aged care facility. As Commissioner Pagone stated about substandard care, **“People receiving aged care deserve better. The Australian community is entitled to expect better”**.

What’s difficult for the government and DoHAC to understand about that?

Brian Corless

A self-managing Home Care Package recipient.

Email: bcorless@shoalhaven.net.au