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**Key Points: A Survey on the Mental Health of Home Care Package
Recipients and Carers following changes in Aged Care in 2023/24.
March 2024.**

*Have a number of older Australians in need of assistance given up
on the Aged Care Home Care/Support at Home Programs?
or have they given up on life, itself?*

These are the key points from the results of an online survey of the psychological health of Home Care Package (HCP) recipients and their carers.

Background:

Aim the HCP program: Provide funding for older people with complex needs to enable them to remain at home rather than enter a residential aged care facility.

During 2023 and 2024, a number of policy and proposed legislative changes in aged care impacted on older people receiving HCP funding, leading to increased reports of significant levels of distress for those living at home, including suicidal ideation.

Changes included:

- The Department of Health and Aged Care published the “*Home Care Packages Program Operational Manual: A Guide for Home Care Providers*” (known as the “*updated guidelines*”) in January 2023, with a subsequent publication and webinar on HCP “*Program Inclusions and Exclusions- FAQs for Providers – version 1*” in April 2023.
- A stricter and universal approach by the Australian Quality and Safety Commission (the Commission) to regulating providers who supervise HCP funds, regardless of the individual circumstances of HCP recipients and carers who access those funds.
- Release of the Exposure draft Bill for a new Aged Care Act, published in December 2023, including the removal of all references to consumer-directed-care (CDC) from the current Aged Care Act. CDC is an internationally evidenced model of aged care and part of Australian aged care since 2015. CDC is the theoretical foundation upon which the model of self-management of HCPs in Australia, rests.

The *updated guidelines* resulted in **more providers declining requests from recipients and carers for services and items from their HCP funding, more often**. Anecdotally, this created significant hardship for many HCP recipients and their carers, and reports of this distress increased on social media and aged care forums, including reports of suicidal behaviour.

The stricter and unitary approach to auditing providers by the Commissioner resulted in at least one provider, who offered clients self-management of their HCP, being sanctioned for not providing more monitoring and oversight of workers engaged by HCP recipients e.g. gardeners, cleaners etc. That provider has since closed the business and left the aged care sector.

The assumption underlying the Commission’s approach for mandatory surveillance by all providers of HCP recipients, is that **all older people cannot be relied upon to manage their workers at home without being subjected to elder abuse. There is no dignity of risk or choice for older people who capably self-manage their funding and workers, to opt out of this mandatory surveillance**, and it seemingly constitutes an ageist and thus discriminatory practice. Not surprisingly this has been very distressing for HCP recipients and carers who value their human rights, autonomy and sense of self-determination.

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Finally, the Exposure draft Aged Care Bill released to the public just before Christmas 2023, when politicians, bureaucrats, legal advisors and others went on leave, resulted in older Australians trying to understand a complex legislative document with little assistance from policymakers or others. Over this period **older people reported feeling anxious, uncertain and fearful of the consequences of the new Act**. As if to reinforce this anxiety, a number of experienced social commentators and researchers have since questioned aspects of Bill as not being in the best interests of older Australians. The Government has since announced that it is delaying the presentation of the Bill to Parliament, for now.

Examples of reports on social media and forums of the impact of these changes included:

I am a full-time carer for my elderly mother who has dementia and is paralysed from a stroke. She requires daily laxatives, suppositories and enemas, which I administer. The provider has told me that, under the new guidelines, these bowel-movement inducers are not covered from her HCP. This is on top of a sequence of other exclusions over the past year. Why, Minister Wells, has your government adopted such a paternalistic attitude to aged care? What if it was your mother?

After 20 years of taking magnesium supplements for my cardiac health, I stopped because I can't afford to buy them. I ended up in hospital with a pulse of 40 and so tired! The minute I got to hospital, staff inserted an IV line with a dose of magnesium. It took 25 minutes for me to say that I was ready to go home! It was like a miracle. My cardiologist agrees that for me and my strange heart issues, magnesium is critical. But even with his support I won't be able to get around this exclusion. For me this is a life-threatening situation and I'm really upset and worried about it.

I am a 64 y/o fulltime carer of my 96 y/o mother. I have been lucky to have found some great support staff through my mother's Self-Managed HCP which have helped me clean the house, maintain the lawn, prepare some meals for my mother and do some minor plumbing. But I have lost them all over the last couple of months because of the excessive compliance demands and regulation by the government. I fear that I will now be forced to go for a Full-Managed HCP, but I have been there before and all it means is zero control or say, unreliable staff, extremely excessive fees and ongoing stress. Why can't I choose the staff I need without all this government interference? I am a very committed and capable carer. I need to be supported, not treated like I am incompetent.

I am a carer for my father-in-law. He has multiple amputations on his feet. He melted the skin off his foot from being next to a heater trying to keep warm (he couldn't feel the burning). He spent months in and out of hospital recovering, then months in a wheelchair. We were funded for an air conditioner, but the exclusions cruelled that. I can't guarantee that it won't happen for him again.

The survey

An online survey of 142 HCP recipients and carers was undertaken in January 2024.

They completed the Kessler Psychological Distress Scale (K10), the brief Older Persons Quality Of Life Questionnaire (OPQOL-brief), demographic questions and questions about the impact of the "updated guidelines", and the stricter regulatory approach towards HCP funding.

Of the 142 participants, **44% were HCP recipients and 56% carers, 89% were female and 11% male, 77% of recipients self-identified as having a disability and 33% identified without a disability, 65% self-managed**

their HCP and 35% were fully managed by a provider. The age range of most recipients was 65 years to 84 years (37%) whereas most carers were under 65 years of age (39%).

Psychological distress:

Overall, on the K10, 72% of recipients and carers reported on the K10 “Very High” (53%) to “High” (19%) levels of psychological distress, 21% reported Moderate levels and 7% reported low levels of distress.

Figure 1: 41% of carers and 31% of recipients reported “Very High” to “High” levels of psychological distress.

Clinical cut-off scores reflecting DSM-V criteria (Vasiliadis, 2015), show that:

- For carers, 70% reported features of major depression.
- and, over 80% reported features of minor depression.
- For recipients, over 65% reported features of major depression.
- and, over 80% reported features of minor depression.

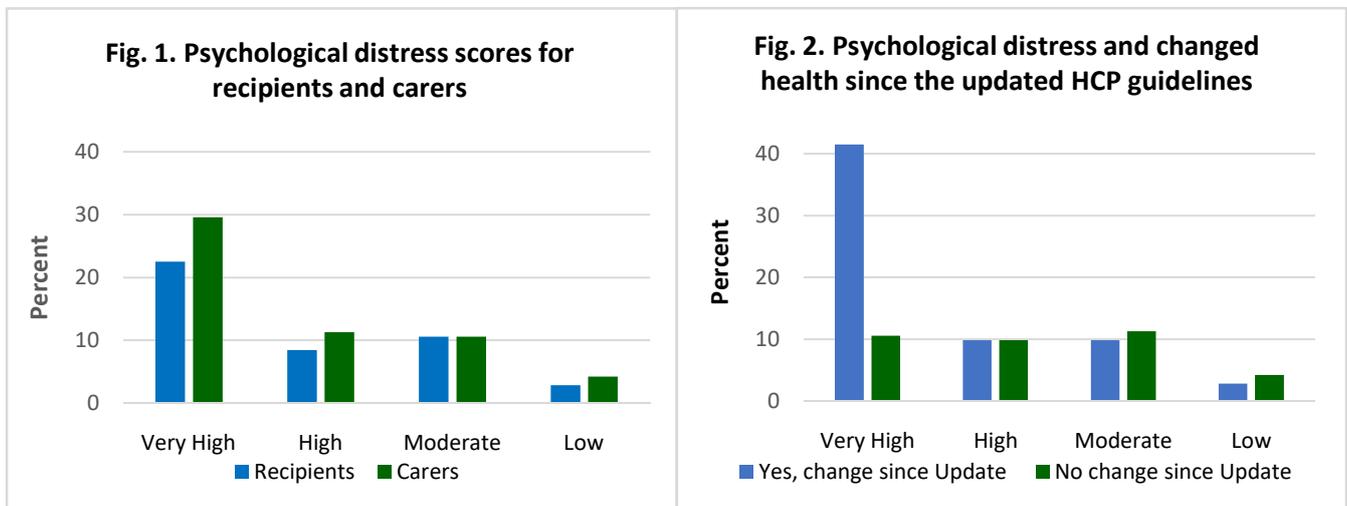


Figure 2: Question on changes to guidelines: Has there been a noticeable change in recipient’s mental and physical health since the January 2023 “updated HCP guidelines”?

- For recipients and carers, 65% said that there had been a noticeable change in recipient’s health since then.
- Of those, 80% rated “Moderate” to “Very High” levels of psychological distress on the K10.
- Those who reported a change in health since the guidelines reported significantly more psychological distress on the K10 (M=32.08, sd=9.78) than those who reported no change in health following the updated guidelines (M=24.61, sd=8.42, r=-0.367), z=-4.38, p<0.001).
- Most of this difference in psychological distress was attributable to “Very High” K10 scores.

Quality of Life:

Figure 3: The OPQOL-brief is a measure of quality of life (QoL) in older people. A question about quality of life “as a whole”, resulted in:

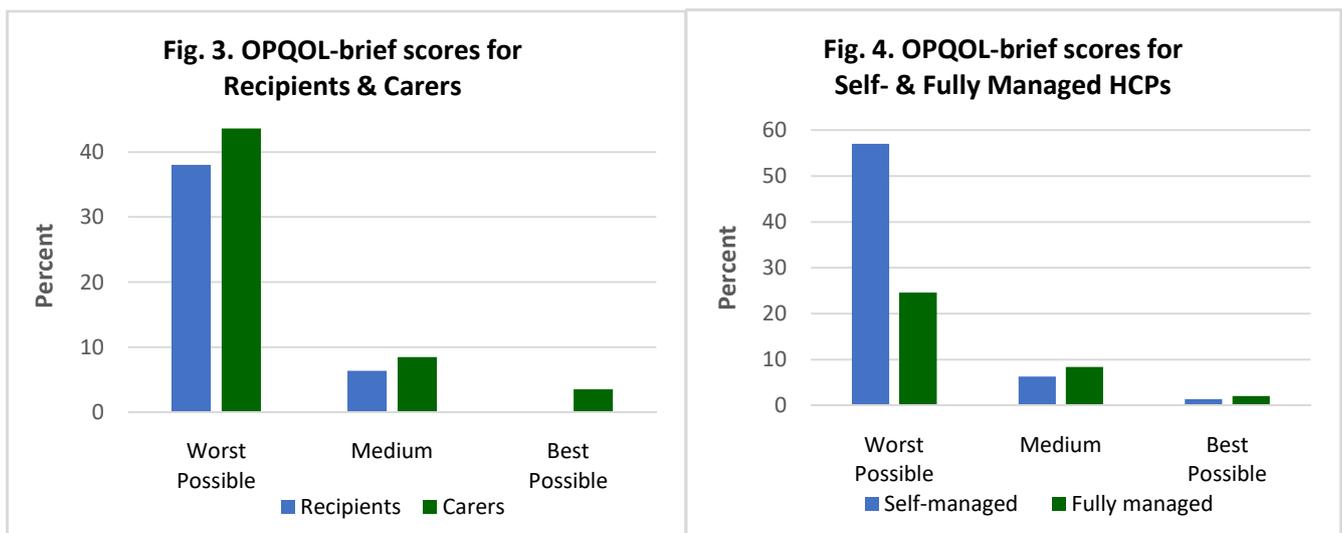
- 45% of carers and recipients rating their QoL on the whole as “Bad” or “Very Bad”;
- 35% rated it as “Alright”;
- 20% rated it as “Good” or Very Good”.

Summed total scores for the OPQOL-brief showed that:

- 82% of recipients and carers rated their quality of life as “the worst possible outcome”.
- No recipients and 4% of carers rated their quality of life as “the best possible outcome”.

Figure 4: Comparing those who self-manage their HCP and strive for more autonomy and self-determination over their funding, compared to those who are fully-managed by a provider who recruits, engages and schedules workers for HCP recipients:

- 60% of self-managed HCP recipients and carers rated their QoL as “the worst possible outcome”;
- For both self-managed and fully-managed HCP recipients and carers, 3% rated their QoL as “the best possible outcome”;
- Compared to OPQOL-brief normative scores for older adults, both self-, and fully managed groups experienced a worse quality of life than older people of a similar age (Kwaamba et al., 2015).



Analysis of Qualitative Data:

- *The “updated guidelines” for providers*

Question: How have the updated guidelines impacted their lives?:

- 79% of recipients and carers reported that the updated guidelines had impacted their lives.

A content analysis of the responses of those people shows increased levels of distress associated with the:

- confused and inconsistent application of the guidelines by providers;
- exclusion of medically necessary medications and supplements;
- restrictions on home maintenance and basic repairs;
- the negative impact on quality of life;
- lack of understanding by government of individual needs;
- the enforcement of the exclusion of non-PBS medication from HCP funding was the reason that many older people are going without essential medication and their physical and mental health is suffering accordingly.

Question: What would like to see changed in the guidelines for providers?:

A content analysis of responses showed that recipients and carers want:

- greater autonomy over the allocation of funds;

- a more flexible approach, including the setting of precedents for approving funding in exceptional circumstances;
 - the inclusion of essential items for living;
 - reduced bureaucratic hurdles;
 - restoring and maintaining the dignity of participants and a better quality of life.
-
- *Surveillance – “oversight and monitoring” at home by providers.*

Question: How much monitoring/oversight by providers of participants’ health and safety do recipients and carers want in their homes?:

- 87% said that they wanted “provider surveillance” to occur on “no occasions or rarely/sometimes”.

Question: Do recipients and carers want more or less regulation of support workers by a Provider in their home?:

- 88% of recipients and carers wanted either “less regulation or no change”.

Clearly, mandatory surveillance by providers of all recipients in their homes, and more regulation of support workers is not what participants in the survey want.

A content analysis of the impact of mandatory oversight and regulatory behaviour showed that recipients and carers are distressed by:

- a perceived loss of autonomy and freedom of choice;
- excessive regulation and bureaucratic hurdles;
- mandatory reporting by support workers of recipients to providers without recipients’ or carers’ knowledge or consent;
- impact on mental wellbeing;
- additional regulation and greater difficulty finding support workers in rural areas, with more regulation.

Conclusions:

The impetus for this online survey was threefold and came from increased reports of significant levels of distress on social media and aged care forums, following:

- the “updated guidelines” and “inclusions and exclusions FAQs” for providers in 2023.
- the stricter and one-size-fits-all approach by the Quality and Safety Commissioner late in 2023, and
- the rushed publication of the Exposure draft Bill for a new Aged Care Act in late December 2023.

A majority of HCP recipients and carers surveyed (n=142) were significantly distressed by these policy changes. This level of distress persists today.

Alarming and severe levels of distress among HCP recipients and carers should be treated as a warning sign for government, medical and health professionals to act and address the emotional toll of these changes on older Australians.

53% of recipients and carers reported “Very High” levels of psychological distress on the K10.

“Very High” levels of distress on the K10 should flag the need for further assessment and the presence of suicidal ideation. (Rainbow et al., 2023).

Factors such as burdensomeness, financial wellbeing and belonging, compound this “Very High” risk.

Carers needs are often overlooked. Given that over 80% of recipients reported the presence of features of clinical depression on the K10, **the significant personal and emotional cost to carers is reflected in 80% reporting features of clinical depression.**

82% of recipients and carers rated their quality of life as “the worst possible outcome”, with no recipients and 4% of carers rating their quality of life as “the best possible outcome”.

These results are alarming for older Australians and their carers living at home and receiving HCP funding.

Much of this psychological distress and poor quality of life is a consequence of government policy that has introduced harsh funding guidelines, strict and discriminatory surveillance by the Safety Commissioner and a perceived loss of autonomy and control in the lives of older Australians.

Given that the aim of Support at Home funding is to keep older people at home longer, rather than enter a residential aged care facility, the results of this survey shows that in terms of very high psychological distress and poor quality of life, the government is undermining its stated aim.

Most HCP recipients and carers are aware of the need for financial compliance, accountability and fiscal responsibility when receiving taxpayer-generated funding. The majority of older people receiving HCPs want to stay at home and they generally behave with restraint and good sense in regard to the spending of those funds. However, a marketized and profit-driven aged care sector has been handed a policy regime where providers are declining requests for services more often and inconsistently, and thus retaining more funds to invest for profits. Together with a Safety Commissioner who applies a strict, ageist and mandatory one-size-fits-all approach to regulation, increasingly makes it more difficult each day for older people to stay at home and not enter residential aged care.

Recommendations:

Encourage more not-for-profit organisations to become involved in the aged care sector. These organisations, such as cooperatives, generally have a values-based, humanitarian approach to aged care rather than seeing older people as commodities from which to drive profits. As well, local government has relinquished its role in aged care, yet maintains its organisational structures to service regional, rural and remote areas and should be considered as an option for those residents.

If the government has a duty-of care towards all of its citizens, and has assumed that duty for older Australians, we believe that it needs to act now to remedy the distressing set of circumstances that has created this alarming level of distress. We recommend that the government urgently:

- Provide a counselling helpline, independently funded and run by an independent organisation that has the capacity and training in counselling to understand and act on the stories of older people in distress, e.g. Lifeline, Beyond Blue, etc. We believe that neither COTA nor OPAN have the skill set for this or are appropriate organisations to offer this service.
- Adopt a more flexible and individualised approach to the spending of HCP funds for those living at home, such as allowing precedents to be set for the purchase of medically supported services from funds in exceptional circumstances. These precedents are to be published on a publicly accessible website, with explanatory information and searchable metadata for universal reference.
- Also, as occurs in the commercial world, a discretionary allowance would address many of the challenges for governance. A set, non-accumulative discretionary monthly allowance would empower individuals to use this support on services that would address their individual and unique needs.
- Offer the choice to opt out of mandatory surveillance (a dignity of risk approach) for those recipients and carers who have the cognitive capacity to protect themselves against elder abuse and choose to do so. Many older people who self-manage a HCP have been doing that all of their lives and want to continue to do so.

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- Include specific references to consumer-directed-care as the model underpinning self-management of Support at Home funding (Laragy & Vasiliadis, 2020; 2022).
- Encourage more involvement of not-for-profit values-based service providers, such as cooperative organisations, to play a role in aged care, particularly for those who live in regional and remote areas.
- Encourage more involvement of local government in aged care, with its potential links to Primary Health Care Networks, to better serve the physical and mental health of older Australians receiving HCPs.

As the saying goes, *the true measure of a society is how it treats its most vulnerable*. The important question for government is: will it measure up to this challenge while ensuring self-determination and autonomy for older Australians receiving a HCP and their carers? Regardless of the answer, the “Very High” levels of reported distress and poor quality of life in this survey, indicates that the clock is ticking, and a proactive approach is needed urgently.

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