

Do Home Care Packages improve carers' lives?

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Home Care Packages aim to provide support services to older people who wish to continue living in their own homes. Many of these individuals also receive significant amounts of care and support from family members or friends who may also indirectly benefit from the Home Care Package. With the introduction of Consumer Directed Care and an increasing emphasis on person centred, individualised service provision, carer advocacy groups, including Carers NSW, have raised concerns that such changes risk eroding the autonomy of informal carers and restricting a carer's right to be supported in their caring role. Carers NSW has attempted to track the progress of these reforms in the Carers NSW 2016 Carer Survey, and will continue to do so in subsequent surveys and our ongoing advocacy work.

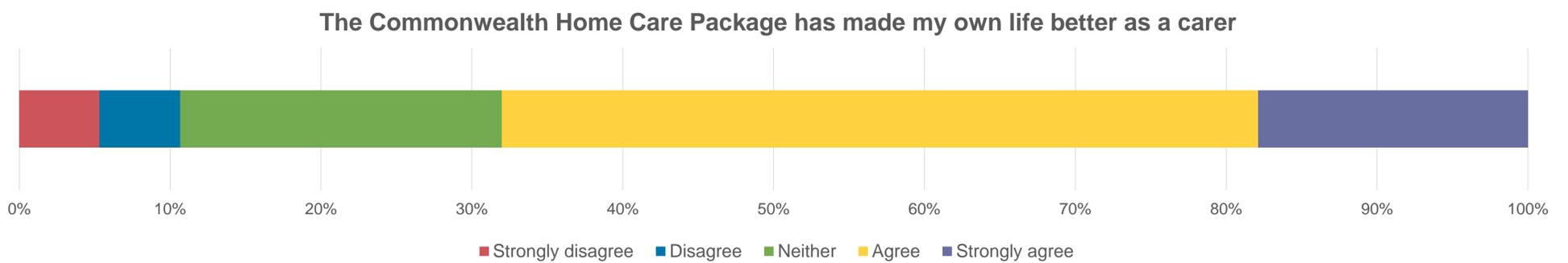


Figure 1. Has a Home Care Package improved your life as a carer?

Most carers benefit from Home Care Packages

Carers NSW conducted a survey of NSW carers in April 2016, less than a year after Consumer Directed Care (CDC) was applied to all Home Care Packages (HCPs). Carers were asked if their care recipient's HCP made their own lives better and a significant majority agreed and strongly agreed with this statement (Figure 1). Qualitative responses from the survey indicated that HCPs enabled carers to sustain their caring role, continue employment or engage in social and personal wellbeing activities.

"Without home care support I would seriously contemplate abandoning her."

"It has allowed me to continue doing some activities which I consider important to myself."

"I would not be able to have a job, or my own family, if it was not for this package."

Ongoing and Future Challenges

Too little too late

Department of Health data indicates that wait times for a HCP exceed 12 months and as of July 2017, 85,000 people were on the waiting list to be allocated a package at the level they were assessed for. Lack of information as to when a package will eventually be allocated can affect a carers ability to plan for interim care arrangements while they wait. This uncertainty and long wait times put pressure on carers to leave paid work in order to provide ongoing care or enter the care recipient into residential aged care prematurely. Since the Carers NSW 2016 Carers Survey, the HCP waiting list is now managed nationally by the Commonwealth and the My Aged Care call centre has begun to provide estimated waiting times. While this transparency is welcomed by carers planning for the immediate future, without a significant increase in HCP availability, waiting times are unlikely to change.

"Their standards are not as high as mine."

"The hours provided are not enough to make my life better."

"I have had appalling services provided at times, that just made everything harder"

'Sharing' a package

CDC has in many ways positively increased the autonomy of care recipients and encouraged engagement through consumer choice, however individualisation has arguably increased carers' dependency on the person they care for. Carers are not entitled to home care, service coordination and case management in their own right and must depend on the assessment and cooperation of the care recipient for support. Furthermore, the limited funds of the HCP must be negotiated between the provider, carer and care recipient, meaning that to increase services that benefit the carer, funding would need to be reallocated from other services within the package. Minor improvements to support carer autonomy have included reinforced guidelines to clarify the role of representatives and increased options for carers to register as a representative but carers still rely on the recognition of their care recipient to be included in their own right.

Quality concerns

Of the carers who felt that the HCPs did not improve their lives, poor quality of service, inconsistencies of staff and understanding the system were key themes amongst negative responses. Carers felt that services did not benefit them if they had to constantly 'retrain' new staff on how to care for their care recipient and navigate their home as well as foster trust with inconsistent casual staff. Unfinished or inadequate domestic assistance was a particularly common concern.

Conclusion

For the most part, carers' lives are improved by their care recipient's HCP. However, a significant number of carers are still waiting for their care recipient to receive a package, and that the only way a carer can receive certain subsidised services to support them in their caring role is through services designed to support their care recipient. Arguably, ongoing aged services reforms have increased carers' dependence on their care recipient and the limited number of HCPs and lengthy wait times can mean that carers are faced with dropping out of work or relinquishing care. While some reform measures to increase transparency and retrospective additions to representative arrangements have been implemented, Carers NSW will continue to monitor the progress of HCPs in subsequent carer surveys and advocate for better accessibility to services for carers and increased autonomy over supports designed to benefit them such as respite, case management and care coordination.