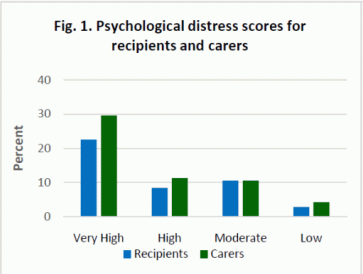
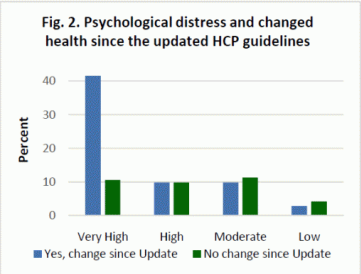
Summary of Results of a Survey on the Mental Health of Home Care Package





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.

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."

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 discretional allowance would address many of the challenges for governance. A

set,non-accumulative discretional 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.

- 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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