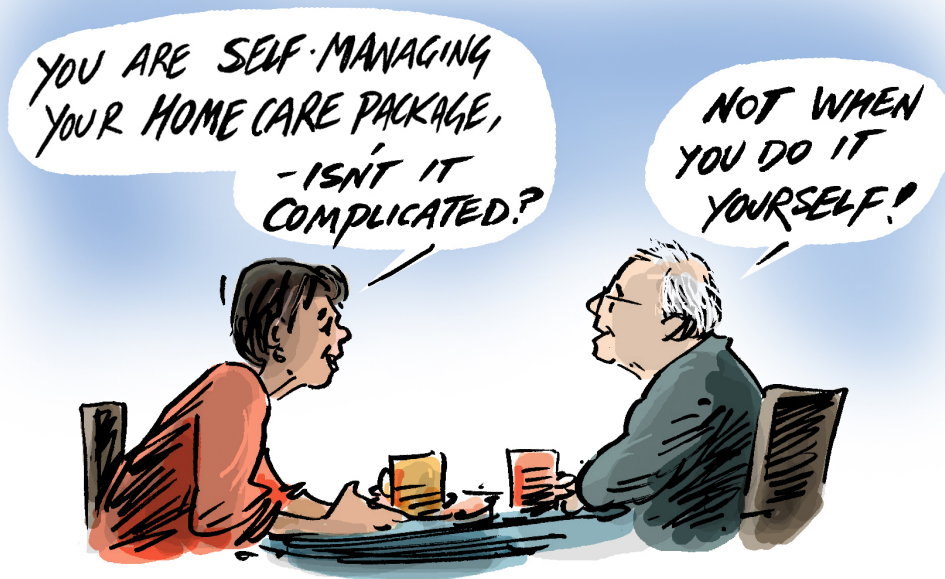


# Consumer experiences of self-managing a home care package



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# Consumer experiences using a self-managed home care package

Research report October 2021

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I offer my deepest thanks to those people who so generously shared their insights of self-management. I also wish to acknowledge the robust discussion of the pros and cons of self-management in my Facebook group “Self-Management of Home Care Package for Consumers Only”. Over the past year, members of this Facebook Group have assisted each other to self-manage.

I undertook the current research project in a voluntary capacity because an honest public discussion about self-management needs to include what is good and not good about self-management. Policy makers also need to listen to consumers about how self-management can be improved.

This study did not receive any funding.

## Executive Summary

This research investigated consumers' experiences of self-managing a home care package. It also compared experiences of self-management with the traditional model of home care (i.e. provider-managed).

Thirty participants were asked to describe what was good about self-management and what was not good. Participants were also asked for suggestions about ways to improve self-management. The sample size allows confidence that a wide range of views were captured.

Participants appreciated the opportunity to share their experiences of self-management with an independent researcher, as this enabled participants to speak frankly. The researcher has no vested interest in home care services. So the findings of the research have been shared with the public without the constraints of commercial-in-confidence.

All participants described self-management as improving their quality of life. They were able to obtain more hours of support through self-management than provider-managed. They were also able to choose who worked in their home, when they came and what they did. Participants also described having some "*control*" over what they purchased with their home care package. They received what they genuinely needed rather than what a provider deemed necessary.

Participants described provider-managed and self-managed care as two fundamentally different approaches to home care. Provider-managed is often based on a provider determining what support services, home modifications and consumables older people need. In contrast, self-management is based on shared decision making between the recipient of the home care package, their support workers and the self-managed provider.

Participants described self-management as treating older people as adults. Older people from all walks of life have the capacity to make decisions about their own lives. They have raised children, run businesses, bought houses and possibly self-managed their super funds. Their desire to continue to make decisions about their lives remains integral to their dignity, quality of life and the successful delivery of the support they need to remain living independently.

Participants said it was the government's responsibility to ensure recipients of home care packages knew that self-management was an option. They said *My Aged Care*, *Aged Care Assessment Teams* and health professionals should provide information about self-management. This would enable genuine choice about whether to have a provider-managed or self-managed home care package.

Although all participants spoke positively about self-management due to its person-centred and flexible approach to support, some aged care advocates do not support the self-management model. For example, Combined Pensioners & Superannuants Association claims that self-management puts older people at risk of abuse, neglect and undue influence (Appendix 2).

When I suggested to Combined Pensioners & Superannuants Association that a representative speak with recipients of home care packages who self-manage, I received an ad hominem tweet (Appendix 3). When I offered to discuss the issue of self-management with an academic who is similarly opposed, I was told: “There is nothing to discuss” (personal correspondence). On the contrary, in light of the data comparing provider-managed with self-managed, there is much to discuss.

In this study, most participants began with a provider-managed home care package. Some participants were assigned a home care package before the *Increasing Choice in Home Care* reforms so did not have a choice to self-manage. Others said they did not know they had such a choice.

Participants described choice, control and costs as their main reasons for switching from provider-managed to self-management. As reported in my national study *Older people living well with in-home support* (Russell, 2019), participants said mainstream providers charged high case management fees and excessive hourly rates for support workers.

Participants said some providers were “*robbing the system*”. Evidence from the final report of the Royal Commission into Aged Care Quality and Safety supports this claim. According to the Final Report, the average amount of support on a Level 4 home care package (i.e. \$52,000) is only eight hours and 45 minutes a week.

Several participants described receiving twice as many hours of support with self-management than they received with their previous provider. Lower administration fees and case management fees meant participants had more money available from their home care package to spend on their needs. Participants also valued being able to negotiate directly with support workers about their hourly rate. With self-management, while participants paid the support worker less than they had been charged with the provider-managed, the support worker still received more money. This was described as a “*win-win*”.

Participants described how they spent their home care package. They said it was often easier to get what they needed through self-management than provider-management. However, there was a discrepancy among self-managed providers about what was allowed.

Some participants suggested the government should provide clearer guidelines. They also suggested that self-managed providers should educate their staff about the guidelines. Other participants acknowledged that “*grey guidelines*” enabled them to argue their cases for consumables and home modifications based on their care plan.

Some participants spent most of their home care package on hiring support workers. They said the best thing about self-management was having genuine choice about, and control over, who worked in their home, when support staff worked, what they did and their rates of pay. Several participants described themselves as “*consumers purchasing services*” to enable them to live well at home.

The most common way to engage a support worker was to hire people in the local community they knew and trusted. Support workers required an ABN, a police check and, for those providing personal care (e.g. assistance showering), a Certificate 3. Participants also preferred support workers to have liability insurance.

Other ways to find support workers included word of mouth, local community groups on Facebook, advertisements in both local papers and online (e.g. Gumtree). Some participants engaged support workers via online employment platforms (e.g. Mable, Careseekers, Find a carer, Airtasker). The main criticism of these online platforms related to the trustworthiness of support workers’ profiles. Participants said some profiles did not accurately reflect skills or availability.

Some participants said they used the online platforms as a “*selection process*”. Once they established a relationship with a support worker, they encouraged the support workers to invoice them as independent contractors. They claimed this was better for them and the support workers because it removed the online platform’s fees.

Although it was sometimes difficult to find the “*right*” support workers, participants said they were more likely to get the required support through self-management than with their previous provider. The process of getting the work done was “*easy*” because they could discuss what they wanted directly with their support workers, who were able to decide whether to do a task without having to check with a case manager.

Participants said they chose support workers with the skills to undertake the required task. Unlike the traditional model, in which a single support worker might need to do a number of tasks, including showering, cleaning, cooking a meal and shopping, participants said they engaged a number of different support workers with appropriate skills. They could engage specific support workers such as cleaners, gardeners, qualified carers, an experienced cook and someone with whom they were compatible, who spoke their language and had similar interests.

The qualities of a good support worker depended on what qualities participants were looking for. Some participants valued qualifications, compatibility and experience; others valued trustworthiness, location and hourly rate. With self-management, older people could choose support workers with the attributes that best suited their individual requirements.

Participants said hiring regular support workers ensured workers got to know their clients – and vice versa. This led to genuine relationships between the older person and their support workers. Several participants described the different types of

respectful relationships: professional, friendship and loving. Some participants described the support worker as “*part of the family*”.

Rather than providers sending different support workers into the home, self-management enabled recipients of home care packages to develop ongoing relationships with their support workers. Such relationships improved recipients’ quality of life and the job satisfaction of their support workers.

## **Report overview**

This report begins with some background information followed by a section explaining the research methods. Although this study did not require approval from a Human Research Ethics Committee, the research followed ethical principles of informed consent and confidentiality. All data has been de-identified, including the names of companies that managed the home care package.

The findings section relies heavily on the consumer voice. It begins with a general discussion of home care, including the difficulties participants had navigating the aged care system. Consistent with the findings of my national study, participants said that living at home was preferable to living in an aged care home. Several participants said the older person with a home care package would not have been able to remain at home without family and/or community support.

The next section describes how participants chose their initial provider after being assigned a home care package. Most participants said they were not aware of the option to self-manage. As a result, most participants began their home care ‘journey’ with a provider-managed home care package.

A brief discussion about participants’ experiences of changing from provider-managed to self-managed is followed by a much longer section comparing participants’ initial provider with self-management. Many findings in this section echoed the findings in my 2019 national study. However, unlike that study, participants in this current study found a light at the end of the tunnel: self-management.

The next section describes what participants like about self-management followed by a section about what they do not like. The final section shares participants’ suggestions for improving self-management.

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## Introduction

This research project explored consumer experiences of self-management.

Thirty participants were asked to describe what was good about self-management and what was not good. They were also asked for their suggestions about ways to improve self-management.

Most participants began their home care 'journey' with a provider-managed package. The reason participants gave for changing from provider-managed to self-management was dissatisfaction with their initial provider. Several participants described feeling "*exhausted*" when they first transferred to self-management.

The reasons participants gave for being dissatisfied with their initial provider were similar to those identified in my national study (Russell, 2019). These included:

- High case management and administration fees;
- Inadequate hours of support;
- Poor quality of services;
- Lack of financial transparency;
- Inadequate financial statements;
- Poor communication;
- Staffing issues;
  - Large number of different support workers
  - High hourly rate of support workers
  - Inadequate training of support workers.

The current research project identified additional factors that caused dissatisfaction with provider-managed packages:

- Lack of control;
- Poor value for money; and
- Disrespectful attitudes towards clients.

Participants said that the ability to choose what they purchased with their home care packages had improved their quality of life primarily because they felt empowered. However, they sometimes had to "*fight*" to get what they needed because the guidelines on what they could purchase were unclear.

Participants also valued choosing who worked in their home, when they worked, what they did and how much they were paid. However, finding the "*right*" support workers was sometimes difficult.

## Background

### Types of home care

My Aged Care is the entry point to the aged care system.

There are two types of home care services.

1. The Commonwealth Home Support Programme
2. Home Care Packages

The Commonwealth Home Support Programme is the entry-level tier of support. It is designed to provide a small amount of care and support to a large number of older people to help them to remain living at home and in their communities.

Underpinned by a 'wellness and re-ablement model', the Commonwealth Home Support Programme focuses on activities that support independence and social connectedness.

Home Care Packages provide a higher level of care. They are designed for older people with more intensive, multiple or complex needs to remain living in their homes. The Home Care Packages program provides four levels of packages (1 – 4). The government subsidy for each package level is as follows<sup>1</sup>:

Level 1 – \$9,026.45 a year to support people with basic care needs;

Level 2 – \$15,877.50 a year to support people with low level care needs;

Level 3 – \$34,550.90 a year to support people with intermediate care needs;

Level 4 – \$53,377.50 a year to support people with high care needs.



<sup>1</sup> Accessed from My Aged Care website, September 2021

## Aged care reforms

The Federal Government is the primary funder and the regulator of the aged care system. The Aged Care Act 1997 and the associated Aged Care Principles (2014) set out the legislative framework for the provision of home care packages.

In 1984, federal and state governments implemented the Home and Community Care (HACC) program. Under this program, money was allocated to approved providers, each of whom delivered a set number of packages.

In 2011, the Productivity Commission's inquiry report *Caring for Older Australians* recommended fundamental reform of the aged care system to improve quality, affordability and sustainability. Reforms have been progressively introduced in response to the report.

The *Living Longer Living Better* reforms were introduced in 2013 with bipartisan support. These reforms introduced a more consumer-driven and market-based aged care industry.

In July 2013, *My Aged Care* was established as a single-entry point to access government-subsidised aged care services. My Aged Care comprises a website and a call centre. The two services were designed to be a 'one-stop shop': to provide information on aged care services, refer older people to appropriate experts for their needs-based assessments and help them find a provider in their local area.

In 2014, income testing for home care packages was introduced. As a result, recipients whose income was above a certain level were required to pay a fee towards the cost of their care. The government subsidy was reduced by the amount of the income-tested fee. The fee compensated the provider for the reduction in the government subsidy.

In 2015, home care packages became 'consumer- directed'. Consumer-directed care is a model for delivering and financing services. Home care packages and the National Disability Insurance Scheme (NDIS) are both examples of a consumer-directed care funding model. However, unlike the NDIS, home care package funds are paid to an approved provider (i.e. not paid directly to the recipient).

In 2017, the *Increasing Choice in Home Care* reform was introduced. This was intended to give recipients control over how their allocated funds were spent and choice over the services they received (e.g. how and when they received them and who provided them). It also enabled recipients to be able to change providers at any time and transfer any unused funds to the new provider.

In 2019, a single *Charter of Aged Care Rights* came into effect. It replaced previous charters of care recipients' rights and responsibilities. The Charter underpinned the new Quality Standards. The 2019 *Aged Care Quality Standards* expected providers to include older people in decisions about their home care package, including around their health, lifestyle and daily living requirements. This has been a significant cultural change for recipients and providers.

## **Managing a home care package**

Recent reforms have given recipients the option of choosing their level of involvement in managing their home care package. The level of involvement ranges from, at one end, fully supported by a service provider to 'self-managed' at the other.

Many providers offer fully supported home care packages as this was the model of service delivery in place prior to the aged care reforms. With a fully supported home care package, fees are paid for both care/case management and package management (i.e. administrative fees) as well as for the services provided.

Some providers offer recipients a choice of levels of support (e.g. fully supported, partnership, self-management), each with different fees depending on the amount of care/case management. Providers are not obliged to offer a self-management option. However, the principles of consumer-directed care must underpin all provider models of care.

A small number of providers offer only self-managed home care packages. Under a self-managed approach, the approved provider is responsible for package management, care/case management and for complying with the Aged Care Act, the Aged Care Principles and the Quality Standards.

Self-management requires recipients and/or their representative to be responsible for choosing and engaging health professionals and support workers. The recipients buy their own equipment and consumables provided they follow the guidelines of the home care packages program. Recipients who self-manage pay lower fees.

Most self-managed providers have no relationship with employment platforms. However, an online employment platform company recently received approval to be a licensed provider. HomeMade Support is a related entity of Mable, although it has a separate board and management/operations team. Several members of the Self Management of Home Care Packages for Consumers Only Facebook group question whether this close relationship is in the spirit of self-management's "choice" and "control".

## **Models of care**

The terms 'consumer-directed care' and 'consumer-centred care' are sometimes used interchangeably. However, these terms describe distinct models. With consumer-directed care, consumers are in charge of how their home care package is spent. With consumer-centred care, consumers work in partnership with health professionals and support workers to receive the care and support they need.

The types of support older people receive in the home depends on the health models that underpin this support. The biomedical model focuses on illness and treatment; the social model focuses on health and prevention. Both models have a part to play when providing support for older people at home, as does the relationship formed between recipients and their support workers. Ongoing relationships between recipients and their support workers positively affect recipients' quality of life and the job satisfaction of their support workers.

Services that keep older people well, independent and safe at home are important. However, social isolation can have an adverse effect on health and wellbeing. Hence, services that keep older people socially connected and engaged with family, friends and local community are vital. Having an ongoing relationship with the same support workers also prevents loneliness.

Informed consumers in aged care will increasingly demand responsive and flexible support services. However, some traditional providers continue to deliver 'institutional'-style services underpinned by rigid models of care. According to Sammut:

Traditional providers' rigid models of care invariably involve centralised rostering by head office managers of care workers who rotate in and out of homes and perform set tasks in a set timeframe. This 'institutionalised' style of care is replete with paternalistic and ageist assumptions about knowing what's best for passive and vulnerable elderly care recipients. It does not allow for the personalising of services according to the diverse needs, expectations and preferences of today's more demanding consumers<sup>2</sup>.

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<sup>2</sup> Sammut, J. (2017) Real Choice for Ageing Australians: Achieving the Benefits of the Consumer-Directed Aged Care Reforms in the New Economy: Research Report 24 The Centre for Independent Studies

## **Methods**

### **Recruitment**

Members of a Facebook group that I administer, “Self-Managed Home Care Package For Consumers Only”, were invited to participate in this research project.

A snowball sampling technique was also used. This technique involves participants telling other 'potential participants' about the project.

### **Inclusion criteria**

To be included in the study, participants must have (1) a home care package; and (2) self-managed for at least two months.

### **Data collection**

Data was collected in February 2021 via an online survey (Appendix 1).

### **Sample**

The sample contained 30 participants from urban and rural Australia.

Nine participants self-managed themselves; 21 participants self-managed for a partner, parent or friend.

One participant self-managed on behalf two recipients (i.e. mother and father).

So 30 participants described the experiences of 31 recipients of home care packages: one recipient on Level 1; two recipients on Level 2; ten recipients on Level 3; and eighteen recipients on Level 4.

It is noteworthy that five participants who self-managed their own home care package were on Level 4, the highest level.

Participants used different providers to host their provider-managed and self-managed home care package. These providers are not named in this report. In addition, some participants used online platforms to engage support workers. These online platforms have also not been named.

**Table 1: Participants' level of the home care package (1-4) and who manages the home care package (self, family member, friend).**

<b>Participant</b>	<b>HCP Level</b>	<b>Who Manages HCP?</b>
1	3	Family member
2	3	Family member
3	4	Self
4	4	Friend
5	2	Friend
6	4	Family member
7	4	Family member
8	4	Family member
9	4	Family member
10	4	Self
11	4	Self
12	3	Family member
13	3	Self
14	3	Self
15	3	Family member
16	4	Family member
17	4	Family member
18	2	Family member
19	4	Self
20	4	Family member
21	3	Family member
22	4	Friend
23	1	Self
24	4	Family member
25	4	Self
26	4	Family member
	3	
27	4	Family member
28	3	Self
29	3	Family member
30	4	Family member

## Data analysis

Data were critically analysed using thematic analysis. This method is a qualitative research method used to generate common themes. The aim was to produce themes that were solidly grounded in the data.

## Strengths and limitations of research

A strength of this research was that the researcher was independent. This enabled participants to speak frankly and without fear of repercussions. The researcher has no vested interest in home care services. So the findings of the current research have been shared with the public without the constraints of commercial-in-confidence'<sup>3</sup>.

Research shows people are disinclined to be critical of health services in face-to-face interviews with staff because of not wanting to jeopardise their care or a fear of consequences. Research also shows the limitations of satisfaction surveys.

Another strength is that respondents volunteered to participate in the research. Self-selected samples ensure that those who volunteer are informed about the issue. Self-selected samples may also be biased towards people with strong opinions – both positive and negative.

A sample size of 30 allows some confidence that the study has captured a wide range of views. However, the results of the research are not intended to be generalisable, nor was the sample representative in the standard scientific sense.

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<sup>3</sup> In 2019, *Mable* commissioned a research project to explore their clients' views of self-management. Some critical feedback, sensitive data and suggestions on how to improve *Mable* were not made public. Participants' views about how to improve *Mable* were deemed commercial-in-confidence.



## Findings

This section relies heavily on participants' data (i.e. 'consumer voices').

All text in italics is a direct quote from a participant. In longer quotes, a number identifies the specific participant. An effort has been made to ensure that all participants have a voice, and that no individual participant dominates the discussion.

As is customary in reporting qualitative data, terms such as "most", "the majority", "more than 50%" etc. are not used. Rather than quantify the responses, the intention is to present in-depth insights. To indicate a small number of participants the descriptor "some" is used to indicate less than five participants and "several" to indicate between five and twenty participants. When more than twenty participants share a specific insight, a general descriptor "participants" is used.

### Choosing to live at home

Consistent with the findings of my national study, all participants said that living at home was preferable to living in an aged care home.

*As a family we are very happy knowing that Mum can 'age in place', that we get a choice over her carers and that the government is contributing to the ongoing cost of Mum being at home. In general we are relaxed about Mum's care, unlike when she had respite in residential accommodation and felt that her needs were not being met. (Participant 8)*

Several participants said that self-managing a home care package enabled their parents to live at home. Without the extra fees and charges of a provider-managed home care package, they were able to purchase significantly more hours of support.

*Without self-management, there would not be enough funds to keep them at home. In fact, my father would probably be dead if it wasn't for self-management as he would not have survived long in a residential care facility. Keeping him at home would not have been possible. (Participant 26)*

*As the grown daughter of a traditional Southern European mum, I would have been expected to move back home (interstate) to look after Mum as she aged. Self-management enables Mum (94) to live independently with the assistance of an experienced enrolled nurse six days out of seven, for three hours a day. I am able to manage Mum's care while continuing my life with my children and to work, knowing that Mum has amazing care in her own home. (Participant 2)*

## Family support

Several participants said the older person on a home care package would not have been able to remain at home without family support. This provides further evidence that unpaid carers – family and friends – often undertake most of the work of caring for older people.

*I feel I am doing the government a favour by keeping my father at home and looking after him. I have given up my home to care for my father at his home... I don't feel I have much of a life as I'm on duty 24 hours a day – self managing, caring. I can't always get support workers in when I need them. Having said that, it will be over my dead body before I put my father in the hands of one of those greedy overpriced providers. (Participant 15)*

Some participants said family members were the “back up” when support workers cancelled a shift. Due to the complexity of the aged care system, and the difficulties “navigating” *My Aged Care*, many older people rely on family members to help them make decisions about their home care.

*My mother cannot comprehend the complexity of the home care systems and has relied on me to help her navigate the Aged Care Assessment Team, service providers, occupational therapy assessments etc. My mother is fiercely independent and has the capacity to choose her own supports with what she requires. I provided Mum with the options that were presented to her in a more simplistic form. (Participant 1)*

## Assigned a home care package

Participant 4 was excited when his friend was “approved” for a home care package. Like several participants, he did not understand the difference between “approved” and “assigned”.

*When I received the letter to say he was approved, I was excited. But “assigned” is not the same as “approved”. Do bureaucrats realise how confusing this all is? (Participant 4)*

Some participants described feeling overwhelmed when assigned a home care package. They were unsure how to go about selecting a provider. No one had told them it was possible to self-manage.

Participants expressed disappointment about their initial lack of awareness about self-management. They said *My Aged Care*, Aged Care Assessment Team and health professionals should provide clear information about self-management when they assign a home care package. This would enable genuine choice about whether to have a provider-managed or self-managed home care package.

*I did not know about self-management at the beginning when I was assigned a home care package. It was never discussed with me. I had to find this out myself after extensive research and collaborating with others who had knowledge and experience of the system. (Participant 26)*

Participants said more people would self-manage if they were told about it and knew how easy it was to do.

*A lot more people would self-manage if they knew how easy it is to do. This Facebook group has helped enormously... Being able to choose how we spend our money has improved our lives. It is so much easier now to get what we need, not what some case manager says we need. (Participant 30)*

*At no stage did anyone tell us about self-management. I raised it at every stage – assessment, approval and when assigned the package. They all said: “Don’t know anything about that, you just need to pick a provider off the list”. (Participant 2)*

Participants said it was not in the interest of their providers to offer self-management because it would decrease their profits.

### **Initial provider**

### **Self-managed provider**

After being assigned a home care package, some participants were aware of the option to self-manage. They described themselves as “*the lucky ones*”.

Participant 30 hoped self-management would become the norm within a few years.

*I hope in a few years’ time, most people will choose to self-manage. The traditional model is currently the norm – so it will take some time for this shift to occur. And I am sure the traditional providers will resist this shift. There is big money to be made with provider-managed home care packages... My husband and I have raised a family, bought several houses over the years and we manage our own super fund. And yet these traditional providers tell us we can’t choose who cleans our house. (Participant 30)*

Although participants said everyone should have the option to self-manage and engage their own support workers, they acknowledged that self-management might not suit everyone (e.g. those who need Public Guardians).

Several participants described learning about the option of self-management “*by chance*”. Participant 4 said he talked with many people on the phone trying to understand how the aged care system worked. His intention was to go with a large faith-based provider before he “*stumbled upon*” a self-managed provider.

*I had endless phone discussions with faith-based providers. But I was getting different information. I just couldn’t believe how difficult it all was to get my head around all this... I stumbled upon a [self-managed provider] after quite a bit of Internet searching. (Participant 4)*

*We found the “Self managed home care packages for consumers only” Facebook page while researching provider options. This was a purely an accidental discovery. We had not realised that self-management was even an option. (Participant 14)*

Some participants found out about self-management by undertaking their own research.

*I found out about self-management just by general research. It’s not something that is actively talked about, always seemingly put in the too hard basket. (Participant 18)*

Several participants found out about self-management via my Home Care Packages for Consumers Only Facebook group.

*I enquired about managed packages but I noticed that management costs were very high. I found Home Care Packages for Consumers Only Facebook group with people who self-managed their home care package. They made it sound do-able. So I went straight to self-management. (Participant 5)*

*I did my research in Home Care Packages for Consumers Only Facebook group. I met others who self-manage. I could not find answers to my questions via My Aged Care but found people who could answer them in this Facebook group. (Participant 8)*

*I jumped on a few Facebook groups and asked many questions... We were so green when this started. Facebook has absolutely been my best friend. (Participant 15)*

Several participants found out about self-management by “googling” different providers. Other participants had professional contacts who knew about self-management.

*I’m a social worker. So I try to keep up-to-date in case family or friends ask for my advice. I’d heard it was possible to self-manage. I’d read an article about [a self-managed provider]. It sounded like a new and different approach – they were a disruptor and I wanted to find out more so I could best help my Mum. (Participant 2)*

Participant 2 described “shopping around” before deciding on a provider to self-manage her mother’s home care package. She was shocked that a provider was operating under several different names. She questioned whether they were trying to “trick the consumer”?

*I phoned [provider] and spoke to [Name]. I then phoned [another provider], and got the same woman! She told me they were the same company and then had the audacity to ask me if I was shopping around! “Of course I am shopping around,” I replied. I now know this provider has various names but was the same company. I felt they were trying to trick the consumer - pretending people had choice. I didn’t like this but, at the time, it was the only company doing genuine self-management. (Participant 2)*

Some participants said their initial provider offered self-management but it was not “*genuine self-management*”. Participant 10’s initial managed provider agreed to trial self-management. However, they “*slipped back to the traditional attitude*”.

*I discussed self-management with a local, traditional provider that was happy to trial self-managing just with me. They did their best but seemed to slip back to the traditional attitude without even realising, which was stressful for me... I felt as if things were happening “over my head” and that my needs were not kept in sufficient consideration. Also, I kept finding mistakes in the financial statements, which were often sent with considerable delays too... (Participant 10)*

### **Traditional provider-managed**

Most participants began their home care ‘journey’ with a provider-managed home care package. Participants said they found their initial provider via either the *My Aged Care* website or a health professional’s recommendation.

Like my national study, some participants described the persuasive strategies some providers use to encourage older people to sign a Home Care Agreement with their company.

*I’ve always self-managed but the provider providing Commonwealth Home Support Program services thought they were a shoo-in getting Dad (and Mum’s) packages. They brought their A-Team out to the house... Thank god I couldn’t find the approval letter from My Aged Care on the day with the approval number because they wanted that number. I did not realise at the time how important it was. They would have ran with it and set themselves up as Dad’s provider, no question and I wouldn’t have known any different. (Participant 15)*



Participants said health professionals often recommended large faith-based providers rather than self-management.

*The social workers recommended the local church provider. But they were just ripping my husband off. They took case management fees even though we didn't see or hear from any case manager. And they didn't have good staff – we hardly saw the same support worker twice. This confused my husband so I asked them to stop sending anyone. They kept charging fees but provided no service. Quite extraordinary. (Participant 30)*

Participant 20 described being “traumatised” by her initial provider.

*When Mum first received the package, we were very grateful and did not question our provider on any of their decisions and rules. As time went by it became clear that they were not the caring organisation we had believed them to be... Looking back it was quite traumatising dealing with our original provider. I'm not the vulnerable recipient of the package and was able to advocate on Mum's behalf. But I was very concerned for other recipients who don't have someone to look out for them and are very vulnerable to exploitation and bullying by their providers. (Participant 20)*

### **Changing from provider-managed to self-managed**

Several participants described transferring from provider-managed to self-managed because the service they received was “poor and unprofessional”.

*I changed because of the poor and unprofessional service I was receiving from the traditional provider. Different workers came to the house to either be around while I showered, put the washing on and mop the floors. I felt very uncomfortable with strangers coming inside my home. The washing was left wet in the washing machine because the one-hour service was reached before the worker had time to hang it out. Sometimes when feeling poorly, I'd turn the worker away, but I was still charged for the service. After a while the provider arranged to have the same worker for me. The worker came about three times and then refused to come anymore because I spoke rudely to her. I have Alzheimers and, according to the provider, the worker was experienced with people who have Alzheimers. Another time the provider phoned me about half an hour before the worker was due to come to offer a different worker because the usual one was sick. I declined the offer but was still charged for the service. (Participant 13)*

*I changed from provider to self-management because of the incompetent companies sending inappropriate workers. I was not able to change days/times to suit me for appointments etc. Every week there were too many different workers that I had to train to do things the way I liked them to be done. And these support workers were not allowed to do so many things... Most importantly, there was no disciplinary action for inappropriate behaviours in my home such as racism, inappropriate clothing, refusal to wear gloves etc. (Participant 11)*

Participant 21 described her initial provider as lacking a consumer focus.

*There was a lack of respect for the actual needs required. The care plan was determined by the case manager without explaining how that plan was developed. Also without considering Mum's input, it lacked any consumer transparency in terms of what should be available to Mum, the costs associated with support staff. They insisted on products such as incontinent pads that weren't necessary or requested. They continually rejected requests for needed services and products that ensured safety in and around the home. Case management fees were extremely high and additional charges were deducted for admin, travel and paperwork over that fee, equating to 43%. Mum felt thwarted and frustrated with them continually denying her needs without proper justification. She felt that it was a deliberate money-grabbing gravy train to steal away funding that was for her explicit needs directly and that it was beyond a joke that providers could legally get away with this. At that time Mum asked on multiple occasions what was actually available or not allowed. It was a simple request to ascertain how she could best utilise her home care package but they never outlined or explained. The decision to change was driven by high fees associated with the provider along with them dominating how it was best used according to them. They didn't respect or understand Mum's needs at all. (Participant 21)*

*I've helped two of my elderly friends move from traditional providers to self-management based on what I've learnt while self-managing my Mum's package. Both had ceased using the services of their traditional providers because of the poor service they had experienced and were distressed about how they were treated. Now they self-manage and cannot be happier and more satisfied with the results and their improved quality of life. (Participant 2)*

Some participants in rural areas changed to self-management because there was little choice of local traditional providers.

*Dad worked for [Provider Z] as a volunteer driver before his death and Mum wanted to stay with them for the comfort of familiar faces. I didn't understand self-management at that time. Now changing because we are rural and no reasonable choices out here at all for providers... Another local provider is Provider BB... There are too many bad stories out here about the level of service provided by Provider BB. People in our town actually would rather have no help at all than Provider BB. (Participant 18)*

Participants said some providers made it difficult for them to transfer their provider-managed home care package to self-management. Some providers not only charged exit fees but also delayed transferring unspent funds to the new provider beyond the 70-day limit.

Participant 30 had been unhappy with Provider X's support workers because they did not have training on how to support people with dementia. When she transferred her partner's home care package, it had a large surplus because Provider X did not offer services her husband needed. Since engaging support workers herself, Participant 30 was able to employ support workers who had undertaken training, or were willing to undertake training, on dementia care. She spent the surplus in his account on services and home modifications he needs to remain at home safely.

Like my national study, participants were sometimes "exhausted" from the "road blocks" and "argy bargy" they experienced when dealing with their initial provider. It is not surprising, therefore, that some participants described feeling "depressed" or at "breaking point" when they first transferred from provider-managed to self-management.

### **Commencing self-management**

After commencing self-management, participants said they no longer had to "fight" with their provider for their entitlements. However, several participants found the first few months of self-management difficult. They did not know where to access advice and help.

*I needed help at the beginning. I didn't know what was going on. I didn't find anyone to be particularly helpful. I found out most stuff about how to self-manage on Facebook. Thank god for Facebook. (Participant 16)*

Participants noted the difference between self-managed providers. Some were better than others.

*The first provider was great initially but then later became very pedantic as to what could be claimed. I then began arguing and had to explain almost every single purchase. In the end it came down to not approving vitamin supplements for my folks. It was clear that they had been audited. I was advised that my current provider approved supplements and because they were very important to my parents' health and wellbeing I switched across. This was the only reason. To be honest, the first self-managed provider seemed to be more focused on watching their backs and being audited rather than the needs of their clients and alter the rules accordingly. I called the Aged Care Commissioner's office to enquire as to whether there were any specific rules or a list of what can be purchased and subsidised. They advised there was no actual rules and guidelines, and it is up to the provider as to what they approve and based on the specific needs of the individual. Clearly this is not the case and very apparent that the commissioner office is not aligned with the actual providers and has no idea what is going on. (Participant 26)*



## Spending home care package subsidy

Participants said that self-managed providers had different views about what was allowed under the guidelines. Participant 10, for example, tried self-management with three different providers. The fourth provider allowed her to get services and consumables that she needed to live well at home with a Level 4 home care package.

*I get help with cleaning and maintaining my home; garden maintenance; general support work. I purchase kitchen and cleaning equipment to make my life easier. I try to grow my own vegetables, and used the home care package to purchase a few extra garden beds and equipment for my veggie garden. I also access physiotherapy and physiotherapy equipment, myotherapy, osteopathy, podiatry, dentistry. I use my home care package to purchase doctor-prescribed herbal supplements. I also use my home care package to pay for some tests that are not covered by Medicare. I have an annual subscription to a supermarket delivery service. Any delivery related expense. I also have an air and water filter. Some home modifications. Laptop. Internet connection. The home care package covers occupational therapy report expenses and transport. (Participant 10)*

Some participants said an advantage of “grey” guidelines is that services and consumables could be negotiated with the self-managed provider – to determine how they fitted with recipients’ care plan. For example, a member of my Self-Managed Home Care Packages for Consumers Only Facebook Group was able to hire an animal behaviourist to work with her 58kg dog and then educate the carers on how to do their work with the dog in the house. However, a request to fund puppy training would most likely not be approved.

The following lists the services and consumables that recipients received based on their care plans.

- Support workers (assistance with showering, dressing, toileting, meals, laundry, accompanied/unaccompanied shopping, attending appointments)
- Socialisation - to maintain connection to peers and community
- Gardeners
- Cleaners
- Handyman
- General house maintenance (e.g. gutter cleaning)
- Home modification
- Fence repairs
- Ramps
- Stair protective strips
- Hand rails
- New bathroom
- Continence aids
- Barrier creams
- Q.V. wash (gentle on skin)
- Dressings
- Pressure care (e.g. dressings, sheepskin, sheepskin boots)

- Items recommended by my doctor (e.g. vitamins, skin creams, eye drops,
- Dental
- Special toothbrush
- Glasses
- Health supplements
- Heat pads
- Medical cannabis
- Non-PBS medications (e.g. magnesium)
- Hydralyte
- High protein meals
- Allied health – myopracitics/ massage; osteo/chiro; acupuncturist; exercise physiologist; podiatrist; physiotherapy
- Mobility aids (e.g. walker, wheelchair, scooter)
- Servicing of equipment
- Transport (e.g. taxis, maxi-taxis, Uber, public transport)
- Hospital parking
- Air conditioner
- Bed
- Chair
- Pest control
- Veterinary care
- Vacuum cleaner
- Carpet cleaning
- Replace damaged carpet
- Deep clean the apartment every 3 months (including a carpet clean)
- Personal alarm
- Security door (front entrance for safety)
- Security lights
- Kitchen appliances - stove, microwave, blender, fridge, oven
- Foxtel (since Covid)
- Key safe for care workers
- Mobile phone
- Laptop
- Art therapy
- Tube-feeding nutrition
- Fees for nursing home when Mum was on respite
- House move expenses (e.g. moving van)
- LED therapy lamp
- Medical ID
- Pool cleaning
- GPS tracking device
- In-home respite
- Respite carer
- Aquatics
- Vision Australia equipment for reading and lighting
- Replacing necessary home appliances as they breakdown

- Dementia approved products
- Disability approved products
- CPAP
- Computer
- Apple watch/iPhone for registering falls
- Light n' Easy meals (70 per cent cost reimbursed)

## Experiences of getting funding approval

Participants' experiences of getting approval differed depending on their self-managed provider. Some participants described the process as easy.

*If I can think of anything that can make my life easier, I send an email and/or make a call. The provider replies and lets me know. I would say that 99% of the things I proposed have been approved. (Participant 10)*

*No issues as well documented in plan and developed jointly so shared understanding. I have developed a template that records payment summary aligned with goals of care and supporting documentation (invoices, background information, insurances, police checks and the like as appropriate). (Participant 29)*

In contrast, Participant 28 described getting approval from her self-managed provider as "like pulling teeth".

*It was like pulling teeth. Initially everything was "no" – but when I heard other people with similar needs were funded [via a different self-managed provider], I made an appointment with my case manager. I went through the fine print. The case managers [at this self-managed provider] don't seem to know what is in the guidelines. (Participant 28)*

Participants appreciated self-managed providers who understood the guidelines.

*I know I can trust him to listen to my request and give it due consideration. If my request stands within his interpretation of the guidelines, we promptly review my care plan to include the item and to set the steps for validation if needed. If it is somewhat unusual and outside his field of experience, he will research the possibility that it may be allowable and get back to me promptly. If he needs to deny a request, he explains the reasons and helps me look for other options. He never makes me feel I am wasting the funding or wasting his time. (Participant 19)*

Some participants said it used to be easy to get approval for what they need. However, after the Aged Care Quality and Safety Commission audited their self-managed provider, many items that were previously approved were no longer approved. In addition, some purchases required an occupational therapist or a general practitioner to approve.

*Initially we were able to use a Load-and-Go card for day-to-day expenses such as taxi fares, medications, etc. This system ceased and we then had to purchase items with our own money and submit the dockets for reimbursement. We were then also asked to provide a list from Mum's doctor with all the items we may need to purchase. Our provider has approved most of the items we have enquired about. Sometimes we have been asked for a letter from allied health worker such as occupational therapist or dietitian. (Participant 20)*

*When we first signed with [name self-managed provider], it used to be easy to get approval for what we needed. Now it's ridiculous. I'm being asked to provide GP approval for items we have already purchased. (Participant 7)*

*It used to be easy. Now it's a bloody nightmare and I dread it. Rejecting stuff that I believe should be allowed (e.g. fridge, bandaids, gardens etc). We now have to waste time getting doctors' approval letters for the most basic of stuff. (Participant 15)*

*At first I didn't have the trouble that we are encountering now. It seems the money is sitting in an account earning interest and we can't spend it on things to make it more comfortable for our family member in and around the house. For example, the fridge is not working and the food is not cold enough - this is a hygiene and health issue but not coming to the party at all regarding this. There is absolutely no way my family member as a pensioner will be able to buy a new one. Another example, I feel I have to have my phone on me 24/7 whereas a smart watch would eliminate this problem but again [the self-managed provider] will not come to the party. So frustrating having to have the phone on me all the time. A third example involves our gardens. We used to be able to get some funding to keep the gardens going. My family member used to love coming outside when the gardens were in full bloom. That is no longer available either which I think is a bad mistake. Nice gardens and colour is so important. (Participant 16)*

*[Self-managed provider] has tightened the rules over time. But we respect the rules and follow procedure. Everything we use is covered under the guidelines... Most things are approved immediately. Any queries I get a doctor's supporting letter. It is generally sorted then. (Participant 17)*

Some participants questioned the need to get occupational therapists' approval before purchasing items.

*I have a problem with having to get occupational therapists to approve purchases. As soon as you mention Home Care Package to an occupational therapist, the amount they charge goes through the roof. For example, we had a bathroom that had a hob in it. We could not get it fixed without an occupation therapist's report. Mum had already fallen through the glass and was a serious falls risk. We could not get an occupational therapist for much less than \$1,000 to come and tell us that the hob was dangerous and needed to be removed so we could get the bathroom fixed. (Participant 15)*

Participant 26 described the process of getting approval as “burdensome”.

*It can be quite burdensome and an explanation is required if it is not within the norm. At times they will ask for a doctor's letter for some items, others they will outright reject. I have found another lot of supplements that would assist with my mother's health and wellbeing. So I now have to go through all the rigmarole to seek approval. It's very annoying. (Participant 26)*

Some participants challenged the self-managed providers' decisions.

*I had a problem once when [name of self-managed provider] refused to fund an item that was within the guidelines. So I phoned My Aged Care. I got a receipt number for my call and the person's name. I told [name of self-managed provider] to phone My Aged Care to confirm that it was not an excluded item. (Participant 11)*

### **Compare self-management with previous provider**

Participants described numerous differences between provider-managed and self-management. They were “night and day” and “chalk and cheese”. Despite some challenges (e.g. those discussed in the previous section), participants described a self-managed home care package as “much better”, “much easier” and “less stressful” than a provider-managed home care package.

*The main differences between self-management and provider-management are (1) Control of own needs and services. Greater choice and flexibility; (2) Lower fees therefore more services and care can be provided; (3) I know my parents and can meet their needs better than anyone else; (4) I am a strong advocate for them both; (5) Not confined to the rules and regulations of traditional providers; and (6) Don't need to liaise and communicate with staff who may not really know what is best for my parents. (Participant 26)*

The main differences between previous (i.e. provider-managed) and current (self-managed) providers are discussed under the following headings:

- Choice and control
- Continuity of care
- Impact on quality of life
- Treatment of clients
- Value for money
- Financial transparency
- Hours of support
- Case management

- Models of health
- Support workers
  - Engaging a support worker
  - Types of support
  - Replacing a support worker
- Communication

## Choice and control

The words ‘choice and control’ have become buzzwords for those who advocate for the free market in aged care services. So it came as some surprise to hear so many participants use these words.

Participants valued choosing the people who worked in their home, what they did, when they came and how much they were paid.

*I like almost everything about self-managing. We have much freedom and choice to do the very best we can for Mum. We generally get trusted that we are doing the right thing and as such are supported by our provider. We are not constantly hindered, belittled, patronised and having to beg the provider for the basics. We get to make our own decisions about who to employ as a care worker, allied health worker etc. Our provider doesn't interfere in our lives and yet is open to considering our requests if it's something that will help the recipient. Almost every time I have called our provider, I am put through to someone who can help and is willing to problem-solve. (Participant 20)*

*I like all aspects of self-management. This includes choosing own services/carers, control of how package can be spent, not having to argue with most aged care providers and services. There is nothing about the traditional home package system that I like. (Participant 26)*

Several participants described having “no control” when their home care package was provider-managed.

*We had been with a traditional provider for a couple of years and were finding it very difficult to get the help and resources Mum required. We felt that we were being very restricted and ‘controlled’ by the provider. I felt it was easier to do most things myself rather than struggle to get some help from the provider with the result that the funds in the package kept growing and I became more exhausted from doing so much and stressed from having to deal with our designated Care Coordinator from our provider. As soon as I heard that it was possible to self-manage, I wanted to leave our provider straight away. (Participant 10)*

Participants described it as “disrespectful and undignified” when providers dictated the type of care and support recipients of home care packages receive.

*Self-management is appealing as it gives recipients control and a degree of freedom to choose the way they prefer to live within their own environment. It's terribly disrespectful and undignified to have that right dictated to you like you are incapable of knowing what your rights are. (Participant 21)*

Participants described feeling empowered since they began self-managing their home care package. Some participants described having their “life back”. Self-management gave them autonomy, choice and control.

*With self-management, we have been able to get things we want rather than the rubbish the provider wants to supply. (Participant 15)*

*To be able to direct care according to needs, not just take whatever is on offer. Country people have different requirements and deserve to be treated accordingly. (Participant 18)*

*Provider management is expensive and I have no freedom to choose what I want, when I want it. Services are sub standard as they put the safety of their staff well above ours. Self-management is much cheaper and I have choices. I have control over who I hire, what I want, the standard I want. I can prioritise and I still have support via my care manager. I just feel free and not an old person depending on strangers to run my life. (Participant 23)*

*Gives us more autonomy and control. Able to leverage best value for available funds. (Participant 29)*

*The immediate difference was one of freedom and empowerment, being able to capably direct and guide the home care package in a way that relieved an enormous amount of undue previous stress and frustration. (Participant 21)*

Participants described the importance of the recipient of the home care package being actively engaged in the process.

*Important that my husband is actively engaged in the process and not treated as a passive recipient of services and products. Gives us control with the added comfort of a facilitator/agency that provides support, direction and advice to assure quality and compliance... Also appreciate that we get to choose the goods/services and support workers matched to need. (Participant 29)*

*It keeps me strong knowing that I can control my own care because I know my needs better than anyone else... I am in charge of my own life. It empowers me and makes me feel strong because I don't feel like a victim of old age. I enjoy getting older even though I know my body is deteriorating*

*but to me it gives me more respect for elderly people. I can employ people who understand. (Participant 25)*

Participant 20 described the importance of recipients “making their own decisions”. She was also delighted that the support worker continued to visit her mother when she was receiving respite in an aged care home.

*Self-management allows us to make a lot of our own decisions and determine exactly how we are going to use the funds provided to us. We are able to find our own care workers and negotiate hours and hourly wages. We are also able to order our own supplies, and have the supplies paid for promptly. If there are any complications with delivery of items, we are able to sort things out quickly and efficiently by getting in touch directly with the supplier. We are able to create a small community with the carers and are able to provide a reciprocal supportive environment that is enriching for Mum. Over time these relationships allow us to have mutual trust with the carers. This allows for genuine respite in that we feel confident that Mum will feel safe and be well cared for if my sister and I are not there for a couple of hours... One of Mum’s carers is able to visit Mum daily when she is on a 2-week respite in a nursing home... Prior to self-managing for example, when we accessed respite for Mum at a nursing home we would have to visit daily to make sure she was OK. Mum has very high needs and is very vulnerable and there have been some horror stories from her nursing home respite stays. With self-management we were able to ask Mum’s carers to visit her at the nursing home for 2-3 hours per day. This has been an enormous help as we have been able to rest and recharge while Mum is away on respite. (Participant 20)*

Participants said they were more likely to get the type of support they required with self-management than provider-managed.

*I can decide who comes to my home, when they come and what they do to support me. I can use my package funds more effectively and have a more personalised service from my provider. I can work within the guidelines to make my support effective for me. I am treated with dignity and respect by my provider who appreciates my business and perceives the funds as mine rather than the provider’s. Invoices are paid promptly, and I have complete control over who I employ and what they are paid. I have a sense of my opinions being valued on how the funds are utilised. Where there are restrictions they are explained to me rationally and with compassion for my situation. (Participant 19)*

Self-management enabled participants to choose how they lived each day. They said they welcomed “calling the shots”. With self-management, participants described feeling “in charge” of how they spent their home care package. They also received what they needed in a timely manner.

*We receive the support we need as we organise the workers ourselves. When it comes to equipment or consumerables, there is no delay in getting them. (Participant 8)*



*Amongst social and community work environments, we often hear the word “empowerment”. I would instead say we should aim to avoid disempowerment by not adopting a patronising attitude, which is itself disempowering. Being able to maintain a certain level of control over my life helps me psychologically. I am still myself, even though I now have a disability. (Participant 10)*

*I control the funds that have, after all, been allocated to me. I am a retired accountant and while I may be disabled there is nothing wrong with my brain! (Participant 14)*

Participant 10 referred to a “sense of oppression”, suggesting this occurs when someone else decides what is good for older people.

*Self-management helps me avoid the sense of oppression that I’d get if I had someone else decide what is good for me. (Participant 10)*

Participant 19 did not want others without lived experience deciding what she could and could not have as part of her home care package.

*I know I have the capacity to plan support for my needs. I do not want others without lived experience deciding for me. I enjoy the freedom of working directly with my support people to get what I want and need in a flexible manner. I have an abhorrence of the underpayment and poor treatment of workers in the home care field. I can set the payment rate and working conditions to reflect their value to me. I have a lot of flexibility. I can directly negotiate with workers regarding their work hours, what jobs they do on any particular day and how they carry out those tasks. I can use generic contractors to cover cleaning and gardening. My workers do not arrive in a provider’s uniform, thus their loyalty and responsibility is to me not the provider. I can approve what they report about my wellbeing and help them reframe any negative demeaning comments and attitudes they may have inadvertently formed about aged people. (Participant 19)*

Participant 22 described “freedoms” from those “who know best”.

*Freedom from “we know best” pressures. For example the previous provider pressured my friend to move out of home and into residential aged care because they thought it was best. Also, freedom from time-wasting and irritating case management meetings. (Participant 22)*

## **Continuity of care**

As in my National Study, participants described their initial provider sending a large number of different support workers to their homes, many without the required skills and training to competently provide care. Some participants also expressed concern about providers sending support workers who were overworked and unreliable (i.e. arriving at different times).

Unlike provider-managed, participants who self-managed were able to ensure a continuity of care. This enabled support workers to get to know their clients – and vice versa. Knowing an older person's preferences and routines removed the need for time-consuming briefings/handovers.

*Having the same carers has improved my mother's care. I hated getting a schedule of people and times when we were with Provider BC because this schedule was never correct. I also hated begging for everything.  
(Participant 17)*

*Mum has consistency of support workers, we are able to choose people who Mum is comfortable with and has good rapport with. We choose times that work for us and for the support workers and can determine the salary level for each worker commensurate with their experience. (Participant 20)*

*The only way Mum was going to accept care (from someone she did not know), was that she first needed to get to know them – to see if they could work together. Most of us would call this forming an ongoing relationship – what is it about this basic human need and idea that we don't seem to get?! Self-management has given us total control to do this. (Participant 2)*

Participants said continuity of care enabled genuine relationships – and sometimes friendships – to develop.

### **Impact on quality of life**

Participants said changing their home care package to self-management had improved their health, independence and quality of life.

*With a supportive and understanding provider it has enhanced my life immeasurably. I was slipping in to accepting that my life was being taken over by opportunistic providers who, due to their greedy money grubbing focus on building a business, rather than enhancing seniors' quality of life, were diminishing my independence and self-esteem by taking my funds while providing inferior and demeaning service. (Participant 19)*

*Life-changing. [Name] is well looked after and his needs are fulfilled and he can live at home which was his main wish. As his friend and carer, my life is so much easier as I know Geoff is well cared for. (Participant 5)*

*My mother is ongoing grateful for the support people in her life. She knows that her children are busy with their families and jobs and this allows her to remain independent in her own life as much as possible. (Participant 1)*

*Self-management changed my life completely. It has given me confidence because of the genuine care and support I get from my main carer.  
(Participant 25)*

*In hindsight it's greatly enhanced my quality of life... Mum hates having control and direction of her wants and needs taken out of her hands.  
(Participant 21)*

Some participants said transferring to self-management reduced their stress levels.

*I am very grateful to have found out about self-managing. It has impacted our quality of life in a very positive way. Almost from day one, my stress levels went down significantly. We have also been able to ask for what Mum requires and usually it has been approved. (Participant 20)*

Some participants described their quality of life improving because they were able to choose their own support workers. These support workers not only provided continuity of care but also developed relationships with the older person.

Some participants said the increased hours with self-management had improved their quality of life. Other participants described their quality of life improving because they were able to get the services and consumables they needed.

Some participants welcomed no longer being the primary carer. They described delegating many of the tasks to support workers. This enabled them to return to their role as wife, husband, son or daughter.

*The support workers we hire are terrific with my husband. I've gone back to being his wife, not his full-time carer. (Participant 30)*

Although participants said self-management involves more work for recipients and families, they described their quality of life improving because they are in control of their own care. Participants also described the positive impact self-management has had on their self-esteem, dignity, confidence and peace of mind.

*Self-management has improved my self esteem – knowing I am still capable of running my own life. This is priceless. Also the extra money saved with self-management and the freedom of choice. (Participant 23)*

*My Mum has a lot more dignity since she has been with a self-managed provider. (Participant 1)*

*I have peace of mind knowing who is coming into my home. I'm treated with dignity and respect even when I have bad days because of my health condition. Also I can get in contact with my support worker at any time. (Participant 13)*

## **Value for money**

Participants described not only choice and control but also costs as their main reasons for switching to self-management. They described self-management as much better value for money than provider-managed care.

Several participants described a significant difference between costs for managed and self-managed packages. Participants described provider-managed fees as “excessive”. One participant described home care packages as “a cash cow for providers”.

*There should be law against providers taking so much of our home care package in fees. This is taxpayers' money. It is intended to help us live at home. It is not intended to make some providers rich. (Participant 12)*

*I think a lot of the providers are money hungry sharks and are not working for the benefit of their clients but only to line their pockets. (Participant 16)*

Consistent with my National Study, participants complained about traditional providers' high case management and administration fees. Some participants were surprised that not-for-profit providers were also charging high fees to manage home care packages. Some participants complained about paying large case management fees yet rarely seeing a case manager.

Participants also complained about the excessive hourly rates traditional providers charged for support workers. They noted the discrepancy between what they were charged and what support workers were paid. Participant 15 noted the importance of paying support workers an appropriate hourly rate.

*The wages for support workers is nothing short of disgusting. Nothing will change if they don't start paying appropriate wages. I honestly think these providers see the aged care sector as a money ticket for their own selfish needs. (Participant 15)*

My National Study showed providers charged travel costs to clients when support workers travelled large distances between clients. Participants said being able to choose a local support worker was much better for both the support worker (who did not have to travel large distances) and clients (who did not have to pay the support worker's large travel costs).

Participant 30 said Provider X arranged numerous occupational therapy assessments for her husband. She considered these occupational therapy assessments as "rorts".

*A lot of my husband's package was spent on unnecessary occupational therapy assessments. I reckon this is one big rort. I often wondered whether the provider got a percentage as a fee for commissioning all these assessments. Aged care is seen as a money pot, a giant cash cow. They all have their hands in it... There is always someone ready to make a dollar in aged care. (Participant 30)*

Participant 30 suggested some health care practitioners increased their costs for those who received a home care package.

*I checked how much others were charged for a physio appointment. My husband was charged much more for this physio than his private patients. Surely these unscrupulous health professionals realise that my husband needed every cent of his home care package. This is just another example of rorting in the system. Why can't the government stop this? (Participant 30)*

Several participants preferred self-management because providers were not “ripping off” the government.

*I strongly object to billions of dollars of taxpayers’ money going to for-profit companies or admin-heavy non-profits rather than be spent on the actual care. (Participant 5)*

Although self-management had fewer overhead costs, Participant 3 said some self-managed providers were charging excessive fees.

*Self-management often has lower fees, but you need to understand the breakdown of fees. With self-management, you pay an administration fee to the approved provider. This is somewhere between 10 and 13 per cent... On top of that, some self-managed providers charge for each invoice... And if you hire support workers via an online platform, they also charge fees. (Participant 3)*

## **Financial transparency**

One of the findings of my National Study was the frustration with unclear, complex and inaccurate financial statements. In contrast, participants said self-managed providers sent them clear, straightforward, timely and accurate financial statements.

Participant 5 said her initial provider charged about 70 per cent in fees if she included the profit the provider made on the hourly rate of support workers.

*In addition to the case management and administration fees, providers charge an exorbitant fee for support workers. For example, if a provider charges clients \$60 per hour for a support worker yet the provider only pays the support worker \$25 per hour, this \$35 profit should be included as part of their “fees”. (Participant 5)*

Although participants appreciated the increased transparency in self-management, several participants said there was a possibility of rorting the system.

*The packages are generous. My husband gets over \$50,000 plus the dementia supplement. There is quite a bit of money involved. I am sure a handful of self-managed recipients abuse this. But the scale of rorting would be nothing like the rorting by these big companies. (Participant 30)*

Participant 2 suggested that some oversight of home care packages, by the regulator is needed, to ensure that the older person is receiving the services and support they need to live at home, and that others are not using the money to buy items for themselves.

*Your home care package is not additional income for the broader family to buy TVs, kitchen appliances and iPhones for their own use. Monitoring and audits to ensure the money is being spent in a way that supports the care needs of an older person is just part of good governance. (Participant 2)*

However, Participant 4 said: "Sending someone into people's homes to audit might be not well received."

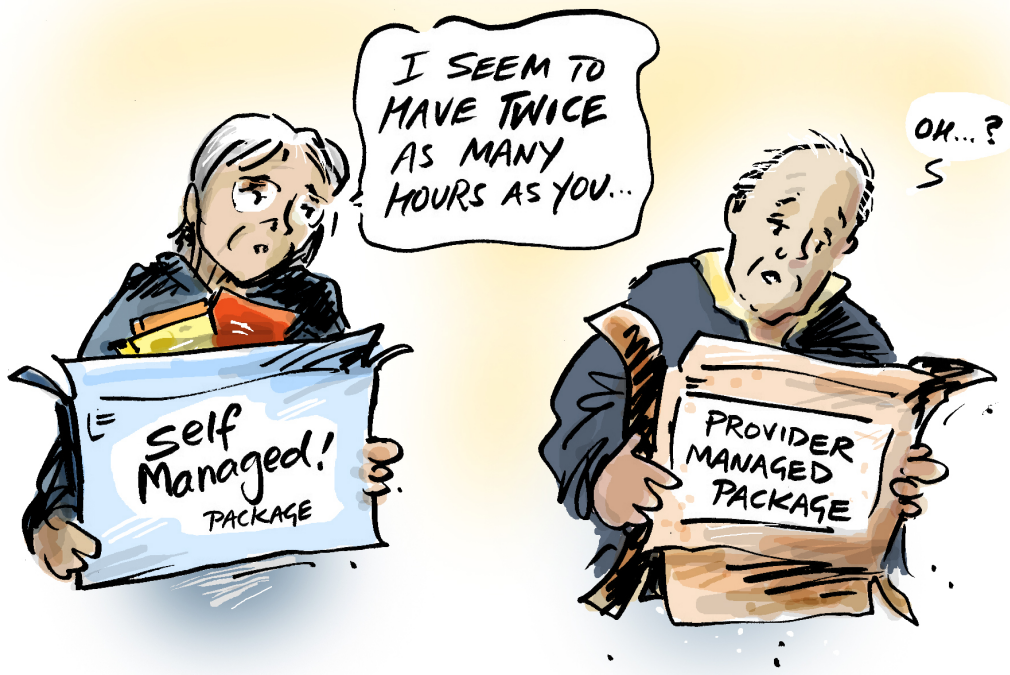
## Hours of support

Several participants described receiving twice as many hours of support than they received with their previous provider. By paying less in both case management/administration fees and hourly rates for support workers, participants had more money in their home care package to spend on hiring support workers to assist them in the home.

*If [my friend's Level 2 home care] package was provider-managed, it would allow only for 3-4 hours of care per week. This would not have been enough for him to stay at home... He is getting twice more hours with self-management than provider-managed care. (Participant 5)*

*The lower fees gave Mum more hours of support and allowed her to have many necessary home modifications for her safety. (Participant 21)*

*Mum's entire package Level 4 goes into her direct care, which means even at \$50 an hour for her worker, Mum has about 18 hours of amazing care a week. (Participant 2)*



## Model of service delivery

Participant 13 suggested traditional providers used a business model.

*From my personal experience the provider-managed home care package is more aligned to a business model where time and cost is the essence of service delivery. In comparison, the self-managed home care package is aligned to my wishes to remain independent and to make my own decisions so I can stay in my own home. (Participant 13)*

Participants valued self-management's focus on the social model of health. In contrast, they described their initial provider as operating within the "old system".

*The old system is paternalistic. The provider knew what was best for my husband. They assume us oldies are all too stupid to know what we need. Of course we know what we need. How dare they assume they are the experts about our lives. (Participant 30)*

Participants expressed different views about whether home care packages should focus on health and medical needs or the social determinants of health. Participant 30 described how her husband's support workers help him to have a meaningful life.

*My husband's dementia is quite advanced. But when he is in the garden, he seems just like his old self. I specifically chose a local woman who I knew loved gardening to be one of his support workers. They spend the morning out in the garden together – planting, pruning etc. When there is an open garden, she takes him to visit it. They talk about plants and garden design. He comes alive. (Participant 30)*

Participant 4, on the other hand, said he wanted home care packages to focus on health and medical needs. He said there should be limits around what should be provided in a home care package. In his opinion, home care packages should focus on health and medical needs, not social and lifestyle. He would prefer social and lifestyle activities to be provided by the local community at no cost to the government.

*I get annoyed when I see how some people spend their home care package. It is absurd that people can get their lawns mowed at the Commonwealth's expense. Why can't they get their kids to do it – or their neighbours? I think home care packages are about your health. They should not be spent on maintaining your house and garden... It's not fair that someone can buy potting mix when someone else who can't even get out of bed is not able to get services at home. I don't think that's legitimate when people are waiting for home care packages and dying at home because they haven't got one. Funding is scarce so it has to be rationed. The Aged Care Assessment Teams are rationing Commonwealth funding based on need. I don't consider an untidy garden as a health need. A health need is whether an older person can get up, clean themselves, get dressed, cook a meal and not fall over and fracture their hip. I don't think Aged Care Assessment Teams should consider things like pot plants... There's people who don't yet*

*have their home care package because there isn't enough money. There aren't enough packages allocated because there is a fixed budget for aged care divided by the number of people who need it. I really think that there has to be a limit around what can be provided in a home care package based on health needs. So somebody might be unhappy because they haven't got potting mix, but they're not at risk of dying tomorrow because they haven't got somebody coming in to care for them. So, I think it's a tough call, but if you ranked all of the needs, I think the priorities would become pretty clear... I think self-management will face a backlash from right-wing politicians if home care packages fund everybody's life interests... There's things on offer all the time for older people in the community. University of the Third Age and private reading groups and all sorts of things. That's kind of the community supporting community members at no cost to the government. I think this is a better model. What you could do is provide funding to help the community support itself; coordinators of community centres to help create activities and spaces for older people to meet and so on. Community transport. So home care packages would focus on health not social support. (Participant 4)*

## **Quality standards**

Participants described traditional providers as more regulated than self-managed providers.

*Traditional providers more often than not would have the policy and procedures in place that meet or be seen to working at meeting the aged care quality standards, which is reassuring around the standard of services/care needing to be delivered. (Participant 1)*

Participant 1 engaged her support workers via an online platform. She expressed concern about how these support workers are regulated given that the approved provider, not online platform, is responsible for support workers complying with quality standards.

*The support workers on [online platform] are not regulated. The only checks are the qualifications of the support worker against the services they deliver. For example, nursing needs a registered nurse, personal care requires the certificate 3 or 4 qualification... I have been told there is an agreement between [online platform] and the approved provider. The [online platform] has no responsibility for their support workers. (Participant 1)*

Several participants noted that a particular self-managed provider's behaviour changed after the Aged Care Quality and Safety Commission audited it. Participant 1 said it became more difficult to have services and supplies approved.

*Prior to my self-managed provider having a quality review, the system for approving was quite seamless. With no communication to clients, the process suddenly changed. The process became instantly red taped after*



*the quality review. When I emailed the provider seeking approval for items, they responded saying: "You will need another occupational therapist assessment to have this approved," or "We will support x% payment to go towards an easy to use vacuum". Thankfully, I was able to draw on my knowledge to seek approval for items that I knew fell into the home care package guidelines. But for many this knowledge does not exist. They find the guidelines very hard to find and comprehend as there are many grey areas. I certainly think the self-managed provider has a responsibility to inform their clients about how a home care package operates and provide clear boundaries of the services, supplies and supports they can access with the funds. (Participant 1)*

*An older person's needs and context must be considered holistically. Discretion is needed and guidelines need to be just that – guidelines. People's needs are all different and if you can put forward a reasonable case, that should be considered. Being more regulated doesn't equate to receiving higher quality services or care. The regulator needs to listen and learn from older people and what's actually working for them, for a start, rather than just writing up rules and saying: "These will improve standards and quality". They're dreaming. (Participant 2)*

## **Communication**

Participants described communication between themselves and the provider and support workers was much better with self-management.

Some participants found communication with their initial provider's case manager unsatisfactory. This was often due to the case manager having a large workload, sometimes with up to 100 clients.

*Mum's first 'traditional provider' was a very poor communicator, the clinical nurse who was the case manager for 100 HCP clients was not able to keep up with the workload. This left my mother feeling like this provider was only in it for the funding... The second 'traditional provider' was of a similar vein but offered more of a person-centred case managed service. Again, the case manager was over an hour away and had a heavy case load and was not responsive to my mother's queries and needs. (Participant 1)*

Participants described communication with their support workers as difficult because their initial provider would not allow them to talk directly with their support worker. They were required to ask head office or a call centre to pass on messages to support workers.

Participant 3 said her previous provider did not inform her when her carer was unable to come. Fortunately, her carer would text her "on the sly" to let her know.

*When I was with Provider A, if the worker didn't turn up that day, they didn't even bother to let me know she's not coming. Fortunately, the carer would text me on the sly – she wasn't allowed my phone details, but she would do it for me and told me 'I'm sick, I can't come'. Provider A would never let me know. It was just appalling. (Participant 3)*

Participants said self-management allowed them to negotiate the most convenient way to communicate directly with their support worker: text, email or phone. Being able to contact the support worker directly, rather than go via head office, enabled good communication. For example, participants appreciated support workers informing them if they were unable to do a shift or were running late. Participant 2 checked in with her mother's support worker regularly to give her an opportunity to de-brief.

*Mum's nurse and I check in on a daily basis, especially over these 18 months of Covid. When Mum's feeling down, it can be difficult spending time with her. Now that she hasn't seen her grandkids for such a long time, it makes it harder on her nurse. I see it as part of my role to make sure Mum's nurse knows that I value her, and appreciate her work. The daily contacts provide an opportunity for support, debriefing, and for me to take some of the load. For example, following up on medications, doing on-line shopping – anything to support both Mum and her nurse, from a distance. (Participant 2)*

## **Case management**

Consistent with my national study, participants reported being dissatisfied with the quality of case management with their initial provider. They described being charged case management fees irrespective of whether they used a case manager. Some participants said they were charged case management fees even though a case manager never visited their home.

Participant 26 acknowledged that case managers often have large caseloads. This limits their capacity to provide a “quality and targeted service”.

*It was apparent the case manager was working for the agency and not the clients... Case managers have a huge caseload and their attention to clients' needs is minimal... The case manager was not very competent and did not know my father's needs to provide a quality and targeted service. She was just crossing off a list of tasks rather than providing a personalised service. Not much interest in how Dad was doing. Care plan was not comprehensive and was almost a tick-a-box. It was very evident that she was not knowledgeable about the elderly and I question the skills of some of the workers employed by these agencies. It was very clear that it was about profit rather than the needs of the recipients. (Participant 26)*

Some participants changed to self-management due to the way they were treated by case managers.

*The disrespect from the assigned care co-ordinator and the inconsistency and unnecessary restrictions applied to the use of the funds. (Participant 19)*

*Our Care Coordinator seemed to begrudge almost every request and it was much easier to do most things myself rather than rely on our provider for support. With provider managed, we had to follow their rules. We were not*

*made aware of what items could be covered by the home care package. In fact, our old provider seemed to strongly discourage any requests for items and we paid for many things ourselves that could and should have been covered by the home care package (e.g. Taxi vouchers). (Participant 20)*

Some participants described themselves as the case manager yet the provider continued to charge case management fees.

*I also found that I was doing most of the work. In fact, I only heard from them once for the entire six or so months. When they did call, it was obvious that [the call] was part of their job task. They said they would visit and touch base monthly but never did. (Participant 26)*

Some participants expressed concern about some self-managed providers' lack of follow-up. This raised the question of how often case managers should visit homes when clients are self-managing – to not only check on clients' progress but also to ensure the home care package is being spent as the government intended.

*Mum suffers from high blood pressure and anxiety and can often have troughs of depression... It is a concern that the current self-managed provider is not monitoring my mother's health/clinical needs that leave her quite vulnerable... My concern as a daughter is knowing whether the clinical needs for my mother are being addressed. The current self-managing provider has no clinical governance framework so it is an ongoing concern on how this should or needs to be addressed. Are families left to just figure this out themselves? There is a serious risk gap in this area. (Participant 1)*

There was some disagreement about who should monitor self-managed clients' wellbeing. Participant 7 suggested GPs should report to a government authority on clients' wellbeing while Participant 1 said providers should check on clients.

*Clients should be regularly checked on via GP and reports submitted to Provider and government authority to ensure clients' wellbeing. (Participant 7)*

*The provider should monitor the self-managing client ongoing to ensure their capacity to self-manage is upheld and the health and safety is not compromised. (Participant 1)*

Some participants said they did not need a case manager because it was easy for them to case manage. Participant 30 monitored her husband's wellbeing.

*It's really easy for me to case manage. Really easy. I don't spend much time on it at all... I don't need the provider sending in a case manager to monitor my husband. If something changes, I will be the first to notice it. (Participant 30)*

## Care plans

Participants said they felt much more in control of their care plan with self-management. They described the developing the care plan “*in partnership*” with the self-managed provider. Participant 8, for example, described her Mother’s care plan was developed with a degree of autonomy.

*My sister did the care plan. She is one of my mother’s carers. [Self-managed provider] recently decided Mum should have some physiotherapy and an occupational therapist assess her. But apart from that, it’s up to us. (Participant 8)*

However, some participants did not understand the purpose of the care plan.

*I don’t fully understand the care plan. My past experience has been they want us to guess what is going to happen to our family member in advance. Also I know now it gets updated when new issues arise. (Participant 16)*

Several participants described developing their care plan over the phone with the self-managed provider.

*This was done over the phone by an experienced staff member who was very helpful and had a good understanding of what was involved in the care of my Mum. (Participant 20)*

*It was a consultative process via phone calls and emails from which a draft plan was generated. Only took a few minor changes to get signed off. We were well prepared, having done the research, compared providers/options and gathered the requisite information to inform the development of the plan matched to goals of care and support. It will be reviewed annually or sooner if changes in health and wellbeing. (Participant 29)*

*Well, I actually developed the support plan myself and they added a few things in line with their policies. It was done via email and not much phone contact. It has never been reviewed. (Participant 26)*

Participant 10 described the care plan as “dynamic”.

*I make a list of the things I need. The provider writes a care plan, which we revise as we go. The care plan is a dynamic tool by nature. It changes as the situation naturally evolves. I constantly think of new things that could make my life easier. This current provider’s attitude and method are ideal. (Participant 10)*

Some participants were wary of the care plan in case it excluded them from getting services and items from their home care package.

*I had no idea about the care plan when we first started. I felt a bit wary about what to say in case I either miss something or it becomes convenient for something we need not to be approved. We have had our care plans reviewed at least twice and when something comes up we now get a changed care plan. (Participant 15)*

Some participants said their self-managed provider reviewed the care plan when necessary.

*My care plan is reviewed as necessary. If I need to make a purchase or add to my plan, I am consulted, my opinion is valued and it is promptly reviewed and rewritten. It is always made clear in the plan what steps I need to make for approval. It is coherent, accessible and a valuable tool for dispersal of funding and accountability. (Participant 19)*

Several said the self-managed provider did not review the care plan.

*I've only had one care plan in the past 21 months – since I started with [name self-managed provider]. Who is supervising my care? Who is documenting my decline and keeping track of incidents? (Participant 11)*

*Someone is meant to do a catch-up monthly regarding my wellbeing. But that has not happened in previous months - I'm not sure what the legalities are at present. (Participant 28)*

Participant 27 has a care plan but does not follow it.

*A support plan was developed by [self-managed provider] but I don't follow it. We do what we like. All funding requests have been approved. (Participant 27)*

## **Support workers**

As in my national study, participants described their initial provider sending a large number of support workers to their homes. They also said the support workers were often untrained, overworked and unreliable (i.e. arriving at different times).

*There were different carers coming into the house every week. They were mostly young and untrained in dementia care. My husband hated all these strangers coming into our house. So did I. So I asked the provider to stop sending anyone. We managed on our own for a while – it was exhausting. I was at breaking point when someone on Facebook told me about self-management. Thank goodness for Facebook! (Participant 30)*

Many participants described becoming “fed up” with their initial provider because it could not guarantee the same support workers. They became tired of training each new support worker, some of whom were incompetent.

*They were offering different people each time. I had to tell the new person every time where the power points were, how to use the vacuum. I had to train each new worker. It was too much work for me - horrible. I thought I'd struggle on my own. I stopped using them altogether. (Participant 25)*

*I suffered whiplash as a direct result of an incompetent care worker they sent me without notice. I was also disappointed they did not pass on my positive feedback to those support workers who I liked. (Participant 9)*

Participant 20's initial provider actively discouraged support workers developing a relationship with clients. This resulted in numerous different support workers being sent to her mother's home.

*It was a struggle to have consistent support workers who Mum could have good rapport with. Support workers who had done an excellent job told us not to commend them to the provider, as they would likely not be sent back to us again. Every time they sent a new worker, we would have to show them the ropes. There are many things that can't be read from the care plan, particularly because Mum has very high care needs and is not able to communicate her needs. It's difficult if they are often sending out new people and also sending very inexperienced people, as my Mum has very high support needs. (Participant 20)*

Like my National Study, participants described their initial provider as not sending support workers at convenient times. They described having to "fit in" with their provider's schedule.

Several participants described the best thing about self-management was having control over who came, when they came, what they did, how long they stayed and how much they were paid. In addition to hiring support workers who are flexible, Participant 21 also described the ease with which her mother could get the consumables she required.

*Mum loves the fact she can engage people who are flexible for what she needs done, that she only has to make a call to check she can get items pertaining to her health and wellbeing. (Participant 21)*

### ***Employing support workers***

Participants described the pros and cons of being able to employ their own support workers. Some participants said employing support workers was "one of the most appealing thing about self-management". Others described employing suitable support workers as an "ongoing issue".

*One of the most appealing things about self-management is the ability to choose my own carers. We interviewed carers directly rather than have them assigned as is the case with managed providers. (Participant 5)*

*This is an ongoing issue. We have had some bad experiences through agencies. We do have three support workers who have been with Mum for a while, my sister included. (Participant 8)*

Participants described many different ways to find support workers to employ support workers. The most common way to engage a support worker was to hire people in the local community they knew and trusted. Other ways to find support workers included word of mouth, local community groups on Facebook, advertisements in both local papers and online (e.g. Gumtree). Some participants engaged support workers via online employment platforms (e.g. Mable, Careseekers, Find a carer, Airtasker).

*I've found support workers by using six different online platforms, a nursing agency, Gumtree, word of mouth. I've also employed travellers as an informal exchange arrangement. (Participant 9)*

*I first thought about what work I was offering, the number of hours needed and what I was prepared to pay and what qualifications workers might need (e.g. aged care certificates, nursing, police check, ABN, insurance)... I contacted the local training establishments to inform graduates and I asked around. Word of mouth, advertised in social media, used [online platforms]. I also looked for advertisements in local media for contract gardeners, cleaners. (Participant 19)*

*I initially used an online platform, however I have not found this solution ideal. I have since realised that there are multiple ways to source suitable people via the internet such as direct advertising, using community FB groups or even resorting to using cleaning agencies when needed... Mum feels that she should be able to get her personal support directly via friends' family and colleagues that she already knows and implicitly trusts, without all the hoops of ABN, police check and insurance. (Participant 21)*

A self-managed provider said approximately ninety per cent of his clients employed people they knew and trusted to be their support workers. In some cases, this was a family member.

*My friend who is my EPA and I discussed my situation. We agreed that she be my support worker... She has known me for over 30 years and we have a very good relationship. (Participant 13)*

*Our daughter is a registered nurse. She signed up with an online platform. We could then hire her as one of my husband's nurses. This is just fabulous. (Participant 30)*

Participant 4 expressed some concerns about the potential for abuse when employing a family member or neighbour as a support worker.

*I've received emails from [online platform] encouraging me to recruit family or neighbours as carers onto their platform. I'm concerned about how that could be abused. For them, it is more business. But I don't think it's right for a daughter who might get a carers' pension from the government also taking money from the government's home care package as a paid carer. I wonder what the regulator thinks about this? (Participant 4)*

Participants described a number of different ways to find support workers. These included:

- Word of mouth
- Local community groups on Facebook
- Advertisements in local papers and online (e.g. Gumtree)

- Online employment platforms (e.g. Airtasker)
- Online social platforms (e.g. Mable, Careseeking)
- Agencies

Several participants described finding support workers via word of mouth. People valued local people recommending support workers with a good reputation.

*I have found my support workers via local recommendations and reputation. (Participant 14)*

Several participants sought support workers online - through local Facebook communities and online social platforms.

*The Facebook community has been particularly helpful for finding support workers. (Participant 24)*

*I found and recruited through local Facebook groups and some through [online platforms]. (Participant 10)*

Some participants posted advertisements on an online platform. These advertisements outlined the work they needed done. They described a large number of support workers responding to their advertisements, although most were not able to do the work that was required.

Some participants posted a job on the online platform for a specific allied therapist (e.g. physiotherapist). Although they received a number of responses, those who responded were not physiotherapists.

*I tried putting an ad on [the online platform] for a physio. I received an overwhelming number of replies. But not one of the people who replied was a qualified physio. It was a complete waste of time. (Participant 30)*

Participants described the importance of first interviewing support workers. Initially the process of interviewing a support worker was easier for participants who had hired employees during their professional life than those who had no such experience. Some also described having a trial period with a support worker before making a final decision.

Some participants described the online platform fees as excessive. To avoid paying a fee every time their support worker visited, some participants used online platforms as a way to select and then trial support workers. If they were happy with the support worker, they negotiated to employ her/him directly via the support worker's ABN. This avoided both the client and the support worker paying the online platform fees for each shift.

*I use the [online platform] platform to trial support workers. If they suit me and I want them to continue, I ask them to do private invoicing. Basically, I use their hire platforms as a selection process. (Participant 3)*



Participant 9 noted that the support workers she engaged from online platforms were often the same support workers employed by traditional providers.

*Many providers are sourcing extra staff from the same platforms or agencies as I do with self-management... However, I get more hours and have fewer issues with staff, fewer headaches, fewer complaints, less stress. I also get more consistent delivery of care, happier staff, more collegiate relationships. more control and more flexibility. (Participant 9)*

Some described engaging a support worker with a Certificate 3 from their previous provider. Participant 17, for example, paid the support worker \$45 per hour. This was approximately \$20 per hour more than the support worker was paid when she worked for the provider. It is also approximately \$20 less than the provider charged Participant 17.

*I kept a register of the good carers at Provider BC. I asked one of these carers if she would she like to work for us at a proper rate of pay. We pay her \$45 per/hour. (Participant 17)*

*One of the support workers from Mum's second 'traditional provider' signed up as a sole trader. She continues to support my mother as they both got along well and this suited them down to the ground. (Participant 1)*

Other participants said they were disappointed their previous provider did not allow their staff to “moonlight”.

Participant 26 hired support workers from agencies.

*I found a service provider that works with private clients and they provide the carers. However this is becoming problematic as one in particular calls in sick a lot and they often need to send unknown carers. I am now considering engaging another service. The only reason I have stayed with this service is because of one carer who has established a rapport with my parents. However, she is becoming quite unreliable now and it is quite stressful for my parents and me. (Participant 26)*

Participants said they valued being able to negotiate times directly with the support worker rather than via a case manager. This enabled participants to have support workers in their home at a convenient time. It also gave participants certainty about when the support worker would arrive. Direct negotiation between recipient and support worker also made it easy to change times if required.

Participant 3 described support workers who are self-employed as being more reliable than those working for a provider.

*I think support workers were less committed when they worked for a provider, and therefore less reliable. (Participant 3)*

With self-management, participants were able to negotiate not only the times support workers visit but also their hourly rate.

## *Type of support*

Participants said they were more likely to get the type of support they required with self-management than provider-managed. They described being in control of what tasks the support workers undertook.

*Employing your own carers they do exactly what's needed. (Participant 5)*

Participants said case managers of managed packages interpreted the guidelines differently from self-managed providers. Consistent with my national study, several participants described having to “fight” with their previous case manager or support worker to get the work they required done.

With self-management, participants said the process of getting the work they needed doing as “easy” because they could discuss their requirements directly with the support workers. In addition, self-management support workers were able to make decisions about whether they could do the tasks without having to check with a case manager.

Participants said they chose support workers who had the skills to undertake the required task.

*With Provider X, the same support worker was expected to do all the different tasks – cleaning, showering my husband and social support... I've now got different people for different jobs. We have a professional cleaner once a fortnight. Most importantly, I've chosen support workers who can engage my husband in activities and conversations that interest him. I've found a support worker who gardens with him (Participant 30)*

Participants valued the diversity of support they were able to get with self-management. Several participants described support workers who were willing to undertake a variety of tasks associated with living independently.

*I needed some help with my computer. So I advertised a job on [an online platform]. A young man responded: “I'm an IT technician, I can help you.” How easy was that? I doubt the bean counters at my previous provider would have allowed me to hire an IT technician. (Participant 3)*

Participant 3 appreciated the fact that support workers worked for her rather than the provider. In addition, as the person hiring the support workers, she could instruct support workers to do tasks exactly as she needed them done.

*Carers always kept checking with head office about everything. They didn't work for me. They worked for Provider A. Now they're working for me and not the agency. (Participant 3)*

### *Replacing a support worker*

Participants described a benefit of a provider-managed home care package was that when support workers were unable to work (e.g. because they were unwell) the provider would find a replacement. With self-management, recipients were required to find their own replacement, sometimes at short notice.

Participants also noted they could ask their initial provider not to send certain support workers into their home. With self-management, recipients were required to end agreements with support workers themselves. Some participants found this easy while other participants found it difficult.

### *Negotiations with support worker*

Participants said that negotiating directly with support workers was much better than negotiating via case managers or head office.

Participants described the process of negotiating a support worker's hourly rates. They also negotiated a work schedule – the time the support worker would start and how long they would work.

### *Negotiating hourly rates*

Some participants negotiated hourly rates with support workers; others preferred to pay the hourly rate the support worker requested.

Participant 30 needed a support worker to stay 24 hours a day with her husband for a few days when she had elective surgery. She negotiated a reasonable rate with the support worker.

Some participants said they were happy to pay their support workers a high rate. Participant 30, for example, paid one of the support workers more because she made her husband so happy - assisting him to participate in activities that were important to his quality of life.

Some participants had employed the same support worker for several years. They insisted that their support workers increase their hourly rate each year.

### *Negotiating work schedules*

Participants said they valued being able to negotiate the work schedule directly with support workers. This enabled participants to have support workers in their home at a convenient time. Participants said they negotiated with support workers to determine when they arrived and how long they worked.

Some participants who employed several different support workers prepared a roster.

Some participants described the importance of having a back-up plan in case a support worker was not able to do a shift or there was a personal emergency.

*I live over 100 kilometres away. So if the support worker can't be there on any particular day, I call in some backup. He has friends who live close by, so I get one of them to check in on him. They make sure he eats some dinner. (Participant 4)*

Some participants chose to employ several different support workers – so if a support worker was unable to work on a particular day, or wanted to take a holiday, there was always back up.

### **What makes a good support worker?**

The qualities of a good support worker depended on what participants were looking for from a support worker.

*I look at their capacity to physically do the job and attitude toward me. Experience may not always be good because some workers have nursing home experience that negatively colours their attitude toward the aged. I also look at references and compatibility. Location is also important so that they are available for shorter shifts. I have found I need to be prepared that they may not work out so I keep a list of applicants. (Participant 19)*

*I needed a nurse to be able to build a relationship with my Mum who has a trauma history. I also needed her to be a caring and competent nurse. (Participant 2).*

While all participants agreed that support workers required a police check, data indicated numerous different qualities made a good support worker. These included:

- Qualifications
- Experience
- Compatibility
- Trustworthiness
- Location
- Hourly rate
- Competency
- Skills
- Reliability and punctuality
- Flexibility
- Language and culture
- Relationship with older person

The importance attributed to these qualities depended on each individual's circumstances.

## Qualifications

Some participants said support workers' qualifications were the most important. This was particularly the case for those requiring a support worker with a Certificate 3 to provide personal care.

*Mum was resistant to having 'just anyone' and this was a barrier to her accepting care in the home. I suggested to her: "how about we find a nurse". She agreed to this. There weren't many nurses [on the online platform]. As I recall, she was the only one. (Participant 2)*

Participants were "shocked" at how few of the support workers registered on an online platform had qualifications.

*I am shocked how few people have aged care certificates on [online platform]. It just makes it an employment platform, nothing to do with aged care. I do notice the difference in workers who have the certificate and those who don't. With those who don't, you have to start educating them about the needs of the aged. They arrive being polite and kind and that's about it. (Participant 3)*

Some participants said qualifications were important, but not as important as other factors such as compatibility, compassion, common sense and experience.

*Qualifications and training but most importantly their empathy and knowledge of the elderly. Being able to take the initiative and understand their needs. (Participant 26)*

Several participants said qualifications were not important. Qualifications did not necessarily indicate competency.

*It's not until people work in your home that you know if they are competent. You don't get that from a piece of paper. You need to see them in action. I watch them closely to see how they speak to my husband, how they treat him etc. (Participant 30)*

Some participants preferred support workers who did not have a qualification. They preferred to train support workers "to be the way I want them to be".

*Common sense and compassion are more important than qualifications. I have a full-time worker with no qualifications. I trained her to the skill level of a registered nurse. This is by far the best arrangement I've had since my husband got his home care package in 2015. I simply had to get her a waiver with [the approved provider] so that she could provide personal care. (Participant 9)*

*I think compatibility and trust. Also skills are very important when you're dealing with old people. But qualifications don't matter so much. I'm happy to teach them the skills they need. (Participant 3)*

## **Experience**

Several participants valued a support worker's experience. Support workers with experience often "see what needs to be done".

*The willingness to see what needs to be done without everything being listed and pointed out is very important. A cheery nature; ability to chat with Mum and draw her out of herself. With pay rates, we just go with the recommended payments. (Participant 8)*

*Mum's nurse had many years of experience in the health care system, in hospitals, aged care, mental health but wanted to leave to support people in their own home. We were so blessed to find her. She's perfect. (Participant 2)*

## **Compatibility**

Several participants chose support workers based on compatibility between support workers and clients.

*Compatibility is very important to us. It's great to find support workers who we can develop trust with and who are kind and respectful to Mum. It takes time, but it's not hard to teach the person what the role involves. (Participant 20)*

*Most importantly compatibility and ability to engage with my husband, build rapport, recognise and respond to his interests and needs. (Participant 29)*

*They have to get my quirkiness and join in the fun. They must also like dogs and have a good work ethic. I need to be able to access their car easily (not too low) and they need to be careful drivers. (Participant 11)*

*I think the most important aspect is understanding a home care recipient's needs and be willing to accommodate quirks, good and bad days - Mum is quite particular about the way she wants things done so she can be seen to be quite demanding. Mum wants someone who is quick and efficient and not a time waster. She feels that many, not all people, with Cert 3 and 4 aren't truly suitably trained, that they lack the true skills that the elderly require. (Participant 21)*

## **Trustworthiness**

Several participants described trustworthiness as an important attribute.

*I will not have anyone I wouldn't trust to be in my home if I wasn't present. So their personal integrity is imperative. (Participant 28)*

*I was looking for someone Mum could build trust with. Without that trust, there would be no relationship. Without the relationship, care and support wasn't going to be possible. (Participant 2)*

Participant 3 needed to trust that the support worker would not leave her when she found a better job.

*Many of the people on [an online platform] park themselves there because there's nothing better and they'll leave when they get a better deal. They're not really interested in taking me shopping and showering me. (Participant 3)*

Participant 4's friend often stays up late at night. So he might be asleep when the support worker did her shift. He needed someone he could trust.

## **Location**

Several participants said it was important that support workers lived nearby. This enabled split shifts and flexibility when plans changed suddenly. It also decreased the support workers' travel time and increased their reliability. Participants also said they chose support workers who lived close by because it enabled flexibility to change shift times at short notice.

Participant 3 said proximity was important because support workers who lived close by were more likely to remain working with the client than those who travelled long distances to work.

*You know if they have to travel across town, they won't last long. As soon as they find work closer to home, they will leave. (Participant 3)*

Participant 30 described the support worker like a daughter who "pops in".

*It's much better if the support worker lives nearby. One of my husband's support worker is like a daughter... The other day, I phoned her to ask her to pick up some milk before her shift... Sometimes she pops in after she drops her kids at school. This is a social visit, not part of her work hours. My husband is always thrilled to see her. (Participant 30)*

## **Hourly rate**

For many participants, the support workers' hourly rate was the most important criterion. Some participants were prepared to pay more for a good support worker. Some participants described remunerating support workers differently, depending on what type of support they provided.

Some participants did not understand why the hourly rates of a registered nurse increased after the transition from a Commonwealth Home Support Program to a Level 3 home care package. They also noted some inexpensive social activities increased from \$10 to \$100. They said they were being "ripped off" when, in fact, the increase was due to the federal government's policy of full cost recovery.

Participant 5 noted that support workers were happy to earn a higher hourly rate when they were self-employed than when they worked for providers.

*Carers are happy as they earn more money than managed companies pay them. (Participant 5)*

*I am regularly asking mum's nurse to up her hourly rate. Women's work is still undervalued and underpaid and yet the expectations are so high. (Participant 2)*

## **Competency**

Some participants considered competency, intellect and compatibility more important than a support worker's hourly rate.

*They have to be sufficiently smart. If they are, we can work towards improvement. If not, it is a lost cause. (Participant 10)*

*We didn't negotiate rates, just agreed to the support worker's request of \$50 per hour. I was focused primarily on her competency. My Mum (and I) believe people should be paid fairly. Mum has an experienced enrolled nurse who is also happy to do the shopping, clean the bathroom, take Mum to specialist appointments when I can't get there (like now because of Covid). When holiday leave, sick leave, superannuation aren't part of the deal for contract workers, even \$50 an hour seems too low. (Participant 2)*

Some participants focused not only on the support worker's professional competency but also their personal competency.

*Support workers need professional competency as well as personal competency. You need someone who isn't going to take over, but can do so in an emergency. (Participant 2)*

Some participants needed the support workers to be competent with equipment such as using a hoist or operating oxygen cylinders.

Some participants needed assistance with meal preparation. They described the challenges in finding support workers with skills to prepare the type of food they enjoyed eating.

## **Reliability and punctuality**

Several participants valued support workers who were reliable and punctual. Participants also appreciated being notified in advance if a support worker needed to cancel their shift (e.g. due to illness). They also appreciated being informed if the support worker needed to change the time of their shift (e.g. when they were stuck in traffic).



## **Flexibility**

Several participants negotiated mutually convenient times with their support workers. They also noted that regular times could be easily changed if necessary.

Participants described fitting in with the support worker's schedule – such as their other work commitments and lecture timetable.

## **Language and culture**

Some participants wanted a support worker who spoke their language and understood their culture. Others did not consider language and culture to be a priority.

*Mum doesn't need a support worker to speak her birth tongue, she prefers and feels more comfortable with someone who speaks English, and isn't part of that cultural community. That way she doesn't worry about her business being discussed with others in that community. (Participant 2)*

## **Relationship with older person**

Several participants described the importance of relationships between older people and their support workers.

*When choosing a support worker, the focus must be on the relationship between the support worker and Mum. It's critically important to spend time to get that right. If there is not the capacity to build a good connection, it just won't work. (Participant 2)*

*Quite often Mum would refer to her two workers as friends and she is so thankful to have them in her life where she knows she can trust them. One of the workers assists Mum to use Ancestry and has helped Mum successfully find her mother's final resting place in Nairobi. It's the bond/connection that Mum has with these workers that really matter to Mum. (Participant 1)*

*After some initial struggle, I found a few [support workers] who come regularly. It is about a constant balance between me letting go and them taking my needs into consideration, with reciprocal respect. It is a work in progress, teamwork. It is about aiming for good communication. (Participant 10)*

Participants described different types of respectful relationships with support workers: professional, friendship and loving.

*I would consider one of my carers as a very close friend. It's a very loving kind, relationship. (Participant 3)*

*They became our friends. They also love the job. (Participant 5)*

*My relationship with support workers is professional and courteous but not familiar. (Participant 28)*

Some participants described the support worker as “*part of the family*”. Others described the importance of professional boundaries.

*Mum’s nurse sees herself as a nurse first. She always has Mum’s health needs front and centre of the care relationship. She is always professional. We totally respect that. But I know, she is like a second daughter to Mum who now sees her as a part of our family – I most certainly do. You can be both. (Participant 2)*

Some participant questioned whether the relationship was “*too close*” and noted the importance of professional boundaries.

*I would say my mother’s relationship with her support workers are very close, possibly too close. Mum does not socialise much and now see’s two of her support workers as her best friends. One of these workers in particular seems to have at times gone over the boundary of her role i.e. minding Mum’s house when’s she’s away and Mum paying her to house sit. Loaning Mum a car when she needed one, getting into family politics with my sister etc. (Participant 1)*

Participant 19 described herself as “the boss”.

*I have a good working relationship. I’m clear that they are here for me not letting them set times and tasks. I found it difficult at first to be out with “carers” not friends. But over time we have a nice open relationship that is respectful on both sides. I am the “boss” though and if someone is coming putting on the kettle for a long cuppa and chat when they should be getting tasks done, I will politely and in a nice way let them know what I want from them. (Participant 19)*

Some participants described disrespectful relationships such as feeling pressured to offer support worker more hours.

*Some support workers are desperate for work. They pressured me to give them more hours. It became all about them earning money rather than them providing me with support. (Participant 3)*

## Problems with self-management

Participants described their difficulties self-managing a home care package. These difficulties are discussed under the following headings.

- Ageism
- Funding approval
- Engaging support workers
- Transient workforce
- Online platforms
  - Lack of variety of skills
  - Trustworthiness of profiles
- Financial abuse

### Ageism

Several participants described the funding disparity between home care packages and the National Disability Insurance Scheme as “ageism”. This disparity meant some older people did not have enough funds to access services and supports that they required.

*The disparity between aged care funding and the National Disability Insurance Scheme creates a two-tiered society. This has meant my husband missed out on funding for physiotherapy rehab, hydrotherapy social and so much more. (Participant 9)*

*I strongly advocate for a universal system of care that does not discriminate on age, rather needs assessed from cradle to grave. We have created systems that are too complex and unsustainable. (Participant 29)*

Several participants described incidents of paternalism when dealing with their self-managed provider.

*I believe that the biggest obstacle is the paternalism ingrained in the whole system. Aged care is a huge system, resistant to change. Change takes time. It would require a change in mentality. (Participant 10)*

*The system has a paternalistic approach. Even some people who work for self-management providers assume they know better than we do about what we need. (Participant 30)*

*Different case managers at (name self-managed provider) treat me like I'm an idiot. (Participant 11)*

Participants expressed concern that some policy makers underestimate older people's capacity to self-manage.

*I have a measure of insecurity that self-management is not well understood by policy makers and concern that it will be watered down by over-zealous policy makers. (Participant 19)*

## **Lack of awareness of self-management**

Several participants were concerned about the lack of awareness and promotion of self-management.

*Information about self-managing is not widely disseminated. It is like it is still a secret. (Participant 10)*

*When you get a home care package, you are not made aware of self-management unless you are Facebook savvy. I literally heard nothing about self-managing and it's definitely a better way to go. (Participant 16)*

*I'm extremely concerned that there's little promotion of self-management by the federal government, and that Counsel Assisting the Royal Commission still referred to "lead provider" in its recommendations. (Participant 22)*

*There is limited information available on self-management for home care packages. The only resource I have found is the COTA toolkit. There is a big gap here for those who don't know what they don't know. That includes consumers and service providers. (Participant 29)*

In addition to lack of awareness about the option to self-manage, participants described a lack of information about how to do it.

*Self-management can be difficult to navigate initially. Also, there isn't much information to compare and understand the differences between self-management and mainstream providers. (Participant 21)*

## **Unclear guidelines**

Participants said self-managed providers understood the guidelines differently.

*I found providers interpreted rules differently - what's allowed and not allowed varied enormously. There were occasions when I challenged their reasoning, asking them for a reference in guidelines (Operating Manual for HCP consumers, Commonwealth Department of Health), forcing them to back down. It pays to be assertive. (Participant 29)*

Several participants had disagreements with their self-managed provider about what they were allowed to purchase.

*The funding approval can be difficult with my current provider. They use too narrow interpretations of the guidelines. (Participant 9)*

*Not having clear guidelines is very hard to manage a HCP. The operational manual for HCP is somewhat grey on expenditures. (Participant 24)*

Participant 16 found it difficult having to question why simple items were rejected.

*It was difficult having to ask the question why our requests have been rejected, especially for simple items. (Participant 16)*

### **Time consuming**

Several participants said self-managing a home care package was time consuming and “laborious”. Some said once they had found the “right” support workers, it was generally “smooth sailing.” However, others said they spent a lot of time following up on their reimbursements with providers.

*It is time-consuming. With my self-managed provider, it is hard to get an immediate answer. I spend a lot of time having to chase up receipts, and follow up on their knockbacks. (Participant 15)*

*There have been times when I have sent dockets in for reimbursement and they don't reimburse. If I don't chase up then we never get reimbursed. I'm quite time-poor so I found it difficult to keep track of what was owed, until I came up with my own system of keeping track of things – since then, it has been smooth sailing. It was much easier when we had the load and go card. (Participant 20)*

*Of course you have to put time into it. That's a no-brainer. It's **your** care! You get out of it what you put into it. (Participant 2)*

Participant 25 found it difficult to manage all the paperwork.

*I find it difficult managing the paperwork; working on a computer with visual difficulties. (Participant 25)*

### **Hiring support workers**

Some participants described the process of finding good support workers as “trial and error”.

*Finding and recruiting staff requires a lot of research and trial and error, but I don't think having a traditional provider would be easier – in fact the opposite. Sometimes I feel I have to use too much of my very scarce energy. Being sick and organizing care is a full-time job. But I honestly don't see any realistic alternative. (Participant 10)*

Participants, particularly those who live in rural areas, said it was difficult to find the “right” support workers.

*I live in a rural area; therefore support workers and contractors are in limited numbers. I need to work harder to find the right people to ensure continuity of support. Sometimes making my own decisions is stressful but not as much as accepting inferior support from a managed provider. I can't always quickly find back up when a worker drops out or doesn't turn up. (Participant 19)*

## Online employment platforms

Participants described hiring support workers via online platforms as a “great idea”. However, some participants had difficulty finding suitable support workers on these platforms. They expressed specific concern about the lack of qualified staff.

*The problem with these online platforms is the lack of people with certificates... I've currently got three different support workers – they are kind and competent – but they are not allowed to help me shower. (Participant 3)*

*[The online platform] did my head in. I advertised a job and got one response from someone not qualified. I am not in the city so hard to get workers out here. (Participant 26)*

Other concerns about hiring staff from online platforms included the accuracy of profiles and the lack of diversity of skills. Participant 10 said that support workers who advertised on online platforms were often unsuitable.

*Regarding support workers recruited via online platforms: more often than not they focus on their own needs. They come with expectations and ideas. They want someone to take out for coffee. They are not trained to focus on clients' needs. (Participant 10)*

Some participants had difficulties finding a support worker on both online platforms and through social media. They suggested the problem was related to the casual nature of the work. Some participants suggested online employment platforms focused on the National Disability Insurance Scheme rather than aged care.

*I tried to hire staff from an online hire platform that advertised they did aged care. They contacted me to say they no longer wanted to deal with aged care clients. I was very disappointed. I had selected all these really good people with certificates. But he wouldn't budge. I'd like to know why he doesn't want our business. I can see that he would make more money out of people with big National Disability Insurance Scheme budgets. People needing 24-hour care is more profitable than providing a support worker for an old lady's two-hour cleaning each week on a Level 2 home care package. I felt really upset that I couldn't access the hundreds of people on this platform because he tied them up with the National Disability Insurance Scheme only. He made it so that no one without National Disability Insurance Scheme could access his pool. (Participant 3)*

Participant 3 also expressed ethical concerns about online platforms being approved providers. She said this might encourage recipients to hire their support workers via their online platform. She questioned whether this is consistent with the self-management focus on ‘choice and control’.

*[Online platforms] aren't stupid. They saw what they were missing out on, all those extra dollars and they had ready-made staff. I think it's the next level for them. Whether it's ethical or not is another matter. We are likely to see all kinds of fragmentation of home care packages. Anywhere*

*someone can extract easy money they will... This is likely to make them a much bigger company and then they can sell off arms of it as their platform grows bigger in coming years with the ageing boomers. But if they start recommending recipients hire their support workers via their online platform, this will take away recipients' ability to choose our own support workers by other means or indeed via other online platforms. (Participant 3)*

### **Transient workforce**

Several participants said many support workers registered on online platforms were transient. This resulted in support workers leaving them when they found more secure work.

*Mum finds that retaining staff via [an online platform] quite difficult over the longer term. Many personal support staff seem to be using the online platform as a transient or interim platform. (Participant 21)*

Several participants said support workers who advertised on online platforms were mostly either students, who often left when they completed their studies or people wanting temporary work while looking for permanent work. Participants also said that support workers preferred work that was funded by the National Disability Insurance Scheme than home care packages.

*She has found many of the staff she engaged want the most dollars for the least amount of work possible, particularly since the National Disability Insurance Scheme has been introduced, creating a further lack of support staff in her area. (Participant 21)*

Participant 3 suggested many support workers on the online platforms were unemployed people looking for work. They did not aspire to a career in the aged care sector. Participant 4 questioned whether these online platforms should provide a career pathway for support workers.

*[The online platform] does a police check, and checks their qualifications before they are listed [on the online platform]. After that, support workers are on their own. They don't have any sick leave or superannuation... [The online platform] is part of the gig economy trend. It is good for gig economy's business model not to have all the normal payroll stuff, but we've got to do better than that. We need to value this type of work – not just see aged care work like an Uber driver. (Participant 4)*

### **Financial abuse**

A participant was concerned about family members being encouraged to join an online platform as a support worker. Another said family members should not be paid as a support worker.

*I've received [advertising]<sup>4</sup> from [online platform] encouraging me to recruit family or neighbours as carers onto their platform. I'm concerned about how that could be abused. For them, it is more business. But I don't think it's right for a daughter who might get a carers' pension from the government also taking money from the government's home care package as a paid carer. I wonder what the regulator thinks about this?*  
(Participant 4)

*I am also concerned that self-management is open to corruption... Family members being paid to take a parent to doctor appointments, shopping, gardening, cleaning etc. Sometimes the family member also received a carers' pension. (Participant 11)*

Participant 16 questioned whether the rules had become “tough” because some people were abusing the home care package.

*Why have things got so tough to get approval for things? Is it because people are doing the wrong thing and getting things and not using them for their intended benefit? (Participant 16)*

## **Suggestions for improving self-management**

Participants all agreed that self-management suited them better than provider-managed. However, they said more self-managed providers were needed to show government bureaucrats the benefits of the self-managed model and genuine consumer-centred care.

*The sector needs a strong approved self-managed provider to prove that self-management works under the current home care package guidelines, legislation, principles and aged care quality service standards. (Participant 1)*

*The whole aged care sector needs a much strengthened and enforced consumer-focused approach. Lived experience needs to be awarded a high value in decision making and aged people given respected and valued roles in developing policy... There needs to be stricter rules set for providers to value consumers before profits. (Participant 19)*

*Policy makers need to know that self-management works so well for many of us. (Participant 30)*

Participants acknowledged that the self-managed model was not perfect. They made suggestions for how self-management could be improved.

*Self-management is not yet perfect but it's definitely a heck of a lot better than the costs and fees compared to provider-managed companies. (Participant 21)*

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<sup>4</sup> <https://mable.com.au/newsroom/can-i-invite-people-from-my-community-to-work-with-me-via-mable/>



The suggestions for improving self-management are discussed under the following headings:

- Raise awareness
- Information, training and advocacy
- Support workers
- Case managers
- Care plans

### **Raise awareness**

Participants said it was the government's responsibility to ensure recipients of home care packages knew self-management was an option. They said information about self-management should be on the *My Aged Care* website. They also suggested self-management needed to be "demystified".

*Needs to be better promoted on My Aged Care website. (Participant 29)*

*Demystify the whole process. Self-managing is not for all but is a better option than inadequate, very expensive mismanagement. (Participant 28)*

Participant said *My Aged Care*, provider peak bodies (such as LASA and ACSA), consumer peak bodies (COTA, National Seniors) and service providers need to promote self-management as an option.

*Better promotion by My Aged Care and supported by agencies/service providers as for the National Disability Insurance Scheme. (Participant 29)*

*Peaks in the aged care sector really need to raise self-management high on the agenda to ensure key stakeholders like the Department of Health actively promote this as an option for home care package clients. With so many blocks in the aged care system, self-management is one answer to the emerging ageing population. Targeting adult family members and educating them are all ways to get self-management out into the community... What the sector really needs is a provider who genuinely understands self-management and provides that support to clients, families, and significant others to ensure they have the resources, information and support to build their capacity to self manage with confidence. (Participant 1)*

*There is no incentive for big providers to share information about self-management while they are making big bucks out of provider-managed home care packages. But there is no reason why government agencies, professionals in the aged care system, the assessment teams aren't sharing this information. They should be sharing it. It's their role to ensure consumers are informed, so they have genuine choice. It would also help if the regulator spent some time actually understanding how well it works for people. (Participant 2)*

Several participants suggested an advertising campaign to raise awareness about self-management.

*The ability to self-manage needs to be much better publicised. (Participant 14)*

Participant 2 suggested an advertising campaign should target government departments (e.g. Department of Veterans Affairs, Department of Social Services), professional organisations (e.g. Superannuants, Dementia Australia) and civil society organisations (e.g. University of the Third Age, Landcare groups, interest clubs, Country Women's Association).

*It would be great to talk with a whole lot of people about self-management – anyone who is ageing and in need of services; and their families too. There is a whole consumer society out there. Why don't we hear OPAN, Dementia Australia, Carers Australia, the government Departments talking about the benefits of self-management? The government departments and the regulator could also learn by listening to us. (Participant 2)*

Participants said there needed to be more information about self-management when recipients' home care packages are approved and assigned.

*Clients and families need information and resources to help them understand what self-management is in a home care package context. So little is out there or promoted to allow people to explore this as an option. (Participant 1)*

## **Information, training and advocacy**

Participants wanted better information on self-management, especially when they began to self-manage.

*More support could be offered to get started – to help recipients get over the initial fear of taking control of their package... Social media groups are an excellent resource. Much can be learned by joining a group of people who self-manage. (Participant 20)*

Participants said more support for families from non-English speaking backgrounds was required. Participants suggested pamphlets to inform people what is allowed under the guidelines. They also suggested regular information-sharing sessions and training.

*I would like a simple pamphlet with what can be provided and what can't. (Participant 28)*

*Regular information sharing sessions would be beneficial with updates on the current system and upcoming changes... Training for some who may need assistance to self manage. This is not provided and so is not accessible to some who may otherwise be able to self-manage if they knew what was required. (Participant 26)*

*I would've benefitted from some training initially. Instead it was trial and error, sink and swim at first. Even now, I would benefit from training.*  
(Participant 23)

Participants said all self-managed providers should have good information on their website and be transparent in terms of how self-management works.

*There should be a comprehensive information forum from each provider that delivers self-management to help consumers understand clearly from the beginning government policy and how the government directs providers. And then it's up to consumers to navigate it correctly. It should be uniformly stated what is and what is not available from the get go.*  
(Participant 21)

Participants suggested self-managed providers need to be clear about all their fees and charges. One participant described “hidden” charges. Another participant was surprised when a self-managed provider began charging for each invoice.

*If they charge a low percentage fee, it gets people in. Then they flog them with invoice fees... The lower percentage rate is a lure but adding invoice charges makes a difference to the financial outcome. It makes budgeting harder as you don't know all your expenses. With a flat fee you can gauge better.* (Participant 3)

Participants suggested an advocacy service for those who self-manage would be useful – particularly for those who are not familiar with self-management.

*As a whole, self-management is the better service. However it can be quite time consuming and almost a full-time job at times. People who are not familiar with the system and are not assertive or knowledgeable, or English is not their primary language, may struggle. That is where an advocacy service for some would be beneficial.* (Participant 26)

## **Guidelines**

Participants said self-managed providers and case managers need to be familiar with guidelines about what services and items their home care package subsidises.

*Ensure case managers are trained in My Aged Care guidelines.* (Participant 11)

Some participants said less red tape was required when approving services and items.

*It would be better if there were less ludicrous rules and I did not have to chase up doctors for letters for the most simplest of items required. It is also absurd to require occupational therapists' reports on items that are obviously needed.* (Participant 15)

*Make it easier when requesting items/help. Don't restrict on what we need because of stupid rules. Cut the red tape. If we buy something for our family member, have the [self-managed provider] come check the house to make sure the equipment is being used appropriately if that would help. We are made to feel that we are not doing the right thing, when all we want to do is make life comfortable. If the government is encouraging home care for the elderly then they need to change their ways and be accommodating and helpful... It's so demeaning asking for the simplest of things and getting knocked back. I consider myself to be a strong person. It's relentless and I fear the elderly have no chance. (Participant 16)*

Some would prefer Department of Health produced clearer, standardised guidelines.

*I urge the government to make it clearer on what is allowed versus not allowed. (Participant 24)*

*I've also discovered that some people get approval for items and others don't. I feel this could be standardised to a degree. (Participant 21)*

*A comprehensive list of items would be beneficial. When asked, both [self-managed providers] advised this list does not exist as it is assessed according to one's individual needs. But when these needs are discussed some items are rejected with no explanation as to why. (Participant 26)*

*Would be helpful to have a list of policy procedures and guidelines to follow upfront. (Participant 27)*

*[There needs to be] consistency in how 'rules' are applied – again need a single reference point or gold standard... Standard templates, guides, docs held in single reference site. (Participant 29)*

## **Care plans**

Some participants said self-managed providers needed to update care plans regularly.

*My main concern is no one is following my health decline. How am I supposed to recognise it? [Name of self-managed provider] needs to check in at least monthly on current health conditions. They also need to do regular mental health checks (e.g. birthday, Christmas, Covid etc.) (Participant 11)*

*With the knowledge we have now gained, I believe the care plan should be as detailed as possible to include even unforeseen circumstances should medical and psychological conditions further decline... Comprehensive care plans need further clarity which includes all aspects of care to enable a person to comfortably, securely and safely stay at home. To be reviewed and family need to be copied in on this as they are the first to notice decline or impact of mental and physical health of their partner or mum/dad. Families need a road map to refer to and how to navigate and advocate on behalf of their loved ones, after all we are also going to be in a similar situation in the future. (Participant 21)*

## Support workers

Participant 21 wanted family members and friends to be employed as support workers without the usual paperwork.

*Allowing a waiver for friends and family to provide low cost paid assistance without needing to get ABN, Police check or Public Liability Insurance. (Participant 21)*

## Case managers

Participant 21 suggested case managers should check in regularly with self-managed clients.

*Case managers need to speak directly to their clients on a regular basis to get a real picture on their situation with wants and needs noted in writing, recorded and copied into notes that can also update family, and be as supportive as possible. If policy changes are going to be implemented across the board, that needs notice verbally and in writing via email and home mailing details for all clients. (Too many case managers vary in their rulings and this should definitely be consistent.) Also, have found what has been previously approved and agreed to has been reneged on, at times. These approvals need to be notated and recorded. (Participant 21)*

## Engagement with people

Participant 25 said most contact with the self-managed provider was via email. She missed the face-to-face contact.

*It would be nice to have a local provider who I could go and visit, like a shopfront where you could go and have a cup of tea, meet the workers, be more personable. I could discuss if I was having difficulty. (Participant 25)*

Participant 2 suggested there is a risk online employment platforms may become “disconnected” unless they focus on what is “happening in the real world”.

*Online platforms need to be really engaged and stay connected to what's happening (and being said) on the ground – and they need to be able to clearly communicate what they can and can't do. They need to promote the voices of the workers, and those who use their platforms. Tell everyday stories so that the broader community can engage with the ideas and know this is a viable option to finding good care. Some groups have a negative opinion of online platforms because they don't understand how they work. Outreach and community engagement with grassroots groups like the Country Women's Association is really important. Anywhere there is the likelihood of need, the platforms, should be there saying: “We are one option for you (and your members) to consider”. They need to build trust and confidence that it can work for all involved. And they need to deliver on those principles. (Participant 2)*

## Fees

Some participants suggested the percentage given to the self-managed providers was too high, given the recipients and their family do the “*hard yards*”. They questioned the government policy of self-managed providers being the “*middle person*” responsible for the management of the finances. Participant 2 suggested the brokering should be done via Medicare.

*Why do we need to have a provider manage the money? Why can't this be done through something like Medicare. NDIS participants self manage, with the money going straight to them. Saying that, I do know that some people feel more comfortable having a provider manage the money. There should be a range of options for people to consider. (Participant 2)*

*To have an online system like you do a tax return for reimbursements. Recipients could have access to a budget portal etc. This would eliminate the middle person so those funds are directed to actual care. (Participant 9)*

*It's mandated by the federal government so I don't blame [self-managed provider] for being in that space in the middle. They do a little bit more than just broker. They have to account for all that money. They send very detailed monthly reports to me, so I know how the home care package money has been spent. I sent them a lot of invoices involved, so they have to check it's all kosher. However, 13 per cent is excessive. (Participant 4)*

Several participants suggested giving the home care package money directly to the recipient of the home care package. They questioned why a “*middle person*” was needed.

## Conclusion

This research focused on the pro and cons of self- management from the perspective of older people with a home care package and their family.

On August 30, 2020, during a hearing at the Royal Commission into Aged Care Quality and Safety, Mr Gray QC, counsel assisting, said: “Measures for consumer feedback and engagement will be a key element of home care quality regulation.” In addition to assisting with regulation, consumer feedback (including complaints) is a key element for improving the quality of home care services.

All participants who changed from provider-managed to self-managed said that self-management had improved their quality of life. The research findings highlight the importance of relationships between the recipient of the home care package and their support workers. Self-management enables older people and their family to choose support workers according to criteria that are important to them. It also enables support workers to choose their clients.

Being able to choose their support workers was empowering. They chose support workers who had the skills to undertake the required task. Unlike the traditional model, in which a single support worker might do a number of tasks such as showering, cleaning, cooking a meal, shopping and cleaning the gutters, participants said they engaged different support workers with appropriate skills.

The main reasons for using self-management were choice, control and costs. In addition to choosing who came into their home, participants also valued the opportunity to negotiate with the support worker about when they came, what they did and how much they were paid. Having undertaken many complex negotiations during their professional and domestic lives, participants said they were capable of choosing, and negotiating with, their support workers.

Participants said some traditional providers made ageist assumptions that denied older people the opportunity to be in control over their own lives. Participants preferred a self-managed model over a provider-managed home care package because it put them in the driver’s seat. Self-management enabled a personalising of support according to diverse needs, expectations and preferences. Some participants said they preferred being treated as consumers purchasing services than vulnerable older people needing care. One participant said she objected to the word “care” because it was not possible to purchase “care”. She requested I use the word “support” and “support worker” in this report rather than care and carer.

The findings of this research may help to educate health professionals, aged care advocates and the public about self-management. While self-management may not suit all older people on a home care package, everyone is entitled to know that self-management is an option.

## **Appendix 1: Questionnaire**

### **Consumer views of self-managing a home care package**

Thank you for agreeing to complete this questionnaire.

Dr Sarah Russell is collecting consumer views of self-managed home care packages.

Sarah is a public health researcher and Director of [Aged Care Matters](#). This research project has not been funded.

#### **About the project**

The following questions are for people self-managing and those helping a family member or friend to self-manage a home care package.

You will be asked to reflect on what you like about self-management, and what you don't like. You will also be asked your ideas about how to make self-management better. The questions are open-ended, so feel free to say as much as you like about whatever you want.

All information will be kept confidential. No identifying information about you will be published.

The more responses I receive, the stronger the findings. There is no word limit on your answers – type as much as you want.

The findings will be used to raise awareness of self-management and improve policies to ensure that older people who live at home have the best possible quality of life.

**Please email your responses before 15 January 2021 to**  
[sahrussell@comcen.com.au](mailto:sahrussell@comcen.com.au)

If you have any questions, or difficulties meeting this deadline, please email me.

Thank you.



**Introductory information**

1. Who is the recipient of the home care package?
2. How long have you had a home care package?
3. What level has been approved?
4. What level has been assigned?
5. Approximately how long have you self-managed your home care package?

**If you began with a traditional provider, please answer Q 6 and Q 7**

**If you began with a self-managed package, you can skip Q 6 and Q 7**

6. What made you change from provider-managed to self-managed?
7. What are the differences between self-management and provider-management?
8. How did you find out about self-management?
9. How many self-managed providers have you had?  
☐ 1  
  
☐ More than 1. Please explain why you changed self-managed providers.
10. Please describe your experiences developing a care/support plan with your current self-managed provider? How often is it reviewed?
11. What type of things do you spend your home care package on?
12. Please describe your experiences of getting approval from your provider to use your home care package to fund what you need.
13. What aspects of self-managing do you find appealing and why?
14. What aspects of self-managing do you find difficult and why?

15. How has self-managing impacted your quality of life?
16. How did you go about finding and engaging support workers?
17. What is important to you when choosing support workers? (e.g. qualifications, hourly rates, experience, compatibility)
18. Describe your relationship with your support workers.
19. Is there any education, training and ongoing support that would help you to self-manage? Please describe.
20. What are your suggestions for how self-management can improve?
21. Any other comments?

## **Appendix 2: CPSA: Are self-managed home care packages a good idea?**

PEOPLE often ask about 'self-managed' Home Care Packages they see advertised. Is 'self-managed' a good idea?

This is generally how it works.

You go on to an aged care worker recruitment website to find an aged care worker with the experience and qualifications needed to do the care work you need done. Once you have found someone who works out, that worker will then come to you all the time.

The companies which run these recruitment websites will tell you that in this way you will get more hours than you would with a Home Care Package provider, plus you get someone who you are happy with.

That's not a bad story and in many cases it will work out this way.

But there are a few things you should be aware of.

First, you will still have to find a Home Care Package provider, who will receive the care subsidies the Government pays you and who will also receive any care fee contributions you are required to make. This provider does nothing else. It just pays money to the recruitment website company, which will then pay your worker.

The rest you manage. That's okay if you are able to, but if you have care needs beyond help around the house, chances are that it quickly gets too much.

In such cases, the care worker manages themselves without, or very little, oversight or scrutiny. A recipe for disaster.

Second, the contract is between you and the worker. This makes you an employer of a casual worker.

If anything goes wrong, it's between you and the worker to resolve.

If the issue can't be resolved, the Home Care Package provider who pays the recruitment company which (sic) pays the worker won't lift a finger. Neither will the recruitment company.

If you go to the regulator, the regulator will contact your approved Home Care Package provider, who will point out that it is not a party to the contract you have. The recruitment company would say the same thing, only the regulator would not even contact them because the recruitment company is not an approved provider. You would be on your own.

Self-managed home care is a bit like driving a car un-registered and un-insured.

Self-managed home care was scrutinised by the Aged Care Royal Commission and recognised as in need of reform. No doubt the Commission's final report (out on 26 February) will make recommendations to address the glaring possibility for things to go very wrong in self-managed home care.

### Appendix 3: CPSA tweet

I used Twitter to invite the author of CPSA's article "Are self-managed home care packages a good idea?" to discuss consumer perspectives of self-management.

I have included this tweet exchange to illustrate how some consumer advocates have a closed mind about self-management.



I received the following ad hominem tweet from CPSA's Policy Manager. His tweet indicated his unwillingness to discuss self-management with me. It also indicated an unwillingness to listen to consumers, some of whom are members of the CPSA.

