Older People Living Well with In-Home Support

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Older people living well with in-home support

Research report
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The research findings and recommendations outlined in this report do not reflect the position of the Australian Government or the Department of Health. Rather, they reflect the participants' understanding of their experiences of receiving in-home care. In addition, the research does not consider work currently under way to implement a range of federal budget measures to improve the system for older people who receive in-home care.

Executive Summary

Report overview

The report begins with some background information about the aged care reforms, the different types of in-home care, consumer directed care, the wellness and re-ablement model and recent research.

The next section describes the research method, including its strengths and limitations. The strength of this research is that the researcher does not work in the aged care sector, for a government agency or for an agency that receives federal funding. This enabled participants to speak frankly and without fear of repercussions.

Participants were recruited through Peninsula Health, an aged care forum and via an online invitation posted on the Aged Care Matters' website. A sample size of 40 allows some confidence that the research represents 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.

The research findings are divided into three main sections. The first section describes what is working well for those who receive in-home care. The second section describes older people and their family's perception about what is not working well. In the final section, participants share their suggestions about how to improve both home care packages and the Commonwealth Home Support Programme. Some suggestions for improvement have already been funded through the *More Choices for a Longer Life* budget measure.

Executive summary

Significant changes have been made to the way in-home support for older people is delivered in Australia. The Australian Government via the Commonwealth Department of Health funded Dr Russell to investigate the impact of these changes from the 'consumer' perspective. Dr Russell partnered with Peninsula Health to undertake this research.

Involving 'consumers' in an investigation of the way aged care services are delivered is recommended as a means of improving the quality of these services. In a system where the perspectives of government, bureaucrats, providers and professional groups dominate policy and practice, it is helpful to read the views and experiences of recipients of in-home care.

Forty older people and/or their support person described what is working well with in-home care – both the Commonwealth Home Support Programme and home care packages. They also described what is not working well. Participants made practical suggestions to improve in-home care.

When asked to describe the best thing about in-home care, participants unanimously replied: *"It enables me to live at home."* Some described in-home care as a "*godsend*". Without the government subsidy, many older people would be unable to remain in their own homes.

Participants agreed that the concept of the home care package was "*fantastic*". However, they expressed concerns about how some providers deliver it. Several participants suggested some companies should not have licences to be in-home care providers.

Providers of both the Commonwealth Home Support Programme and home care packages must be approved to deliver services. For the Commonwealth Home Support Programme, this is done through competitive growth funding rounds. For home care packages, an application is submitted to the Commonwealth Department of Health to review suitability as per criteria stipulated in the *Aged Care Act 1997*.

Participants suggested the government should restrict licences to only those companies that can demonstrate expertise in aged care. This would include providers that employ qualified staff and provide ongoing staff training.

Participants receiving home care packages suggested it should be mandatory for them to be given a schedule of fees before they signed the Home Care Agreement. Although providers are expected to do this, not all did.

Participants receiving home care packages described the case manager as integral in determining the quality of the in-home service. A case manager who explained entitlements, was easy to contact and met regularly with recipients to ensure the services were meeting their needs was described as "*a good case manager*".

Participants appreciated case managers who listened to the older person and their families, understood their needs and matched them with compatible support workers. They suggested case managers should receive specific training in both person-centred and consumer-directed care.

Participants also appreciated personal support workers who were well trained, experienced, respectful, empathetic and punctual. Some case managers matched the older person with a specific support worker. This often enabled a genuine friendship to develop.

Participants described the hours of support they received on the different levels of home care packages. They were surprised that a Level 4 home care package (worth more than $50,000) purchased approximately 14 hours of support per week, depending on the type of service they received. Some participants on lower level

packages described receiving better services, including more hours of support, on the Commonwealth Home Support Programme than on a Level 2 home care package.

Participants perceived several systemic problems with home care packages. These systemic problems are discussed under the following headings:

- Unable to access reliable information
- High fees
- Unclear financial statements
- No benchmark for costs (e.g. hourly rates)
- Lack of audits
- Poor quality of some services
- Poor communication
- Staffing issues
  - Inadequate training
  - Insufficient numbers of staff
  - High turnover of case managers and support workers
- Ineffective complaints system
- Policy of full cost recovery

Unable to access reliable information

Participants found the numerous fact sheets, brochures and pamphlets helpful. However, when they had "*tricky*" questions about policy, processes and the Aged Care Act 1997, they found it difficult to access reliable information from staff at My Aged Care, the Australian Aged Care Quality Agency, the Aged Care Complaints Commissioner and the Commonwealth Department of Health. Each time they phoned My Aged Care, for example, they would speak to a different member of staff. Some were knowledgeable; others less so. They described their frustrations at the "*merry-go-round*" – when staff at My Aged Care referred them to the Australian Aged Care Quality Agency or the Commonwealth Department of Health or the Aged Care Complaints Commissioner who in turn referred them back to My Aged Care.

High fees

Participants accepted that providers – including not-for profit providers – had to make a profit to remain in business. They objected, however, to "*obscene profits*".

Participants said it was reasonable for providers to charge fees to cover overheads and operational costs, such as insurance, workers compensation, care co-ordination and travel costs.

Participants said it was unreasonable for 50 per cent or more of the home care package funds to go into "*providers' pockets*". Provider KK, for example, charged $607.56 in case management and administration fees (51.6 per cent of a Level 2 package) to supply one service valued at $130.22 (Appendix 5, Example 6).

Data indicated significant differences among providers in both case management and administration fees. The amount ranged from 9 per cent (Appendix 5, Example 2) to 53 per cent (Appendix 5, Example 6). This may indicate differences in the health needs of the older person and the complexity of providing case management. Alternatively, it may suggest overcharging.

There were also significant differences in hourly rates for support workers. The amount ranged from $39 to $61 per hour for a support worker on a weekday. Provider A charged $136 per hour for a support worker on a public holiday (Appendix 5, Example 5).

When a provider took a large percentage of the home care package funds, the recipient did not receive the support they needed – and the support the government and taxpayers intended them to receive. Some participants received less than 10 hours of personal/domestic support on a Level 4 home care package.

Several participants said they were happy to pay for a case manager if a worthwhile service was provided. However, some participants described receiving minimal or no case management. One participant questioned why Provider M charged more than $600 per month for case management during the period she did not have a case manager (Appendix 5, Example 1).

Participants said it was wrong to be charged a fixed cost for case management irrespective of how much case management was used. Those on a Level 2 package questioned why they were charged $400 to $500 per month for case management and administration (Appendix 5, Examples 3 and 4). In their opinion, organising three hours of ongoing support per week (e.g. personal care, cleaning, shopping) required minimal work.

Some participants were charged the 'basic daily fee' of 17.5 per cent of the pension. This fee is the client's contribution to their budget for services, calculated on a daily basis. Some participants were concerned about being charged for seven days when they only received support for one or two days a week. In some cases, this daily fee made it financially unviable to receive a lower level package. Rather than accept a Level 2 home care package, some participants chose to privately fund in-home care.

Unclear financial statements

The monthly financial statements, designed to increase transparency, often lacked clarity. Participants described not being able to make "*head or tail*" of their financial statements. Even participants with business and accountancy experience found the financial statements "*bamboozling*". Participants suggested the case manager should explain the monthly statement to those who had trouble understanding it.

Not understanding the statements was stressful for older people and their families. Several participants also found it extremely stressful challenging providers when costs for services that had not been delivered appeared on their statements. Some participants said they did not have the energy to question these costs.

No benchmark for costs

A recent letter from the Minister for Senior Australians and Aged Care, the Hon Ken Wyatt AM, MP, to all home care providers outlined a phased approach to improving home care pricing information. As part of this approach, all home care providers had to publish their existing pricing information on the My Aged Care Service Finder by November 30, 2018. Disappointingly, some providers with the highest case management and administration fees in this sample (e.g. Provider B – 53 per cent) have not yet done so (Appendix 6).

The interviews for this study were conducted before November 30, 2018. Participants said that determining how much a service should cost was difficult without any benchmarks. They expressed concern at what they saw as inflated costs for labour, equipment and supplies. They questioned whether costs were inflated because home care packages were subsidised by the government.

Participants noted the disparity between what they paid the provider for support workers and what the provider paid support workers. Participants gave examples of providers who allegedly paid support workers below the award rate yet charged the older person more than $60 per hour on a weekday. On a public holiday, Provider A charged $136.10 per hour for a personal support worker and $241.20 per hour for a registered nurse (Appendix 5, Example 5).

Lack of audits

Participants wanted providers to be transparent and accountable and have their accounts audited.

In 2016–17, home care providers submitted their financial performance reports to the Department of Health using the Aged Care Financial Reports. Based on these reports, the Aged Care Funding Authority (2018) provides an overview of the 2016–17 financial performance of home care providers. However, the analysis is limited because it relates "only to those who submitted their useable financial reports" (p 69).

Participants expressed concern about some providers – both for-profit and not-for profit – taking a large proportion of their home care package. According to the Aged Care Financing Authority's (2018), profits in the home care sector increased by $43.4 million during past year: from $141.7 million (2015-2016) to $185.1 million (2016-2017).

According to the Aged Care Financing Authority's (2018, p 69), there was a significant difference between the profits made in the for-profit and not-for-profit sector. For-profit providers made an average profit per 'consumer' of $6,767; not-for-profit providers made an average profit per 'consumer' of $2,621. Government sector providers made a profit per 'consumer' of $1,883.

Poor quality of some services

Some participants receiving home care packages described working hard to receive services from their chosen provider. They described it as like "*pulling teeth*". They said "*fighting*" for their entitlements was "*exhausting*".

The data from this research indicates that the government is giving home care package licences to companies with no expertise in delivering aged care services (e.g. insurance companies). Participants described these providers as delivering poor quality services, primarily due to a high turnover of inexperienced and poorly trained staff. Although a pseudonym is used to describe providers in this report (Provider A, B, C etc.), the name of each provider has been given to the Minister for Senior Australians and Aged Care, the Commonwealth Department of Health and the Royal Commission into Aged Care Quality and Safety.

Poor communication

Participants described many instances of poor communication between providers and recipients. Some case managers did not respond promptly to telephone or email messages.

Providers with policies that prevent recipients contacting their support workers also obstruct clear communication. For example, if older people want a support worker to buy them milk, many providers require the person to phone head office, hoping the support worker will receive the message in time.

This study also found that large providers with a centralised administration were more prone to communication problems than small, local providers. Participants preferred speaking with local people, not people on the other side of the country.

Staffing issues

Participants described several staffing issues. These findings challenge the claim made in the report Accentuating the positive: consumer experiences of aged care at home, commissioned by the Aged Care Workforce Strategy Taskforce, that support workers "are well trained" (p 5). Several participants described inadequate training, an insufficient number of staff and a high turnover of staff.

Inadequate training

Some participants asked support workers to describe their qualifications. They were shocked when they learnt that not all support workers were qualified. According to participants, some providers (e.g. Provider O) required only a police check.

Participants were annoyed when young, inexperienced and untrained support workers came to their home. Three participants described the older person's family having to train a support worker to use equipment safely (e.g.

a hoist). This increased the stress not only for the older person and their family but also for the support worker.

Participants expressed concern when support workers had not been trained to care for people with dementia, including early onset dementia. Some support workers had undertaken online training courses during unpaid time (e.g. the University of Tasmania's Massive Open Online Course). However, participants described face-to-face training as much better for a support worker than online training.

Insufficient number

Participants were concerned that some providers accepted too many clients without hiring enough staff. This resulted in providers being unable to deliver the services they had undertaken to supply.

Several large providers either do not employ their own staff or employ insufficient staff. They employ support workers from another provider. This was a particular problem for participants who chose a faith-based provider because they expected support workers to share their faith and culture.

High turnover

Participants complained about the number of different support workers who were sent to work in their home. Participants were upset when a stranger turned up at their door. Some felt unsafe inviting strangers into their home. They were also dissatisfied when support workers did not arrive on time or, in some cases, did not turn up at all.

Participants said it was difficult to form relationships with case managers and support workers who did not remain in the job for long. High staff turnover disrupts continuity of care. Most importantly, it limits the ability to recognise, and respond to, an older person's changing needs.

In contrast, a case manager who visits clients regularly – and gets to know them – recognises when needs change and a higher level of home care package is required.

Ineffective complaints system

Participants were disappointed by some providers' responses to their feedback. Some were also dissatisfied with the formal complaints system.

There was some confusion about whether the Aged Care Complaints Commissioner covered home care. When one participant contacted the Aged Care Complaints Commissioner, she understood they only dealt with residential aged care. This is, in fact, incorrect.

Policy of full cost recovery

For many people, ageing well requires access to social activities and community life. However, the policy of full cost recovery prevented some participants from being involved in the same number of community social activities as they were prior to accepting a home care package.

Participants who received a higher level home care package (Level 3 and Level 4) described being required to pay the full cost of community social activities. Before receiving a home care package, an activity such as a bus trip or Men's Shed cost around $10. With a higher-level home care package, participants said the cost increased to $100.

A participant on a Level 4 home care package said a bus trip cost her about the same as an hour of personal care. She described being forced to choose between an hour of personal care or a social activity.

Participants also described the policy of full cost recovery as limiting access to nursing and allied health services for those on Level 3 and Level 4 home care packages. Some participants who required nursing services were advised to remain on a Level 2 home care package. They were told they would need to pay full price for nursing services on the higher-level home care packages. Data suggests the policy of full cost recovery may reduce access to nursing services for those on a higher-level home care package.

Royal Commission into Aged Care Quality and Safety

This report contains critical views of home care packages and the Commonwealth Home Support Programme – that is its value and significance. Unlike *Accentuating the positive: consumer experiences of aged care* at home, commissioned by the Aged Care Workforce Strategy Taskforce, which identified "a high degree of positivity about aged care services delivered in the home" (p 5), this report highlights systemic problems.

This study used qualitative methods. Participants were asked open-ended questions (Appendix 4). Rather than ask participants to comment on their degree of positivity/negativity about aged care services at home, participants were asked to describe their experiences with the aged care home care system. The researcher then analysed these experiences as positive or negative.

This research coincided with the announcement of a Royal Commission into Aged Care Quality and Safety. The Royal Commission will focus on both residential aged care and in-home care. The findings of this research will contribute to the Commissioners' investigation into in-home care.

Glossary and definitions

Participants described the home care system as "*inundated with acronyms*". To assist the reader, this report includes an introductory glossary.

It is also necessary to define the terms 'person-centred care' and 'consumer directed care' because some people use these terms interchangeably. For example, Sean Rooney described "consumer-centred reforms being rolled out by Government" (LASA, 2017). The government has rolled out consumer directed, not person-centred, care.

Glossary

ACAS	Aged Care Assessment Service (Victoria only)
ACAT	Aged Care Assessment Team
ACES	Aboriginal Community Elders Services
AIN	Assistant in nursing
AMR	AMR (research organisation)
ATSI	Aboriginal and Torres Strait Islander peoples
CEO	Chief executive officer
CHSP	Commonwealth Home Support Programme
CDC	Consumer-directed care
EBITDA	Earnings before interest, tax, depreciation and amortization
EN	Enrolled nurse
ERA	Elder Rights Advocacy
HCP	Home care packages
LGBTI	Lesbian Gay Bisexual Transgender or Intersex
MAC	My Aged Care
MC	Master of ceremonies
MOOC	The University of Tasmania's massive open online course
NDIS	National Disability Insurance Scheme
OPAN	Older Persons Advocacy Network
PAS	Psychogeriatric Assessment Scales
PCA	Personal care attendant
RAS	Regional Assessment Service
RN	Registered nurse
TIS	Translating and Interpreting Service

Definitions

Person-centred care and consumer directed care

Consumer directed care and person-centred care are distinct concepts.

1. **Person-centred care** is focused on developing partnerships between health care professionals and people they treat. Rather than health care professionals telling people what to do, the focus is on shared decision making. With person-centred care, people have an opportunity to actively participate in their own health care in close cooperation with health professionals (Russell, 2018).

2. **Consumer directed care** describes a model of service delivery and financing. Allowing people to be in charge of their own funding enables them to make choices about the types of services they need and who provides them (Russell, 2018). Home care packages and the National Disability Insurance Scheme are both examples of a consumer directed care funding model.

Case management

Case management refers to the process whereby a person (i.e. the case manager) is responsible for managing all aspects of recipients' home care services. Different organisations have different titles for the person responsible for case management: coordinators, case managers and care advisors all provide case management services.

Aged care 'consumer'

Single quotation marks are used in this report when older people are described as 'consumers'. Although older people who receive aged care services are increasingly described as "aged care consumers", there is disagreement about this term being used.

Some claim this language positions older people as active participants in an economic transaction – that is, purchasing aged care services (COTA, 2018). Others claim the trend to use economic market-based terms is creating an environment in which the older person is being de-humanised (Denniss, 2018; Watts, 2018).

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Introduction

In June 2015, the Commonwealth Government introduced significant changes to the aged care home care system. The aged care reforms are designed to increase consumer choice and flexibility and create a more sustainable aged care system.

In the past, home care providers competed for government funding and then offered older people home care packages. Now, it is expected that older people should be able to not only choose a provider that gives them the best value for money, but also have control over what services are provided, when they are provided and who provides them. But do they have this control?

The aim of the research project was to explore firsthand experiences of both home care packages and the Commonwealth Home Support Programme. Qualitative methods were used. Forty older people from around Australia were interviewed. A family member was also invited to participate in the interview. The criteria for inclusion was (1) having been assessed as needing a home care package, irrespective of whether a home care package had been assigned or (2) receiving home care via the Commonwealth Home Support Programme.

The interviews explored from the participants' perspective what was working well and what was not working well. Interviews also sought participants' ideas about how to improve in-home care.

This research provides in-depth feedback, insights and reflections of in-home care services. The sample includes special needs groups such as older people who are socially isolated, on low incomes and at risk of homelessness. It also includes a veteran, an Aboriginal and Torres Strait Islander person and older people from the Lesbian Gay Bisexual Transgender or Intersex communities.

Importantly, this research provides insights into why some recipients of home care packages are not spending their monthly subsidy. According to the Aged Care Funding Authority (2018), there is approximately $330 million in unused funds. One participant described why she had a surplus of more than $30,000. She described several systemic problems in the implementation of her home care package. Stories like hers provide an opportunity for government, Commonwealth Health Department and providers to tackle some of the systemic problems.

The aged care reforms enable people to change providers if they are dissatisfied with the service. However, recipients of in-home care are often frail older people. As a participant said: "*By the time you're this age, and you have some disabilities, you couldn't be fagged changing.*"

Some participants changed providers – but it was only when they and their families were "*at the end of their tether*" that they started to look around for another provider. Those who changed providers were often happier with their new provider. However, it is unfortunate they had to go through the initial stressful experience.

Participants described the hours of personal care they received on the different levels of home care packages. On average, these were:

- 2 hours per week on Level 1 package;
- 3 hours per week on a Level 2 package;
- 8 hours per week on a Level 3 package; and
- 14 hours per week on a Level 4 package.

Participants described fourteen (14) hours of personal care per week on a Level 4 home care package as insufficient support for frail older people to remain at home. Several said an older person required additional family and/or community support to remain at home.

Several participants acknowledged they would not have been able to remain at home without family support. Although some husbands, wives, sons and daughters received either a Carer Payment or Carer Allowance, several participants provided unpaid labour to support their older relative. Not surprisingly, women predominantly undertook this unpaid labour.

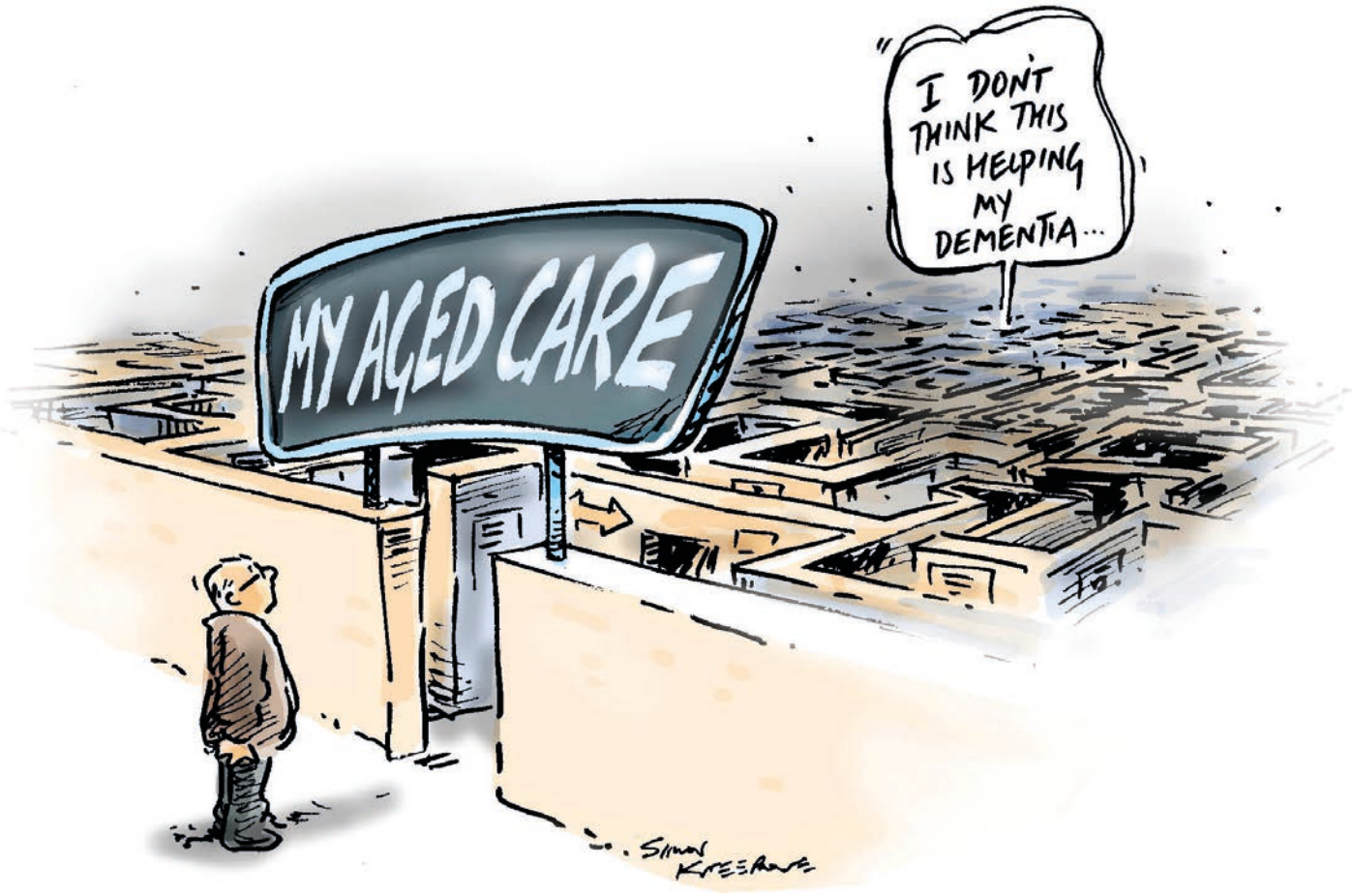
Only two participants were aware of the option of self-managing their home care package. One participant managed her home care package; the other managed her mother's home care package. Both were able to significantly increase the hours of personal care – and, perhaps more importantly, choose regular support workers with whom they were compatible.

Home care has a long history of services being provided to older people rather than with them. In her essay *Dear life: on caring for the elderly*, Hitchcock (2015, p9) claims: "Supporting independence and wellbeing in old age remains a low priority." The aged care reforms (e.g. consumer directed care and a focus on wellness and re-ablement) indicate a shift towards policies that empower older people.

Several participants had experienced the old and new system. They questioned why the government chose to fix a system that was not broken. Although the new system gives the 'consumer' more control than in the past, they described not having full control over how their home care package was spent, what services were provided, when they were provided and who provided them.

The title of this report, *Older people living well with in-home support*, was chosen because the author believes in-home care should assist older people to experience the highest possible quality of life. The living well concept is based on the World Health Organisation's Active Ageing framework (World Health Organisation, 2002). This framework emphasises six areas of life: social, physical, economic, civic, cultural and spiritual.

Many older people have indicated they prefer to stay at home rather than move into residential aged care. In-home care also costs taxpayers substantially less than residential aged care. It is imperative, therefore, that all providers of in-home care deliver high standards of services that are both consumer directed and person-centred.



Background

Aged Care Reforms

The Federal Government is the primary funder and regulator of the aged care system. The Aged Care Act 1997 and associated Aged Care Principles set out the legislative framework. The provision of home care packages is covered under the Act. The Commonwealth Home Support Programme is not.

In-home care is currently provided by a variety of providers – local councils and not-for-profit and for-profit providers.

Home care packages have no minimum age requirements or residency restrictions. However, the packages are not intended for visitors to Australia or people requiring temporary or short-term care. People are eligible for a home care package if they are:

- An older person who needs coordinated services to help them to remain living at home; or
- A younger person with a disability, dementia or other special care needs that are not met through other specialist services.

In 1984, federal and state governments implemented the Home and Community Care (HACC) program. Organisations eligible to provide Home and Community Care services included local councils, community organisations, religious and charitable bodies, health agencies and private for-profit organisations.

Under the Home and Community Care program, funds were allocated to the organisation, not the individual. Local councils, for example, received "block funding" (i.e. a fixed amount of money) from the government. Local councils decided how to spend this money on services for older people.

In 2011, the Productivity Commission's inquiry report *Caring for Older Australians* recommended fundamental reform of the aged care system. The *Living Longer Living Better* reforms were introduced in 2013 with bipartisan support.

The aim of the *Increasing Choice in Home Care* reforms is to enable better 'consumer' choice. The ability for older people to choose who provides support is designed to create a more competitive and innovative market (Aged Care Sector Committee, 2017).

The Federal Government has made a commitment to continue to provide block funding under the Commonwealth Support Home Support Programme until 2020. After that, who knows? [1]

Types of home care

There are two types of home care services.

1. The Commonwealth Home Support Programme (CHSP)
2. Home Care Packages (HCP)

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).

- Home Care Level 1 – to support people with basic care needs
- Home Care Level 2 – to support people with low level care needs
- Home Care Level 3 – to support people with intermediate care needs
- Home Care Level 4 – to support people with high care needs.

My Aged Care is the entry point to the aged care system. Clients are initially screened for the type of assessment that is required. There are two types of assessments: (1) Regional Assessment Service (RAS); and (2) Aged Care Assessment Team/Service (ACAT/ACAS). The Regional Assessment Service assesses eligibility for Commonwealth Home Support Programme and the Aged Care Assessment Team/Service assesses for Home Care Packages.

The Federal Government subsidises the Commonwealth Home Support Programme and the home care packages. In 2016–17, the government provided $2.4 billion for home support and $1.6 billion for home care packages (Aged Care Financing Authority, 2018). The budget for home care packages increased from $1.6 billion in 2016–17 to $2.0 billion in 2017–18, an increase of 28.1 per cent (Department of Health, 2018).

1 Due to the uncertainty around funding, I am aware that some councils in Victoria are decreasing their provision of aged care services. I am also aware that other councils are exploring ways to increase their provision of aged care services by becoming providers of Home Care Packages.

The home care package's daily subsidy is calculated as follows:

1. The basic subsidy amount (Table 1); plus
2. Any primary supplements (oxygen supplement, enteral feeding supplement, dementia and cognition supplement, veterans' supplement); less
3. Reductions in subsidy; plus
4. Any other supplement (hardship supplement, viability supplement).

Table 1: The daily and annual rates of home care packages (applicable from 1 July 2018 to 30 June 2019).

Home Care Package Level	Subsidy Rate (per day)	Subsidy rate (per day)
Level 1	$22.66	$8,248.24
Level 2	$41.22	$15,004.08
Level 3	$90.62	$32,985.68
Level 4	$137.77	$50,148.28

According to the Commonwealth Department of Health *Home Care Packages Data* Report (October 2018):

- At 31 March 2018, 84,971 people had a home care package;
- At 30 June 2018, there were 869 approved home care providers with a home care service;
- At 30 June 2018, there were 64,668 people in the National Prioritisation Queue (the queue), who were either in, or assigned, a home care package. Therefore, it is estimated that about 75 per cent of all people queued were receiving some form of Commonwealth subsidised home care support; either through a lower level home care package or Commonwealth Home Support Programme (CHSP) services;
- At 30 June 2018, 40,345 (70.5 per cent) of people on the queue for a Level 4 package were either in, or assigned, a lower level home care packages, providing them with Commonwealth subsidised home care service; and
- The average maximum exit amount was $244 at 30 June 2018.

Table 2: Summary of financial performance of home care providers who submitted their Aged Care Financial Report, 2016–17 (Aged Care Funding Authority, 2018, p69)

	Not-for-profit	For-profit	Government
Total revenue ($ m)	$1,397.2	$239.5	$96.8
Total expenses ($ m)	$1,264.3	$195.7	$88.5
Profit ($ m)	$132.9	$43.8	$8.3
EBITDA ($ m)	$141.7	$44.8	$8.7
Average EBITDA per consumer	$2,621	$6,767	$1,883

Consumer-directed care

Consumer-directed care (CDC) aims to provide older people who receive support in their home (i.e. community aged care 'consumers') with greater control of their lives by allowing them to make informed choices about (1) the types of services they access, and (2) the delivery of those services, including who will deliver the services and when they are delivered (KPMG, 2012). This change was designed to increase competition among providers, deliver higher quality services and give recipients better value for money than the previous system.

Prior to the *Increasing Choice in Home Care* reforms, providers were approved to provide a set number of home care places through the Aged Care Approvals Round. To access home care services, older people needed to find a provider with packages available at the right level. This was sometimes difficult. Although there may have been a number of providers in the local area, they may not have had a home care package available.

Home care package funding is now assigned to the recipient rather than the provider. Now, older people and their families must choose which provider they want to administer their home care package.

Prior to November 30 2018, it was difficult to determine how much services should cost as there was no benchmark. Older people and their families were required to shop around to find the provider that offered the best deal.

Wellness and re-ablement model

Home care has a long history of services being provided *to* older people rather than with them. The shift towards wellness and re-ablement is significant. It is designed to empower older people. For example, older people are now encouraged to work with health professionals to design the goals for their own care.

A recent review (Nous Group, 2018) found many older people do not understand the wellness and re-ablement model. According to Nous Group "many consumers don't really get it yet" (p 7). They described older people who receive in-home care as the least prepared part of the sector.

To be able to make decisions about the services delivered in their home, older people and their families need to be informed about the aged care reforms, including the shift towards a wellness and re-ablement model. They also need to understand the reason for these reforms.

Previous research

Consumer directed care is being embraced internationally to promote autonomy and choice. However, it has largely developed in the absence of evidence on the views and preferences of older people (Kaambwa et al. 2015). Although there have been numerous 'consumer' consultations in Australia, these are often online. Online surveys limit participation from older people (i.e. community aged care 'consumers') who are not computer literate.

Ottmann et al.'s (2013) literature review suggested consumer directed care approaches have the potential to empower older people. However, when Simons et al. (2016) interviewed 45 older people to determine how well they understood the changes in home care, the study found about 50 per cent were confused about the term consumer directed care.

Kaambwa et al. (2015) used a discrete choice experiment approach. This quantitative study found participants preferred a consumer directed care approach that allowed them to: save unused funds for future use; have support workers that were flexible in terms of changing activities; and choose the support workers that provide their day-to-day care.

Gill et al. (2017) identified the issues and challenges experienced by staff, their clients and informal carers with the introduction of consumer directed care. Their investigation occurred during the period in which services were transitioning to the new model of service provision. They found the current culture and practice within home care services made translation of the objectives of consumer directed care difficult.

McCaffrey et al. (2015) determined what features of consumer directed, home-based support services were important to older people and their informal carers. Eight themes were identified:

1. Information and knowledge
2. Choice and control
3. Self-managed continuum
4. Effective co-ordination
5. Effective communication
6. Responsiveness and flexibility
7. Continuity
8. Planning

Six salient service features characterising consumer preferences for the provision of home-based support services models were identified:

1. Choice of provider
2. Choice of support worker
3. Flexibility in care activities provided
4. Contact with the service coordinator
5. Managing the budget
6. Saving unspent funds

Day et al. (2017) interviewed five people who were receiving home care packages. Semi-structured questions and emotional "touchpoints" relating to home care were used to guide the interview conversation. The researchers identified four emergent themes: seeking quality and reciprocity in carer relationships; patchworking services; the waiting game; and technology with utility. Continuity of carers was central to the development of a trusting relationship and perceptions of care quality among older consumers.

The Commonwealth Department of Health (2018) commissioned AMR, an independent research agency, to conduct research among home care package clients and service providers in August and September 2017. AMR measured experiences and perceptions after the *Increasing Choice in Home Care* reforms were introduced on 27 February 2017. Participants indicated high satisfaction with: the services they received (85 per cent); the services matching these expectations (86 per cent); and the general standard and suitability of the aged care services. About 80 per cent were satisfied with the information received from My Aged Care.

Most participants (74 per cent) considered the waiting time to be approved for a home care package as satisfactory and 65 per cent indicated satisfaction with the length of time they had to decide which provider would deliver the services.

AMR found the most valued service was domestic support (41 per cent), followed by transport, social and personal support. Although 68 per cent agreed the reforms would make it easier to move to a new provider, only 7 per cent in the sample were contemplating changing providers.

The Aged Care Workforce Strategy Taskforce commissioned National Seniors to undertake research on in-home care. McCallum, Rees and Maccora (2018) collected data from (1) a questionnaire survey of National Seniors members aged 50 and over and (2) qualitative interviews of client/care worker dyads.

McCallum, Rees and Maccora (2018) reported that older people receiving the Commonwealth Home Support Programme and Home Care Packages were satisfied with the service. However, evidence suggests most people are satisfied with their health care service regardless of the quality of the care they receive – even those who have negative experiences are satisfied with the care they received (Worth 2013; Haggerty 2010; Kalucy et al. 2009). This is particularly the case for older people. A US study of older patients found that their level of satisfaction with the quality of their health care was not a good measure of the quality or effectiveness of the health service (Mold et al. 2012).

McCallum, Rees and Maccora's (2018) qualitative interviews of client/care worker dyads reported "*strong agreement that aged care workers treat the household with respect, know what they're doing, and are well trained*". However, interviewing clients and carers together can be problematic. Clients might have feared retribution if they spoke honestly in front of a carer (Coyle and Williams, 1999). Also, a health service's culture may prevent staff being critical, particularly when a client is present during the interview (Moore, 2012).

Although McCallum, Rees and Maccora (2018) reported "a strong positive accent to consumers experiences" (p 4), they identified a range of issues including:

- Waiting too long to be assessed, and having to accept a lower level package until a higher one became available;
- Services being delivered at times or in ways that were inconvenient to the client;
- A lack of continuity of care for older people with dementia and poor training for dementia care;
- Lack of duty of care and the occurrence of theft;
- Poor communication from the provider, and poor administration of services generally; and
- Failures in the delivery of consumer directed care

Research method

Ethics

Peninsula Health's Human Research Ethics Committee (HREC) approved this research.

Recruitment

The aim of the recruitment strategy was to inform recipients of in-home care in Australia and their family members about this study. Those who were interested in participating were invited to contact the researcher.

The following recruitment strategies were used:

1. Invitation letter

Peninsula Health sent a letter to clients inviting them to participate in the study (Appendix 1).

2. Community engagement

A community engagement method was used to recruit older people who receive in-home care and their family members. Opinion pieces in newspapers, television appearances and radio interviews encouraged people to visit the Aged Care Matters' website and Aged Care Matters Advocacy Facebook Page. The recruitment flyer was published on the Aged Care Matters website (Appendix 2). Information about the research was also published on the Aged Care Matters Advocacy Facebook Page.

Those who expressed an interest in the research contacted the researcher. They were emailed a Participant Information Sheet to help them decide whether they wanted to be interviewed about their experiences of in-home care.

3. Flyers

Flyers were circulated to colleagues via email.

4. Community forum

A community forum was held to discuss the changes in the provision of home care services and how these changes may affect residents who live in the City of Darebin, Melbourne, Victoria. Dr Russell was the master of ceremonies (MC). Audience members who were interested in participating in the research later contacted Dr Russell.

5. Snowball technique

This widely used qualitative research technique involved asking participants to tell other potential participants about the project.

Inclusion criteria

To be included in the study, participants must (1) have been assessed for a home care package, irrespective of whether the home care package had been assigned or (2) receive the Commonwealth Home Support Programme.

Data collection

Data was collected via either face-to-face or phone interviews between September 25 and November 20, 2018. Some older people were interviewed alone; others chose to have a family member present. In several cases (e.g. recipient was cognitively impaired, asleep during time of the interview) the family member spoke on behalf of the older person. One participant had died recently – his wife spoke about the in-home care he had received. Most interviews were between a half and one-hour duration. Four interviews (Participants 3, 9, 15 and 17) were longer – between one and three hours.

Participants 3, 17, 19 and 21 communicated with the researcher via email after the interview. This correspondence has been included in the data.

The interview schedule was semi-structured with open-ended questions (Appendix 4). Participants were asked to reflect on their experiences of in-home care.

With participants' permission, the interviews were tape-recorded. The recordings were transcribed, though not verbatim. Only data relevant to the research questions were transcribed.

Sample

The sample contained 40 participants from urban, regional and rural Australia.

The average age of participants was 80 years (range 66 – 95 years; median 83 years).

Table 2 describes the type of in-home care that has been approved and assigned at the time of interview. Several participants had transitioned from the Commonwealth Home Support Programme to a home care package. In addition, several participants had transitioned from lower-level packages to higher-level packages.

Table 2: Participants' age and details about their home care package/Community Home Support Programme

Participant Number	Age	Approved	Assigned
1	81	4	4
2	81	2	CHSP
3	75	4	4
4	72	4	4
5	83	2	2
6	94	4	2
7	85	3	CHSP
8	91	3	3
9	67	4	4
10	89	CHSP	CHSP
11	75	2	2
12	83	4	4
13	90	3	3
14	88	4	4
15	68	4	4
16	87	4	4
17	72	4	4
18	88	2	2
19	88	2	2
20	95	3	3
21	69	4	4
22	79	4	2
23	74	4	4
24	86	4	No Package
25	92	4	4
26	89	4	2
27	81	3	2
28	70	4	4
29	72	CHSP	CHSP
30	85	4	4
31	85	4	4
32	Did not meet inclusion criteria		
33	77	3	2
34	82	2	No Package
35	86	4	3
36	71	CHSP	CHSP
37	90	2	2
38	66	2	2
39	92	2	2
40	85	4	4
41	83	2	2

At the time of interview, three participants had been approved for the Commonwealth Home Support Programme. The other 37 participants had been approved for a home care package.

All three participants approved for the Commonwealth Home Support Programme were receiving services from this programme.

Of the 37 participants who had been approved for a home care package, 33 were assigned a home care package, two were assigned the Commonwealth Home Support Programme and two did not receive any services funded by the Australian Government.

Participants were not always assigned a home care package at the level at which they had been approved (Table 2).

For example, although 22 participants were approved for a Level 4 home care package, 16 were assigned a home care package at Level 4, two participants at Level 3 and three participants at Level 2. One participant who had been approved for a Level 4 package was not assigned a home care package. He funded private support services. This participant died before being assigned a home care package.

Data analysis

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

On 27 November 2018, a draft report was sent to five participants, the Commonwealth Department of Health and three colleagues at Peninsula Health for feedback. Their feedback was included in the final report.

The final report was submitted to the Commonwealth Department of Health on 19 December 2018. On 18 January 2019 and 12 February 2019, the Department of Health provided additional feedback.

Strengths and limitations of the research

A sample size of 40 allows some confidence that a wide range of views has been captured. However, the results of the research are not intended to be generalisable, nor was the sample representative in the standard scientific sense.

A strength of this research is that it explored non-professional perspectives of in-home aged care. A further strength is that the researcher does not work in the aged care sector or for a government agency. This enabled participants to speak frankly. Research shows a disinclination for people to be critical of health services in face-to-face interviews with staff who work in the sector because of not wanting to jeopardise their treatment/care or a fear of consequences (Wessel et al. 2012; Coyle and Williams, 1999).

A researcher who does not work in the aged care sector or for a government agency also ensures data is analysed without any conflicts of interest.

Another strength of the study is that respondents volunteered to participate in the research. Unlike surveys that are sent to all members of a 'consumer' organisation (including those who are uninformed about an issue), self-selected samples ensure that 'consumers' who volunteer are informed about the issue.

Self-selected samples may be biased toward people with strong opinions – both positive and negative. In addition, self-selected samples may have included people who want to improve the future delivery of Home care packages and Commonwealth Home Support Programme. This was noted in Part 1, Section 6 of the Participant Information Sheet/Consent Form: "a potential benefit is you will be contributing to research that may help to improve the future delivery of Home Care Packages and Commonwealth Home Support Programme" (Appendix 3).

Finally, Dr Russell is a public health researcher and an aged care advocate. Her role as an aged care advocate may have encouraged participation from older people and their family with negative experiences of home care packages to volunteer.

Findings

In this section, all text in quotation marks and italics are direct quotes from a participant. In longer quotes, a number identifies the specific participant.

Effort has been made to ensure that all participants have a voice, and that no individual participant dominates the discussion. However, interviews with four participants (Participants 3, 9, 15 and 17) were much longer than the other interviews. This was due to the amount of information they wished to share. Their insights have been quoted extensively.

It is also worth noting that Participant 24's daughter works in the aged care sector. Her business helps clients to find the most suitable home care provider. During the interview, she spoke from the perspective of a 'consumer' and a provider.

As is customary in reporting qualitative data, terms such as "most", "the majority" and "more than 50 per cent" 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 20 participants. When more than 20 participants share a specific insight, a general descriptor "participants" is used.

Both participants and providers have been de-identified.

This section is divided into three parts:

A. Positive experiences of in-home care
B. Negative experiences of in-home care
C. Ideas for improving in-home care

Several participants had received in-home care for more than five years. They had experienced the system before and after the aged care reforms. They questioned why the government chose to fix a system that was not broken.

> *Sometimes I wonder: "Why fix something that's not broken?" I think it was because the providers were holding on to the cash, and gouging. I spoke with one provider who boasted: "We are holding $3 million in the bank. That is going to be our profit." I was thinking: "That is terrible. The people are needing the care." That was when providers were holding on to the money and divvied it up. (Participant 24)*

Positive experiences of in-home care

Remain living at home

When asked what was the best thing about in-home care, participants unanimously replied: "It enables me to live at home."

> *The best thing about home care packages is that you are able to get support to live as well as you're able for as long you're able in your own home, if that's what you want to do. (Participant 15)*

> *I am very grateful for this package. It has enabled me to live in my home. Without these services, I wouldn't have been able to stay here. I couldn't do it all myself. I am delighted with the help I get. It has been a godsend. (Participant 18)*

It was not only personal services (e.g. personal care, cleaning, shopping, gardening) that assisted older people to stay at home. Some older people also benefitted from home modifications, equipment, technologies and other products.

> *Having the package is great with all the things I can get to help me at home – products. That is fantastic. If I had to pay for all the things I need to keep my husband at home, we couldn't do it. The package money is a great help. (Participant 21)*

The ability of older people to remain in their own homes benefits not only individuals but also families and the local community.

> *Without home care support, Dad would be fully dependent on me. (Participant 20)*

> *This scheme for the elderly is god's gift. It gives my son in Queensland peace of mind. It gives our daughter peace of mind. It goes much further than the individual. The community – most people know me. It is hopeful that I am still giving to my community – not as much as I'd like – but I'm still giving. You can't put a price on those things. (Participant 7)*

Several participants acknowledged that without in-home support, they would need to move into residential aged care.

I couldn't live at home without help. I have no one to help me. Now that I am paralysed on my left side, the home care package is like a second hand for me… Best thing – it helps me to live independently. If I don't have this help, I can't do anything. I am on a pension – I couldn't afford to get help. I would have to move to one of those institutions. (Participant 4)

Several participants expressed fear about moving into an aged care home. An older woman said she would prefer to kill herself than "*go into one of those hellholes*". Recent negative stories in the media had made her terrified of moving into an aged care home.

What I did know was I was not going into a nursing home. I was coming home. I absolutely wanted to stay home. (Participant 1)

Indigenous Australians were also reluctant to move elders into an aged care home.

Aboriginal people do not want to put their loved ones away. That's why the packages are good. We have packages at Aboriginal Community Elders Services. We have about 60 packages at the moment. (Participant 41)

My Aged Care

Staff at My Aged Care were described as "*friendly*", "*efficient*" and "*empathetic*" people who answered phones promptly.

On the phone, they were quite helpful and very polite. And thank goodness you don't have to hold on for too long. (Participant 16)

Planning ahead

Some participants arranged a home care package in advance of needing help in the home. They knew they were ageing, and they knew sometime in the near future they would need support to stay at home. They decided it was better to get into the queue early.

I work on the philosophy of being prepared for things. I knew I was getting older. And I know how bureaucratic systems work. I thought I should find out about the system, and get involved, in case I should need it. (Participant 11)

We were advised to apply for a Level 4 package now – even though Dad doesn't need it yet. It will take about a year to come through. (Participant 8)

My sister insisted I apply for a package. I live alone and have had a few falls. My sister arranged an assessment. I've been approved for a Level 2 package. But I don't need any help yet which is lucky because I have been told it will take at least nine months before I get it. (Participant 34)

Some participants were advised by others to get some support in their home.

It wasn't so much me realising I needed help but other people realised…I was in a mainstream package at first. Other people said at my age with all that I've done I needed to be looked after. One of the non-Aboriginal nursing supervisors at Aboriginal Community Elders Services phoned me to say: "Auntie, I'd like to set up an assessment interview because I think it would be good for you to have some support." That was about 10 years ago. (Participant 41)

Paperwork

Participants described the written material (e.g. brochures) they received with their approval letter as "*helpful*".

They sent me a lot of paperwork – brochures, advance care planning. It was a substantial package. One of the brochures has a check list for researching home care providers. That is helpful. And a check list for entering a home care agreement. (Participant 2)

Approval letter

A participant described receiving the approval letter as "*like winning Tattslotto*".

By the time Level 4 came through, all I cared about was the first page. "You're approved." And it would have been thrown in the drawer after that. (Participant 3)

After receiving the approval letter, several participants accessed the Commonwealth Home Support Programme while they waited for their package to be assigned. Others relied on family support.

While we were waiting, we had no help except from our family. (Participant 12)

Family support

Participants who described their in-home care working well invariably had family support.

> *How could home care work without supportive children? (Participant 19)*

Several participants said they would not have been able to remain at home without their family supporting them.

> *My husband can't be left alone. My sister-in-law was on standby if I needed to go out to look after my sick mother during the night. (Participant 28)*

> *I could not survive on the home care package without my husband. You have to have a daughter or partner to manage the home care package. (Participant 17)*

> *Dad manages on the package because he lives with my partner and me. He wouldn't be able to manage on his own. (Participant 8)*

Some participants said the home care package was meeting the needs of their parent/partner because a family member advocated on their behalf.

> *It is meeting Dad's needs because I spend so much time advocating, checking everything, challenging the system and asking questions. Every day, I am doing something. If I wasn't here, I have no doubt that Dad could not stay at home. (Participant 19)*

A participant said he and his wife would not have known "*where to start*".

> *My daughter does too much. But we couldn't manage without her. We wouldn't have known where to start. (Participant 19)*

Another participant described her father as "*dependently independent*".

> *Dad is 'dependently independent'. He can still shower himself and put food that I have cooked in the microwave. The carer does seven hours and I do about the same. Plus I do office work. As long as everything is done for him, his life runs like clockwork. He has a good social life – goes out for meals, is a member of Rotary and the Melbourne Cricket Club. (Participant 20)*

A participant who requires assistance in the morning and evening said her Level 4 home care package is not sufficient to buy the care she requires. Fortunately, her husband is able to assist her on the evenings the support workers are unavailable.

> *I'm on a Level 4 package. I get help to get out of bed in the morning, shower and dress. And in the evening, they help me to bed. Seven days a week in the morning, five days in the evening. My husband helps me the other two evenings. It is very expensive on weekends. It all gets back to money. I can't afford carers in the evenings on weekends and public holidays. (Participant 1)*

Waiting for a home care package to be assigned

Commonwealth Home Support Programme

Several participants described receiving the Commonwealth Home Support Programme while waiting for their home care package to be assigned. At Budget estimates (June, 2018), the department stated that about a quarter of the 105,000 older people in the home care queue were accessing the Commonwealth Home Support Programme.

Local councils, private for-profit providers and not-for-profit providers deliver the Commonwealth Home Support Programme. Some participants described the services with the Commonwealth Home Support Programme and a home care package as "similar". Home care packages, however, have the advantage of allowing people to "*save up money*".

> *After Mum's stroke, I became Mum's full time carer. We were on a waiting list for a long time for a Level 4. So Provider X offered us a Commonwealth Home Support Programme until we got the package. Carers came in five mornings a week for an hour. She also had regular physiotherapy. Also an occupational therapist recommended specific equipment. We got everything we needed. The only thing we had to buy ourselves was the hospital bed. They serviced all the equipment. It was brilliant. I learnt a lot from the carer, including how to use the hoist. We were also given a lot of information about our entitlements. I found the case manager of the Commonwealth Home Support Programme much more proactive than the home care package case manager. (Participant 30)*

A participant described the services he received from his local council (under the previous Home and Community Care program in Victoria) as better than services he received on a Level 1 home care package from a private provider.

> *While I waited in the queue, the social worker at the hospital arranged for the local council to help me. I got meals on wheels, someone came twice a week to*

help me shower, and they cleaned my house. Several months after I left hospital, I got assigned a Level 1 package. The council help finished. The council's case manager said to me: "Now you must find your own provider." She recommended Provider I. Someone came twice a week to help me shower and cleaned a little bit – but it was not enough. It was better with the council. (Participant 4)

Self-funding services

Several participants paid for services while waiting for their home care package to be assigned.

I employed a care provider 12 hours a week to help Dad's partner. He also had other family support… Dad put money aside for a rainy day. So we are using it to purchase care for him. (Participant 24)

After being assessed for Level 4 plus, we had to wait for six months. We were told we had to wait until someone who had a package died or went to a home. My partner was placed as a priority. While we were waiting, I got hold of a community provider who gave us four hours a week. We paid for that ourselves. (Participant 15)

Choice

Choosing providers

Some participants chose providers purely on cost. Others based their choice on the quality of the service.

I compared the costs of Provider E with Provider K and there was a 25 per cent difference. Provider K was much more expensive. And that didn't include the daily care fee ($10.17 per day) that Provider E has never charged. (Participant 20)

Even though I am paying more, I'm happy because they are giving me such a good service. I am happy with every aspect of this provider. (Participant 28)

A participant described "*loving*" the philosophy of a specific provider.

I love the philosophy of Provider F. They match regular carers with the person's situation. And try to keep that regularity. They are also the only providers to have an app – and the app has GPS on it. It can notify the care recipient or carer that the staff is 2km away. The GPS also provides reassurance. You know by the GPS that support workers are in the home for the time they say they are in the home. (Participant 3)

Several participants used personal and professional contacts to help them choose a provider. Others used more objective information.

I used some of my professional contacts to find out who are the best providers. They replied: "Who knows?" I phoned lots of them. In the end, it boiled down to cost. This is where it gets complicated. Provider E was cheaper but really short staffed. They told me they don't have many carers – they outsource them. It was in my best interests to keep the same carers Dad had on the Commonwealth Home Support Programme. So I requested Provider V even though their fees were higher. (Participant 19)

I attended a wellness Expo. All the providers were there. The ones that got kicked off my list were the big companies. They don't have their own staff. I put four providers on a short-list. They came to my home to interview me. And I made up my mind to go with a smaller provider – the woman was extremely helpful and explained everything that I was entitled to and what they could do for me. (Participant 26)

Several participants said hospital staff recommended they use a large provider. They were told that large providers were less likely than smaller providers to go broke.

We were given a list of providers. It was impossible to decide which one was which. So we went with the social worker's recommendation. She went through the ups and downs of each one. The strongest factor in favour of L provider was they are the biggest supplier in Australia. A lot of the other ones were small operations. We could rely on the bigger one not to go bust. And also we expected them to have stand-ins if someone was sick. (Participant 8)

Several participants suggested the large providers all offered a similar service.

Provider BB is taking a very large cut for themselves. But all the big providers seem to do that. I phoned three of the biggest providers in our area, and they all said Level 2 gives three hours of support a week. (Participant 26)

Choosing how package is spent

Several participants were unsure about how they could spend their home care package. Those participants who asked questions, challenged case managers and advocated strongly were often told: "*Yes.*"

When I asked the case manager: "What can we use the package for?" she just skimmed the surface. However when I asked if we could use the package for this or that, she would say "yes". I asked Provider E if they could reimburse Dad's nutritional supplements. The case manager initially said: "No." I challenged this – and then the case manager said "yes". I am constantly advocating for Dad. (Participant 19)

When it became hard to walk, I got an electric wheelchair on a trial. During the trial period, a case manager told me I should be able to get that in my package. I hadn't thought of that. You just don't know what you can get. So I asked and I got it through my package. (Participant 1)

A participant described herself "pushing the boundaries" when spending the money in his home care package.

I had $3,000 in my package. I requested a clothes dryer for the winter. The case manager said: "No, it's not on the schedule." I asked: "What schedule?" As far as I know, there isn't one. I had been able to get an air conditioner, vacuum cleaner, computer but not a clothes dryer. I was going on the philosophy of customer directed care. So I gave them good reasons for why I wanted it, and why I needed it. (Participant 11)

Changing providers

Participants understood the process of changing providers. The difficulty, however, was how to be confident another provider would deliver a better service.

I think I just have to say to them: "I'm changing providers." But I have to find another provider and somehow assess them to be a better proposition than what I am getting now. That is a big question mark. How do you know they are better? You don't know what they are like until you start using them. (Participant 1)

Some participants were conflicted about changing providers. Although they described their current fees as "*excessive*", some participants had formed a relationship with their support workers. Other participants focused only on the fees.

When changing providers, the only thing I asked about was their fees. (Participant 11)

I'd change providers but I'd lose these lovely girls. I don't want to rock the boat. (Participant 5)

I know there are other providers who don't take so much money out in fees as Provider JJ. But she likes the support person who visits her. (Participant 37)

I was concerned that I would lose my support person. She was so good. I asked my new provider if I could continue with her – and they said "yes". (Participant 18)

Several participants subsequently moved from a big provider to a smaller one. They found the smaller provider provided better, more person-centred care than the large providers.

Provider Z was a brand new company. She sounded so nice on the phone. She had no health background but had issues with a relative in a nursing home and decided to get into home care packages. They offered 20 hours a week of personal care on a Level 4 package. This is more than the big providers offered. More importantly, they offered us these two amazing women who had experience with dementia care. Mum loves them. Her face lights up when she sees them. (Participant 23)

Changing to a smaller provider has allowed my partner to have more hours of care with more suitable staff. Most importantly staff have dementia training. Provider O did not provide any training to their staff. (Participant 15)

I changed to a much smaller provider. I could not believe the difference between Providers Q and J. Firstly, the case manager is in contact weekly to check how things are going. She makes suggestions about services for my husband – things I did not know he was entitled to have. She also recommended a male carer who is so good. (Participant 16)

Participants who changed providers described being much happier with their new provider than with their previous provider.

I wanted to change provider so I phoned Provider J. I was on Level 2 at the time. She asked me what services I wanted. She gave me all the information. I had to wait a month before I could swap over. And then I got a carer to look after me. It was the same person each time… I told the new provider: "I need someone who understands what I need. I need the same person so I don't have to explain everything each time. Provider J was able to do this. So when the carer arrives, she starts to work immediately – she knows what I want done and how I like it done.

If we run out of cleaning supplies, she writes it on my shopping list. (Participant 4)

Exit fee

Participants did not consider the exit fee an obstacle for changing providers.

We've heard of a small provider who seems very caring. We will wait until she builds up her business a bit. Mum is very attached to one of the care workers. That is the only thing that keeps us with Provider X at the moment. Provider X has an exit fee – but that is not the obstacle. (Participant 30)

Consumer directed care

Participants who were informed about consumer directed care felt they were in a stronger position to negotiate with providers.

At one stage Provider GG said they were going to rotate the roster. I told them if they take [name of care worker] away, I would take my funding elsewhere. I work in the sector so I know I can take Dad's funding anywhere I like. I know I can negotiate. Most people wouldn't know that. (Participant 40)

Self-managed care

Some providers offered self-management as an option – though still charged case management fees.

Provider E offers self-managed as one of their options. However, Provider E charges the advisor fee $272 even though I am not using it. I would be happy to pay an hourly rate if I ever needed to contact the advisor/case manager – on a client-initiated basis. So everywhere they can, they are making money. (Participant 20)

Two participants genuinely self-managed their home care package. The provider was described as "*brokering*" the money rather than "*controlling it*". The providers of self-managed packages charged somewhere between 10-13 per cent of the package in fees. Participants considered the fees for a self-managed package much more reasonable than the fees they had paid their previous provider.

The self-managing is like a gift from heaven. I do not have that middleman. So I can create space for just the carer and myself to make my own arrangements as we see fit. (Participant 17)

A few months after her interview, Participant 17 wrote:

"I am constantly being rewarded with my self-managed package. Yesterday I tried a new carer while one of mine is away. I can't believe what amazing people I am meeting who have compassion, empathy and intellect. Yesterday my carer was a social worker unable to now work full time who lives right near me. I really like the ones who can come any time for you and are not stressed going from one job after another. After being house-bound for so many years, it's such a pleasure now to go out in the world and share my social support time with like-minded people who nurture me. I woke up today feeling so blessed. I now am making some really nice friendships and it's all about me and not obeying the providers rules." (25th October, 2018)

Hiring support workers

The two participants who self-managed their home care package employed support workers via an internet platform. They considered the hourly rates more reasonable than the hourly rates they had paid their previous provider.

Because I'm paying the carer half what I used to pay the agency, I can afford to have her here twice as long… and because they are working for themselves, they are so eager to please. (Participant 17)

The biggest problem with carers on these platforms is most want time blocks. They want three- or four-hour shifts. The aim is to try to find someone within a kilometre of the local area. You figure if they live a few streets away, they won't mind doing half or one-hour shifts … It took me ages to find regular carers through [platform]. But once you find those gems, then you've got them. Mum had three regular people per week through that platform that remained consistent. I found them as local as possible, and they were prepared to do short shifts. The reliability of private carers is brilliant because I hired them and have gotten to know them. (Participant 3)

Spending funds creatively

A participant who self-manages her mother's home care package describes spending the money "creatively" to assist her mother's quality of life. Although the participant refers to "guidelines", the Commonwealth Health Department publishes "booklets, videos, newsletters, fact sheets, other supporting websites and interpretive services", not guidelines.

The guidelines of what you can have are quite grey. And that greyness works to the consumers' advantage. You can push the boundaries a bit. Provider D says: "We've never seen anyone spend so creatively." Because I buy a lot of technology products to help my Mum. People don't realise they are entitled to make their own choices. I also use a company H – another great company. They digitalise the photos and give Mum iPad lessons. Mum adores the company H worker. I have also paid a company to do a storyboard of Mum's likes and dislikes. This is so important in Mum's case – because staff only see the angry, hostile older face in front of them now. (Participant 3)

Staff

Case managers

Participants described the case manager as integral to the quality of the service, particularly in the early days of receiving a home care package.

The case manager was excellent. She helped us a lot at the beginning. Now that everything is in place, I don't need to call her. She visits me once every six months to check that everything is OK. (Participant 8)

Participants said they valued case managers who provided information about services and other entitlements.

I can't believe how good the case manager has been to me. She gives me information I don't even know I need – you can't ask questions if you don't know what to ask. The case manager told me about the cognitive and dementia supplement and arranged the test so we could apply. Without her telling us about it, we would have missed out. (Participant 28)

The case manager is very informative. She comes out once every three months to see how things are going. Each time she reminds me of things I am entitled to have. She recommends I leave my hours as they are so I can accumulate some funds to get the equipment I may need down the track. She is really good. (Participant 28)

Participants appreciated case managers who visited their home regularly. These case managers made suggestions about support services, including recommending an assessment for a higher-level package when an older person's health deteriorated and/or needs increased.

I met regularly with the case manager as Mum's dementia worsened, and her needs changed. The case managers were pretty good – offering good ideas on what would support Mum. (Participant 40)

Provider J's case manager is proactive. I don't feel like I'm on my own. She regularly visits and asks how things are going. Is there anything I need? (Participant 16)

My case manager is Aboriginal. She is not a registered nurse but has had a lot of training in aged care. I feel comfortable to phone her. I have her mobile. Even if I wanted to talk about something that I know she is not going to be able to respond to – it might be something I just want to get off my chest, I can. She's a good listener. She also visits me here once a month – or more often if I want. (Participant 41)

Participants were grateful when they were able to form positive relationships with case managers. Participants considered themselves lucky when they had the same case manager for a considerable length of time.

It's important for case managers to form relationships with families. It is extremely important that there is a go-to person. That you have a name and an email that is a go to. Someone to talk with when I am concerned about Dad. (Participant 40)

The case manager at Aboriginal Community Elders Services phones a couple of times a week to see how I am. The other mainstream provider never ever did that. It was like they were a business and I was just a number. They were there to make money. That's where Aboriginal Community Elders Services is different. It is a community-minded program. They are not there to make a profit. They concentrate on our wellbeing. If you ask for something and they can't give it – they will explain it. They don't say: "Yes we'll get that for you and then leave you sitting on a limb waiting." (Participant 41)

Participants appreciated case managers who were easy to contact and responded promptly to phone calls and emails.

I feel comfortable to phone my case manager. If I ring during hours, the girls on the phone tell me whether my case manager is in the office. If she is out, she phones when she comes back. She is pretty good; 3-4 out of 5 for phoning back. If she doesn't phone me back, I phone again. (Participant 1)

Provider J's case manager has given me her mobile number. I don't have to leave messages at the office. I can talk with her any time. She comes here every month to give me the statement and explain it to me. We talk a little bit about how things are going. If I want to change anything – if something's missing, or I want to stop something. If I want to do something different, I tell her. I plan my support with her. (Participant 4)

We have good communication. I email and she always replies within 24 hours. I can see how this may not work for older people. (Participant 20)

Support workers

Participants who lived alone described the support workers as their only visitor on some days. They valued the social contact as much as the personal care.

They are wonderful, they are good company, cheerful, do anything for me. These women are like my daughters. (Participant 27)

The council staff usually come a bit earlier and stay a bit longer to chat with me. They are often the only people I see during the day. (Participant 5)

If you live on your own, it's like company and something to look forward to… I look forward to the visit from my carer. Knowing there is someone there who I can lean on. It's not so much they will come in and clean my house – I know some people on packages look for that type of support. But it's having a friend who I can lean on, turn to, go out with. It's company. (Participant 41)

Some participants appreciated being able to choose their support workers.

We got council help first. That was quite good. We got cleaning and gardening. The best thing about the package is we can choose who can come to our house. We didn't have that choice with council. (Participant 14)

We were lucky. Provider E allowed us to use our own carer. (Participant 20)

I always ask for older carers. Some are very good because they have worked in nursing homes. (Participant 19)

Participants appreciated meeting the new support workers before they began working in their home. They also liked it when new support workers spent some time "*buddying*" with the regular support worker. They also valued a support worker who provided a handover to a new support worker.

Prior to getting a package, the local council and a charitable organisation (Provider N) supported us. A manager always introduced us to a new person. We would all sit down together and the new person would decide if they were comfortable with us and we would also decide. It was civilised. Provider M was supposed to do that but they never did. (Participant 9)

When new staff are employed, they buddy with the regular person so Dad gets to know them. (Participant 40)

When I changed support worker, there was a handover. "Auntie likes this, she doesn't like that. Don't bother with this." It was helpful. (Participant 41)

Participants appreciated knowing in advance who would be working in their home and when they were expected to arrive.

The case manager emails me the roster every week to confirm who's coming. If it's someone new, I leave a list. If it's someone who comes here all the time, I am able to just walk out the door. (Participant 28)

Since I've changed provider, my carer is always on time. I have the same carer each time. Since the day I started with Provider J, my carer has never missed a shift. (Participant 4)

Participants preferred to be able to communicate directly with their support workers rather than via a case manager or a receptionist.

One of the best things about Provider J is I don't have to communicate via the case manager. I talk directly with the carer. (Participant 4)

I talk to Dad's support workers every day. Some places you have to go through the case manager. As a family member, it's important that I can talk directly with the person who is directly supporting my Dad. (Participant 40)

We have a communication book. They write the times they were there. We can write in red if they need to know something. (Participant 39)

A participant was impressed with a support worker's professionalism.

Provider J has sent a carer to be with my husband a couple of times so I can go out. He spends the entire time just looking after my husband. That is exactly what he is supposed to do. He is professional. He is not texting on his phone like the other ones from Provider R – some were even on their computers. (Participant 16)

Participants appreciated support workers who stayed a bit longer than they were meant to stay. In some cases, a genuine friendship developed.

She sometimes stays more than an hour. But I am always only charged an hour. (Participant 4)

One of the girls who comes is like a friend. I like my own company but I do look forward to her visits. (Participant 5)

Participants appreciated support workers who were flexible.

If I need something different – I need to change my bed sheets – I just have to ask and she does this. (Participant 4)

A participant described what she thinks makes a good support worker.

The way they handle the whole situation. Some of them are quite chatty that I like. They are confident when they help me in the bathroom. They are experienced. (Participant 13)

Participants appreciated a case manager who matched the support worker with the recipient.

[Name of carer] is patient, non-intrusive. It's her personality. She is a very good fit for my parents. (Participant 40)

Some participants who did not speak English as their first language preferred the support worker to speak their language. Others considered the support workers' abilities more important than speaking their language.

The council came first. But Provider J is better because the case manager speaks Mandarin. She arranges people to come to my home who also speak Mandarin. It is difficult for council to get this type of staff. (Participant 6)

We felt the carer's abilities were more important than them speaking Greek. We tried some Greek-speaking carers, but Mum and Dad thought they wanted to know too much. (Participant 19)

Several participants changed providers because they valued support workers who spoke their language or shared their culture.

Both my wife and I on a package – Level 4 and 3. We changed providers because we found a provider with carers who speak Mandarin. They are also able to cook Chinese food – which is good. Provider J not only gives us a statement in both English and Mandarin but the case manager explains it to us. We could not understand the statements we received from the previous provider. (Participant 12)

Some participants organised extra shifts with their support worker. They funded these extra shifts privately.

I employ the carer for an extra four hours. I pay her more than the agency pays her, but less than I pay the agency. So it works well for us both. (Participant 23)

A participant described staying in touch with her support worker after the support worker left her job.

When my support worker left, her boss told her not to contact me. She was my friend. It must be something to do with them being worried I would follow her to her new provider. But she was moving miles away. We couldn't work it out. She still phones me, but she feels a bit nervous about it. (Participant 41)

Home Care Agreement

Some case managers explained the content of the Home Care Agreement before asking participants to sign it. Even so, some participants had difficulties understanding all the details.

I have a new contract now with Provider J. The case manager has explained the contract to me. This time, I understood what I signed. With the previous provider, I just signed it without understanding what I had signed. (Participant 4)

It was important for the provider to go through all of that with us. But I wasn't paying a lot of attention to the detail. (Participant 9)

Daily fee

Everyone receiving a home care package may be asked to pay a basic fee. This fee is 17.5 per cent of the single age pension rate per week. Recipients are also means tested to determine whether they are required to contribute an additional amount, known as the 'consumer' contribution.

Several participants said their provider waived their daily fee and means tested contribution.

> *Some providers charge a daily care fee and some don't. Provider O did. My partner was losing $115 from her pension. Our new provider doesn't take the daily care fee. (Participant 15)*

> *The provider waived our contribution and our day cost. (Participant 14)*

Some participants described their daily fee and means-tested contribution ceasing when they received a higher-level package.

> *Provider Q charged us a daily care fee when my husband was on Level 2 but we pay nothing on Level 4. (Participant 16)*

> *Once Mum moved to Level 3, they stopped charging the contribution. That must mean they get more money. (Participant 13)*

Palliative care

A participant described receiving all the help she needed to support her husband to die at home.

> *They were absolutely wonderful. We got all the help we needed. It gave me the confidence and support so my husband could die at home. The only problem for me was getting enough sleep. At one point, our GP insisted I take a break. The provider offered 24-hour care for three days but my brother offered to sleep here overnight. The carers came for two hours morning, lunch and evening – to help with showering, dressing, meals. And the nurse came to attend his wound care. They also arranged for the podiatrist to come to the house. My brother had to go to hospital for a day, so they sent a carer for 10 hours. I didn't take much notice of the invoices. All I cared about was he got all the care he needed. (Participant 31)*

Person-centred care

Some participants described their experiences of person-centred care. Participant 40 was thrilled when the home care package provider agreed to allow her father's support worker to be with him when he visited his wife in an aged care home. During her shift, the support worker is responsible for the father and the aged care home is responsible for the mother. The participant was delighted when the provider and aged care home gave permission for the support worker to take the mother and father for outings.

> *Seven days a week, the same two women come for about 30 minutes to make Dad a cup of tea, make him a sandwich and have a chat. While there, they check he had his morning medications. I phone every day at 5pm – they answer the phone. Dad's deaf so they pass the phone to him. And they help Dad feed the cats. On a Wednesday, [name of carer] comes for about three hours to clean. She also does Dad's shopping, takes him to appointments – generally checks on him. She also comes for two hours on Friday. On a Thursday [same carer] comes to Mum's nursing home around 9am – she spends about five hours there with both Mum and Dad. As an example of Provider GG becoming more person-centred, they allow me to also pay [same carer] privately (in addition to the five hours) so she can take both Mum and Dad out in the car. We had to get that approved by management because it was the first time they had done that. It was a bit complex – with the package she is responsible for Dad. But now she is also responsible to take Mum. I was over the moon that they allowed it. (Participant 40)*

Connecting older people

A participant praised a program that connected people with early onset dementia who live at home. This program enabled peer support.

> *At that time what was then Alzheimer's Australia had a program called Young Onset Dementia Key Worker program. The key worker for our region contacted us. That allowed us to meet other people living with young onset dementia – and for peer support. (Participant 15)*

Ageing well

Re-ablement

Several participants described an older person's health improving with in-home care.

> *Dad would have been in a nursing home. By staying at home, he has improved quite a lot since the accident. (Participant 19)*

Social engagement

Some participants described feeling lonely and socially isolated in their homes. Some providers arranged social activities. Providing subsidised transport also assisted participants to engage with their community.

> *My new case manager was here the other day. She asked me if I was lonely. I replied: "Sometimes. Most times I am fine here on my own." She thought I needed more people with whom to talk. They are going to start me on a weekly outing. The bus is coming to take me to a talk tomorrow and there is lunch afterwards. (Participant 18)*

> *The worst thing for me was not having any transport. The package provided a taxi account. So long as I'm within my budget, I can use them as much as I like. (Participant 27)*

Aboriginal Community Elders Services

An Aboriginal elder transferred her home care package from a mainstream provider to Aboriginal Community Elders Services. This occurred before the 2017 reforms were introduced.

> *I asked to get my mainstream package transferred to Aboriginal Community Elders Services. That wasn't possible. However, they had a vacant package – and they put me on that. The difference was amazing. An Aboriginal elder going to an Aboriginal program was the way to go because they respect you. With the mainstream package, I was just a number. We're used to different things too. We're used to being respected. We're used to telling our story and letting people know who we are. I mean really know who we are. (Participant 41)*

Negative experiences of in-home care

Participants agreed that the concept of the home care package is "*fantastic*". However, some expressed concern about how some providers deliver it.

> *In concept, the home care package is fantastic. Brilliant. But there are not enough hours in it. These service providers are ripping off the government. (Participant 14)*

Beginning the home care journey

When participants became aware they needed support to stay at home, many contacted their local council. For a long time, councils had been the first port of call for older people seeking assistance to live at home. Several participants had never heard of My Aged Care.

> *I didn't know anything about these things. I only knew there was council help. (Participant 1)*

> *Years ago, when my grandmother needed help to stay at home, she used the local council and the district nurses. They were fantastic. She died at home. Now we have all this choice. But is it any better? (Participant 36)*

Local councils

Several participants were disappointed to find their local council no longer provided aged care services.

> *We used to go to the council. We trusted the council. But now they have given the contract to Provider H. (Participant 7)*

> *I had two years with the local council. I was very happy with the girls who helped me to shower and get dressed. And then I was told the council could not provide this service any more. I had to find someone else to do it. (Participant 8)*

Some participants described feeling angry that their council had outsourced their services to private providers. In the past, Participant 10 had used a council worker to clean her gutters and windows. The council no longer provided this service. Instead, she is now required to employ a private provider to do this work. She is reimbursed a proportion of the cost.

The council has outsourced some of their services to private providers. Rather than clean gutters and windows, the council offers us a subsidy. I have to choose a service provider and then the council will reimburse half the fee. I don't want to choose a private provider. I trust the council maintenance people to do this. It seems to me that our council wants to get out of delivering essential aged care services. They want to focus on an aged friendly city. But it's not very friendly if council can't provide older residents with essential services… The councillors came to a community meeting and told us it would be good for older people to do social activities outside the home. That's all very well, but not if it means they won't help me with shopping and cleaning. The council has to do the essential things – particularly the people who need more help than I do – showers and things. It sounded to me like these councillors want to shove us over to the private providers. I don't like that idea. I've been a ratepayer here for 60 years. I feel angry that the council may not help me to stay at home. (Participant 10)

When my husband was dying, I had support from the council. I had no concerns with the council whatsoever. I've had a lovely man for the past six years. After my husband died, I was told I could continue with council services for cleaning until I got the package. Then out of the blue, I found out that the council had given the contract to Provider K. I am not as comfortable with them. They send young girls who don't know how to clean. And they often leave messages on my answering machine to change the day and time. (Participant 7)

Another participant was upset when she was unable to choose the local council as her home care package provider. She trusted the council support workers.

(Prior to being assigned a package), we used the local council and Provider N. And they were charging a minimal fee. We had two support workers coming for three hours each. They were great. We also had someone who would come to clean the gutters and other 'manly' things around the house – things we couldn't do. He was wonderful. But when we got a Level 2 home care package, the Provider M's district manager told us we couldn't use the council services any more. We had to use Provider M's services. I was upset about this…What really galled me was when the district manager cancelled them. She didn't say that she would be ringing the council. I felt really abused by phone calls being made behind our back. I was furious. One person who had been coming for two to three years never got the opportunity to say goodbye to us… With the council it was: "How can we help you?" They were just lovely. You could ring them up – and there was this friendly respectful communication that you'd have. And with Provider M it was always difficult, strained – they always made me feel as though I was being unreasonable. (Participant 9)

Rationing services

Prior to needing assistance, several participants were uninformed about the aged care system and their entitlements.

Prior to the social worker at hospital telling me about home care packages, I didn't know I was entitled to anything. (Participant 17)

Some participants suggested ignorance about their entitlements helped the government to ration services.

None of my friends who are all in their 80s know anything about these packages. They didn't think it applied to them. People here in the retirement village have no idea how to apply for it. I think that's the way the government wants it. They already have this long queue. If people don't apply, that's better for the government. (Participant 27)

Dementia and Cognition Supplement

People with dementia are entitled to access a Dementia and Cognition Supplement. For example, those on a Level 4 home care package receive an extra $5,015.92 per year.

As anyone would attest, dementia is an extremely expensive disease. Many things are a lot cheaper to do with someone who is elderly and frail – but people with dementia require extra services. I can't pop Mum in a taxi and send her to an appointment. She has to be supervised and watched the whole time. So that totally blows out the care costs. (Participant 3)

Several participants described health professionals being unaware of the availability of the Dementia and Cognition Supplement and the special test that is required to access the financial supplement. The Psychogeriatric Assessment Scales (PAS) is no longer used in hospitals or most memory clinics. This raises questions about why it is chosen as the test necessary to be eligible for the supplement.

Hardly anyone seems to know about the Dementia and Cognition Supplement. Because I'm resourceful, I knew that My Aged Care required the Psychogeriatric Assessment Scales (PAS). The mini-mental test that all geriatricians do is not valid in terms of getting that extra funding. So I raised this with Mum's geriatrician in hospital. I needed them to do the PAS test so Mum was eligible for the Dementia and Cognition Supplement. The geriatrician told me that that it doesn't exist any more – He said: "There is no Dementia and Cognition Supplement." I replied: "Actually there is and I just need this paperwork to be completed." I had to jump up and down for probably another month until Mum finally had the PAS test done. So eventually when she got her Level 4, we had that extra 10 per cent of funding. (Participant 3)

Participant 3 expressed her frustration about geriatricians working in a major public hospital not knowing to do the Psychogeriatric Assessment Scales (PAS) test. She was concerned older people with dementia may not be eligible for the Dementia and Cognition Supplement because health professionals were not doing the correct test.

Health professionals are all doing a mini-mental state exam. Under the legislation, the mini-mental state exam doesn't qualify someone for the Dementia and Cognition Supplement. If GPs and geriatricians working in a major public hospital don't know the PAS test is the correct one to be administered, how is government getting this information to them? It has crossed my mind that they don't make it known so people don't access it. (Participant 3)

After being informed about the availability of the supplement, a participant had difficulty finding someone with expertise to do the assessment.

The case manager told us that my husband would be eligible for the Dementia and Cognition Supplement. So I replied: "That's good. How do we get it done?" So she said that I should get the GP to do it. When I asked the GP, he said: "I don't know how to do this. I've never done this before. You need to speak with a geriatrician." So I wait until our next appointment with geriatrician. I ask her to do the test so we can get the extra supplement. She says: "No I can't do it. The GP has to do it. So I went back to GP and she said she would look it up, and do it. So she did it. Whatever she did, he didn't pass to get the supplement. I went back to geriatrician and told her the results. She said I must get it. I went backwards and forwards. After a lot of performance, my case manager found someone to do it. They didn't tell me that it would cost extra. It took six months. (Participant 28)

Family support

Several participants said they would not be able to remain at home without family support. A participant suggested the home care system explicitly relies on family support.

There is a document about a personal alarm service (MePACS) that describes everything going to the family first, rather than rely on the system. So the system is heavily geared towards all the responsibility falling on family. (Participant 3)

Children who are not available to support their parents had to trust that the home care support being provided was sufficient.

So many kids are caring from a distance – they are overseas, interstate or across other side of town. You literally have to have good faith that care is being provided. (Participant 3)

My Aged Care

Staff

Each time participants phoned My Aged Care, they spoke to a different member of staff. Some were knowledgeable; others less so. This made it difficult to access the required information.

> *I couldn't speak to a specific person. So each time I phoned My Aged Care, I spoke with a different person who gave different answers to my questions. I would hang up and phone again until I got the answer I knew was correct. (Participant 24)*

> *I am totally stressed out talking to all these people on the phone at My Aged Care. They all tell me something different. It's crazy making. (Participant 25)*

> *I phoned My Aged Care several times to ask them questions about this package. And they were completely and utterly hopeless. (Participant 17)*

Participants described staff at My Aged Care as "*call centre people*". They also described poor communication between staff at My Aged Care.

> *When I phone My Aged Care, no one ever knows what's going on. I get passed around the world. I recently had messages to phone My Aged Care about a referral. When I phoned, they did not know what referral I was talking about. This happened half a dozen times. (Participant 25)*

Some participants described staff at My Aged Care as "*inadequately trained*".

> *With My Aged Care, someone answered the phone quickly, unlike my experiences with Centrelink. They were friendly and efficient. However as soon as I mentioned dementia, it was assumed that the person was incompetent. I put my partner on the line, but the person seemed tongue-tied. Didn't know what to say. Remarkable. (Participant 15)*

> *My Aged Care is not a well-informed service. I question the qualifications, skills and knowledge of staff. Many provide a rote response. (Participant 19)*

Complex system

Participants described the in-home aged care system as "*complex and complicated*".

> *I've had two experiences – the first with my mother and more recently with Dad. I've had to deal with Department of Veterans' Affairs, Centrelink and now My Aged Care. The My Aged Care system is far more complex and complicated. There is a lot more bureaucracy involved. (Participant 20)*

> *I have a lot of experience in the disability sector. Aged care system is more difficult to navigate than disability. It breaks my heart to see the number of people who would be lost in this system. (Participant 40)*

Overwhelmed

Several participants described their experience with My Aged Care as "*learning as we go*" and a "*steep learning curve*". They described feeling "*overwhelmed*".

> *This is all foreign to me. I don't have a clue what is going on. I have a big L on my forehead. (Participant 16)*

> *People are overwhelmed – they get this letter that says they have 56 days. This may sound like a lot of time, but when my neighbour transitioned from council services to a Level 3 package, her daughter went in to such overwhelm that she lost her Mum's package… Most of us are in complete overwhelm… As Mum's carer, I am not elderly and frail, and I don't have dementia, but it is all still overwhelming for me… You can go on to the My Aged Care website and find out providers available in your area. It can spit out 50 or 100 results. Who is going to sit on the phone? How do they know what to ask them? They are brand new. (Participant 3)*

Reliable information

Participants said they had many questions about in-home care. However, some found it difficult to get answers from staff at My Aged Care, Australian Aged Care Quality Agency or Commonwealth Department of Health.

> *This is all way too much for frail elderly people to do on their own. And there is no single hot line you can phone that can answer every question … I'll make 20 phone calls if I have to - to get to the bottom of a situation. Some people would think I was exaggerating if I said I was on the phone for eight hours but I cannot tell you how many days I've spent eight hours on the phone. Mostly because you get bounced from place to place. The commissioner will say: "You're not quite us." They might send you to the Quality Care Agency. Then they will say: "Technically that doesn't fall under us." So who does it fall under? I even email questions to the [Commonwealth] Health Department. They are supposed to respond within 10 days but they don't. (Participant 3)*

I would be transferred from My Aged Care to department to department and then back to My Aged Care. I would spend five hours on the phone trying to find answers to my questions. It was like stepping on to a merry-go-round. (Participant 37)

At the beginning of their "*journey*", several participants described being inundated with information.

The trouble when you first start out with all this is too much information. It's all given to you in pamphlets. I was given all these phone numbers and pamphlets. And then providers started phoning me. I would reply: "I'm sorry but I don't know why you're calling me." Everything is abbreviated – and I would have no idea what that is for. I realised some people were phoning me because they were being kind (e.g. Alzheimer's Australia or someone following up from a help line), or someone from a service provider. I couldn't distinguish. (Participant 28)

Despite the numerous fact sheets, brochures and pamphlets, participants had many questions. They described finding it difficult to get reliable and consistent information.

It is really hard to get correct and consistent information. The people with whom we interact need to be better informed. My Aged Care, Centrelink, case managers, Department of Human Services. Everybody does their little bit and it is left up to us to join the dots. Half the time, I didn't know what dots to join. And then you find out from others what they have done – and I didn't even know that was available. I don't know what I don't know. (Participant 22)

There is not a standardised approach. I am not clear about their procedures. I expected Provider E to say: "This is what we do. This is how we do it. If you have this issue, you need to go here. If you have that issue, you need to go there. When you experience this problem, please go here." There is none of that. (Participant 19)

Some participants suggested access to information depended on "*who you know*".

There is no one way to find information. A lot of it is dependent on who you know and who you talk to. A lot of us have friends whose parents are going through similar things. So you learn stuff from your friends. You're lucky if you talk with the right person. It shouldn't be dependent on who you know. There should be a central place you can go. This should be My Aged Care – but it's not. My Aged Care depends on who you talk to. (Participant 39)

Several participants described professionals who helped them access My Aged Care. In some cases, participants needed ongoing professional support to understand the information they received from My Aged Care.

I was homeless. So I went to the Department of Human Services to try to arrange some housing. A very helpful woman registered me at My Aged Care. She organised for someone to interview me. (Participant 26)

I was put in touch with a grief and loss counsellor. I was going to see her once a week. She knew a lot about this system. I would take all this paperwork with me to ask: "What is this? What do I have to do?" (Participant 28)

Some participants found it difficult to access information that would have enabled them to make an informed choice of provider.

I asked around – there were not many people who knew much. I had no way of knowing if a provider was good or bad. (Participant 11)

Lack of power

Participants were disappointed that staff at My Aged Care did not have the power to move them "*up the queue*".

When I call to see where Mum is in the queue, they are very sympathetic. But they can't do anything to move her up the queue. (Participant 26)

I phoned My Aged Care and told them the story how Mum had been on a package and then spent some time in residential care and was now in hospital. I wanted to bring her home. He was quite helpful but said he couldn't promise anything. (Participant 23)

Referral service

A participant described the role of My Aged Care as a "*referral service*" rather than a one-stop-shop where people can access information and receive answers to their questions

My Aged Care staff are extremely limited in their knowledge and what they can do. So there is really nowhere to go to get answers when you need to. Everywhere you go, people say: "Have you tried My Aged Care?" And you just want to scream and say: "Do you people understand that staff at My Aged Care don't know anything. They really don't. They are pretty much a referral service… I've been told they have six minute KPIs and their main aim

at the end of the six minutes is to have referred someone on to somewhere else. (Participant 3)

Outdated processes

A participant complained about My Aged Care's outdated processes (e.g. using fax not email) as "*crazy in this day and age*".

I was blown away by the 1980s attitude. I had to get forms posted to me. Or download them from the My Aged Care website, print them out and either post or fax them back. This is crazy in this day and age. (Participant 24)

Paperwork

Several participants commented on the large amount of paperwork. Some older people kept all the paperwork from My Aged Care – in boxes, filing cabinets and spread across the dining room table. Others relied on family members to take responsibility for all the paperwork.

An important piece of paperwork was the approval letter. Some participants questioned whether they might be dead before they received their letter.

I had the assessment in January. It's now September – and I haven't had a letter to say it's been approved. I don't think I'm even in the queue yet. The assessor told me I may have to wait 12 months. I said I could be dead in that time. And she didn't contradict me. (Participant 7)

Website

Although the website provides a search function to help people find local providers, this search engine is not refined. When participants tried to find local providers, they were given a long list of providers from around Australia. Participants said this was not helpful.

I found the My Aged Care website is a complete disaster. It is very crude. It has no finesse. This searching thing is hopeless. I put in my postcode – and I got providers from all over Australia. All the large national providers – that's why you get so many of them. I just wanted the local ones. (Participant 11)

Foreign languages

Although some written material is accessible for those who speak languages other than English, the staff at My Aged Care spoke only English. Participants who spoke languages other than English were unaware they could access the National Translating and Interpreting Service free of charge.

It is very difficult to phone them if you don't speak English. I always get other people who speak English to phone. (Participant 6)

Some participants noted the approval letter was written in English. Although the letter has an insert (with various translations of the information) advising recipients they can contact the National Translating and Interpreting Service, participants who spoke languages other than English had a family member or friend translate the letter. The family member/friend explained the content of the letter to them.

The letter was in English but our son could translate it. (Participant 6)

Assessments

Number of assessments

Participants were cognisant of the large number of assessments. Several participants discussed the unnecessary expense of "*all these assessments*".

She's had at least four ACAS assessments. She's also had an interview with council just to get on a bus trip. I can't even get Mum on a council bus trip unless someone comes out to do an assessment. It's ridiculous. (Participant 3)

The person who assessed me came from miles away. It must have taken her half the day just to get here. (Participant 7)

A participant questioned the resources spent on assessments. She described assessments as a "*profitable industry*".

Here we are saying we don't have enough resources and money within system to release more packages. But we are wasting so many resources. All of this red tape. It's not just all the phone calls, they physically send people out. This is like wasting several hours out of someone's day to assess just one person… Instead of saying we've already ticked all of those boxes. They prefer to constantly send people out to people's homes driving around all day. Grossly inefficient. (Participant 3)

Process

Participants described a long process before getting an assessment. This process included different people asking the same questions.

> *At the beginning of June, I talked to [name] at My Aged Care. It was a phone interview. She gave me an ID number. On the basis of that phone interview, she said she would refer me on for a more in-depth assessment. A few days later, I got a call from [name] who was part of the assessment team. She asked some more questions. I told her that she should already have most of this in her notes. She referred me on to the next step – another phone call with some more questions. As a result, I was told me that I would have an interview with the assessor on 1st August. So after three phone calls and a two-month wait, I had an assessment. (Participant 2)*

A participant was concerned that the information given to My Aged Care was not given to the assessor. As a result, information had to be repeated to the assessor.

> *The girl who came to do the assessment looked about 16 years old. She told me she had been a registered nurse for two years but not in aged care… She asked Dad about his cardiac issues. I told her Dad had vascular dementia. She said: "Does he?" All the information was sent to My Aged Care – including that Dad has lost capacity. She replied: "I don't have access to the My Aged Care portal because of privacy. We only get told what is wrong with the person over the phone." This explains why we have to repeat all the information again and again… The Aged Care Assessment Service and My Aged Care are just not speaking to each other. The Aged Care Assessment Service should have access to his file and do an analysis of his condition before they visited. (Participant 24)*

Some participants described the questions asked during the assessment as "*irrelevant*". They were also concerned that the assessor was not qualified to correctly interpret the answers.

> *They asked Mum questions like "Who is the Prime Minister of Australia?". Mum doesn't follow politics. Asking that sort of question is meaningless to her. The questions were asked by clerical-type people, not people who are able to interpret the answers. (Participant 22)*

> *They asked: "Can you feed yourself?" If you answer "yes", they go on to the next question. What they don't ask you is: "How do you get the food? Can you go shopping? How do you cook it?" (Participant 29)*

A participant expressed concern that the assessment questions were not "*personalised*".

> *They are not personalised. You all must fit into this box. They might ask a question about my father's mobility. Can he walk? Yes. Does he use an aid? Yes. However, it doesn't go into the detail that he can only walk about two feet. Is it likely to get better/not get better? No room for that type of detail. (Participant 40)*

> *She told me that she just follows the template of questions to be asked. I thought: "Anyone could do that. A customer service representative could do that. Why are we using registered nurses to do aged care assessments if that is all they are doing?" (Participant 24)*

Assessment duration

Several participants described the assessment interview as "*too long*". They were also concerned that the assessments were rigid.

> *Mum has now had many assessments. They are way too long. Two hours. Stressful. You don't grill an elderly person – what was your last address, what is your phone number… The nursing staff who assessed Mum seemed interested only in ticking the boxes. (Participant 14)*

> *Mum found the assessment extremely stressful. She put her head in her hands. A couple of times she almost fell asleep. It was far too long for her to cope with. (Participant 35)*

> *I've had several assessments. Always by the same person. I had one of those mini-mentals sprung on me – it was not 'a mini' – it was nearly an hour. I got quite agitated by the end. (Participant 13)*

Assessment outcome

Several participants suggested that having a daughter available to help their elderly parents influenced the outcome of the assessment.

> *I think they assessed Dad as medium priority and not high because he has a daughter. I challenged this. I have to go to work. (Participant 19)*

Approval

After receiving the approval letter, several participants were unclear about what they had to do.

> *The social worker had to explain it to us. Have you ever had a letter from government that you can understand? (Participant 8)*

> *I read the letter and wondered how my parents were supposed to know what they had to do. How on earth could they find a provider? (Participant 19)*

> *He was recommended for Level 4. But they approved only a Level 2. But I stupidly didn't take it up. I didn't understand what I had to do. When I got back on to My Aged Care, they told me I had to find a provider. (Participant 16)*

Assigned a package

Queue

Participants expressed confusion about how people in the national queue were assigned packages.

> *You can log in to My Aged Care and it will give you an estimate. In my Mum's case, it started at 6-9 months, then it said a further 3-6 months and then one day it dropped to 30 days. And then out of the blue, she finally got her package. But there is no way to really know how this queue operates. (Participant 3)*

Participants wanted to know exactly where they were in the queue and how long it would take for their package to be assigned.

> *I'd look online and I'd phone. But no one could tell me how long it would take. (Participant 16)*

Some participants were concerned about the lack of transparency about how the queue works. They wanted to know whether a human being or a computer algorithm was responsible for assigning packages.

> *I wonder about this algorithm that sorts out the national queue. So you have people like my Mum that had high-priority urgent listed in her profile. Nobody can tell me whether a human manually reviews this, or if it is a computer-generated algorithm… I would hear stories that so and so only had assessment for a Level 4 package weeks ago, and they have already got it. My jaw would drop. How is that possible? My Mum was listed as high-priority urgent. How did Joe Blogs around the corner get it? This is something in the system that totally lacks transparency. (Participant 3)*

A participant questioned the criteria that enabled some older people to be assigned a package much quicker than others.

> *Mum had been on a package prior to moving into an aged care facility. She was subsequently in hospital. I wanted to bring her home. Mum had an ACAT assessment the day before leaving hospital. The approval letter was online by the end of the week. Maybe there was priority for someone leaving a mental health ward. (Participant 23)*

> *It's not like when you phone and you are told you're 10th in the queue. Why not? It's the same when I talk with aged care facilities - they tell me they have a triage system. Well, what is that triage? Triage based on urgency, needs, money? I'd say a lot of it is based on money. Why don't we have a right to know that? (Participant 3)*

One problem with waiting so long for a package to be assigned was that older people's health status deteriorated. In some cases, they needed to be reassessed for a higher-level package. In other cases, they needed to move into a residential aged care home.

> *Dad was in the queue but nothing was happening. Dad had deteriorated. He was no longer Level 3. So I phoned My Aged Care to request an urgent assessment. The same young girl came back three weeks later. She agreed he had deteriorated and recommended Level 4. (Participant 24)*

> *Dad is fretting terribly without Mum. He wants to bring her home. We sat with the provider and discussed getting the bathroom renovated and more support so maybe they could spend their last year together. I doubt they have much more to go. She could be at home rather than in the aged care facility. The provider told us quite rightly: "No chance." She is in the residential aged care system and we will be waiting over a year or more for a package. (Participant 40)*

Lower level package

Some participants were assigned a package at a lower level than had been approved. In some cases, the lower package did not provide enough assistance for the older person to remain at home.

> *Mum is in an aged care home because I couldn't look after her on a Level 2 package. I want to bring her back home. However, she will go to the back of the queue. We have already waited two years for Level 4. I was told it might take a year before I can get any help. Our Level 2 package has gone. (Participant 6)*

Transitioning from Commonwealth Home Support Programme

Several participants transitioned from the Commonwealth Home Support Programme to a home care package. They were surprised when the home care package did not provide more support than they had received with the Commonwealth Home Support Programme.

> *During the three months Dad was waiting for a package, he went on to CHSP. This was reasonable compared to all the rigmarole with the package. It was $5 per day. Dad was getting an hour of care every morning. Then our Level 3 package came through and we chose Provider E. But it was no more support than CHSP. With Level 4, we noticed a difference. (Participant 19)*

> *We were given similar services on Commonwealth Home Support Programme and home care package Level 4. Probably the home care package is better for us because we can save up our money if there is some equipment that would help Mum. Plus we have the freedom to change providers if we want. (Participant 30)*

> *When we moved from Commonwealth Home Support Programme to home care package Level 2, the hours did not change. Maybe one extra hour. When I queried this, I was told in some cases it would be fewer hours. This didn't make any sense. (Participant 35)*

Participants were disappointed that the transition from Commonwealth Home Support Programme to a home care package required them to stop receiving council services. They described the council providing excellent in-home services.

> *I realised we needed more support so we applied for a package. I didn't realise we had to stop the other services (and transfer all our services to the private provider). The council and a charitable organisation (Provider N) had provided us with excellent services for several years. We were much happier then. The relationships were important – people wanted to help. These organisations worked so much better because they are set up differently. The charitable organisation was established to support people. For profit wasn't part of the culture at all. The people they employed are different – a much higher standard. The quality of the support workers was so much better – they had done dementia training. (Participant 9)*

> *I told My Aged Care in no uncertain terms that I wanted to stay with the council. I'm not happy with the move to private providers. In a council meeting, this young Greens' councillor spruiked the notion that we will be able to have choice. What type of choice? If I am not happy, I phone My Aged Care and talk with someone in Darwin or Sydney? I want to deal with local people. I want to deal with the local council who know the local area. I want to know who I am talking to. With My Aged Care, I could be talking to anyone. They couldn't care less about me. It's important to have a relationship. I have a relationship with the council. (Participant 10)*

When a participant was sent a letter from Centrelink, he misunderstood the contents. He became very upset.

> *When we moved from the Commonwealth Home Support Programme to a home care package, there was an incredibly complicated form for registering income, savings. We tried to be scrupulously honest. They replied it may take us six months to determine how much Dad needed to contribute to his own care. We got a letter recently that we had to pay Centrelink $200. And then we got another letter telling us Dad needed to complete tax returns. He's a 91-year-old pensioner who hasn't earned any money… Dad thought he was being asked to pay $42,000 after the sale of his house. He was very upset. The thing that concerns me – if Dad was on his own when he got this letter. (Participant 8)*

Full cost recovery

For many people, ageing well requires access to social activities and community life. However, participants described the policy of full cost recovery as preventing them from being involved in as many community social activities as they were prior to accepting a home care package.

Participants on a Level 3 and Level 4 home care package said they are required to pay the full cost of community social activities. They reported that a home care package is subsidised by the federal government whereas the social activity is subsidised by either the state government or a local council. Several participants had been told they could not "*double dip*".

A participant on a Level 4 package described being forced to choose between an hour of personal care or a social activity. They said they could not afford both.

Social activities

Participants were shocked when the cost of social activities increased substantially when they transitioned from the Commonwealth Home Support Programme to a home care package. A participant who accessed four local social activities every week for many years was forced to reduce his local activities when he accepted a home care package. This negatively affected his mental health.

A participant decided to continue with the Commonwealth Home Support Programme rather than transition to a Level 2 home care package so she could continue to afford to access the local council's social activities.

> *I've decided to continue with Commonwealth Home Support Programme – I've had people who have been helping me for ages – with the cleaning and shopping. And it doesn't cost me much to do the council activities. To transfer to a package would cost me a lot more. I wouldn't get the same level of services I get now. I'd have to pay a lot for the District Nurse who comes. And I couldn't afford to do all the social activities that I currently enjoy. They charge about $100 for the bus trip when you're on a package. I currently get it for $10. It's a much better deal for me. (Participant 36)*

> *I am in a men's group in a community centre. I used to pay $10 a week to be there. But because my package pays for it, it now costs me $100. (Participant 8)*

Several participants previously participated in council activities but could no longer afford to do so on a home care package due to the policy of full cost recovery.

> *Sometimes I am so lonely, I don't want to live. I would like to join some council activities. They have bus trips and other clubs. But they are expensive. (Participant 4)*

Some participants found a way around the problem of full cost recovery by continuing to pay cash for the social activities (i.e. not use the home care package to pay for the social activity).

> *Mum attended a day centre. It was only $20 a day. They told me if it came out of her package, it would cost $65. (Participant 23)*

> *Mum goes on outings four times a week – they do different things. They take Mum to different venues to do different activities. Provider X couldn't offer her any social activities. I haven't pushed for a Level 4 because I was told there was a risk she would lose the outings. These outings were in place before the package. After we signed the package, we just continued things as they were. The case manager told me they may have to cut back the outings because of the package. They told me the government is cracking down on them. They are currently charging $15 but the full cost is $60. This equates to an hour of personal care. I could afford that if it was just one outing – but Mum has four outings. She needs these outings – they are very social and she loves them. (Participant 35)*

> *One of our big things is social isolation. Getting them out into the community to all those things that are listed as critical to wellbeing. Once you have a Level 4 package, all these activities shift to full cost recovery. So Mum's $15 bus trip is now $95. There is no money there for that. So on the one hand we are saying that one of the critical things for older people to stay in their home for longer is wellbeing activities, social activities and participating in the community. How many $95 bus trips do you think you can get out of the package if they are already requiring personal care seven days a week? None. (Participant 3)*

Some participants chose not to tell their provider about the social activities. Some community organisations also "*looked the other way*" so the cost of the social activity was not taken from the home care package. Participants said the subsidised rate enabled them to continue the social activity.

> *I had been using services from a community organisation. They do a lot of social activities. They take me to hydro exercises. I'd been paying them directly long before My Aged Care came on the scene. It costs me about $20 per session. The case manager said: "It should come out of the package, otherwise you're double dipping." I asked the manager of the community organisation about this, and was told the case manager was right. If I charge the package, it is $99 a session. So the manager of community organisation said: "We will look the other way and pretend we don't know you're on a package." Then they came back and told me about a grandfather clause – that says you can keep getting services from an old provider from the old rate. So I just pay $20. (Participant 11)*

> *I've found this wonderful private day care centre. I pay them $21 a day. We pay cash. We haven't told My Aged Care. (Participant 25)*

Palliative care

The daughter of a woman who was dying needed expert palliative care. She was initially told it was free. However, when the palliative care service found out her mother was receiving a home care package, she was asked to pay the full price.

> *I've arranged palliative care for Mum. I was told it was free. They even offered to help with her showers. Then they found out she is on a Level 4 package. I was told she can't have a package and have free palliative care. We'd have to pay $99 per hour. (Participant 14)*

Nursing services

Participants said they were charged a reduced hourly rate for nursing services on the Commonwealth Home Support Programme and Level 1 and Level 2 home care package. Some participants were told they would be required to pay the full price for nursing services if they accepted a Level 3 or 4 home care package.

A participant was advised to remain on a Level 2 package because she required several hours of care from a registered nurse per week. She was told if she transitioned from a Level 2 home care package to a higher-level home care package, the hours of nursing care she received might be reduced.

Providers

Choosing a provider

Several participants described feeling "*overwhelmed*" by having to choose a provider.

> *At first it was overwhelming, because I didn't understand it. I had all these phone numbers I had to call. I phoned all the individual providers to see what they had to offer, how much it would cost. I didn't really understand any of it when I started. The provider I chose was the one that always answered the phone, returned my calls, responded to my messages. (Participant 28)*

> *On the My Aged Care website, there are over 100 providers listed in Mornington alone. It is overwhelming. They don't tell you which ones have a good reputation. Am I expected to phone each one? (Participant 2)*

> *As soon as you get assigned a package, you are told you have 56 days to find a provider. Providers marketing their wares attack you on all sides. You have to set up all these appointments. People in our area are getting quite frenzied. Mostly choices are made by word of mouth. (Participant 15)*

Some participants described choosing a provider as time consuming. The main problem was not being able to compare "*apples with apples*".

> *I had to put a spreadsheet together. I spent days. There is no easy way to do a comparison. And a lot of providers don't put necessary information on the My Aged Care website. I had to make a lot of phone calls. I was comparing apples with oranges. I worked in corporate for 30 years and I struggled. God help those who aren't as savvy as me in doing that type of analysis. (Participant 22)*

> *All the providers call things by different names and structure things in different ways. (Participant 17)*

> *You get the list from My Aged Care, and how do you know which ones are good? The biggest problem is you can't compare apples with apples. If we knew there were only two or three charges, case management, administration and exit fees – and your daily fee. If it was as clear as that, you could have four questions to ask each provider, fine. Maybe you'd just phone 10 of the providers on the list. You would come out the other end and make your decision based on whether cost was important or quality of care or whatever. But it's not like that. Each one that I phoned had some other hidden fee that didn't come out in conversation until I had really grilled them. Sure enough I'd find out about this extra fee that wasn't clear from their website. So it's overwhelming for people. (Participant 3)*

Contact by providers

Several participants described receiving phone calls from providers soon after they were assigned a home care package.

> *As soon as my partner's approval came through, we were contacted by phone by a range of providers. The first were council services – but they didn't have anyone who was trained in dementia. And the second lot was Provider O. They told us they were dementia specialists. And they had the only early onset dementia cottage in the country. (Participant 15)*

> *After we got the package, Provider P called us straight away. They came to us with the contract. (Participant 12)*

> *I was assessed for a Level 3. This pushy woman put heat on me to take Level 2 while I waited for Level 3 – so I could have it sooner. The village I live in has a contract of some sort with Provider CC. We were all urged to sign up with them. I wasn't all that happy about being pushed into a specific provider. I wanted to make my own choice. (Participant 27)*

Some participants described receiving phone calls from providers before they had received their approval letter. One participant described feeling "*bullied*" into signing with a provider.

> *Provider JJ provided a cleaner under CHSP. They phoned to tell us Mum had been approved for a Level 2 package before she got the approval letter. Mum just wanted cleaning – so we were not going to accept the package. But Provider JJ told us they could not continue to provide cleaning unless we accepted a package. Mum really liked the cleaner. We felt bullied into accepting the cleaner. Provider JJ was intending to give the paperwork for Mum to sign without any family member being there. I felt this was wrong given Mum has dementia. (Participant 37)*

Some providers provided incentives to encourage older people to sign a Home Care Agreement with their company.

A provider I spoke with was offering a new Dyson vacuum cleaner if I signed with them. There is heavy persuasion going on. (Participant 3)

Overpromise and under-deliver

Participants described providers' advertisements about home care services as misleading.

The providers use typical marketing ploys. When I read all their glossy brochures, I thought "wow". Provider E advertise "trained carers". After Dad signed the contract, they phoned me to say they had no carers and would have to outsource for carers. (Participant 19)

Provider M's services were very limited. That's been the ongoing problem. It would have been so helpful if they could have offered us an overnight – so my partner could have stayed at home, and I had a night/weekend off. We had lots of money for that. But they refused to provide it. They didn't have the staff to do it. (Participant 9)

A participant felt the provider made promises simply to "*shut her up*".

They promised me things and I never got them. It was like they promised me things to shut me up. That happened to me quite often. It was really disturbing. (Participant 41)

A participant described feeling shocked when the provider appeared to be more focused on profits than care.

We don't understand what we are entering into. Profit motives are far from our minds. [When we sign up], we think they really have our best interests at heart… The system cannot work as it is when there is so much financial gain. (Participant 17)

Battles with providers

Several participants described dealing with providers in the home care system as a "*battle*".

It is an uphill battle. I don't know how people who are unwell deal with some of these administrators. (Participant 30)

I needed a bed for Mum. They said we had to hire it, not buy it. I've battled with them for over a year about this. (Participant 14)

Some participants described having "*to insist*" to make services happen. They described "*pulling teeth*" and "*fighting*" for their entitlements as "*exhausting*".

All this – navigating the aged care system, packages – has been horrendous. It's exhausting. If I didn't have 30 years working in the welfare sector, we could not have managed. Mum and Dad didn't understand. I took leave to look after Dad. Part of the reason I'm caring for Dad is because Mum can't. If my parents didn't have me, my Dad would either be dead or in a nursing home. That's a fact. (Participant 19)

I said I want someone to help me with the gardening so I could spend more time with my partner. To get Provider M to approve that was like pulling teeth. And that was something the council had provided. (Participant 9)

It was like pulling teeth. I would constantly be phoning and emailing Provider B. It was a fight to get basic chores done. (Participant 3)

One participant described "*going to war*" with providers. Another described "*the fights*" as constant.

I've heard of providers literally going to war with care recipients when they ask: "Can I have x. Can I have y?" (Participant 3)

We had a fantastic gardener for 12 months. But then they sent another gardener. I phoned and said: "Never send that person again." These are the fights that are constant. (Participant 9)

A participant described her interactions with the provider as "*stressful*".

It's really stressful. It is traumatic and frustrating. I want to wring their necks… I don't want to be angry all the time that we can't get the things we need. It blows me away how ridiculous it is when the government is trying to help but the provider won't help. It's like they sit in a gold office chair in front of a gold desk with a gold phone and do nothing. That's how it feels to me. (Participant 21)

Unsuitable providers

Some participants were concerned that the government was giving home care package licences to companies with no expertise in the delivery of aged care services (e.g. insurance companies).

> *Provider M doesn't know how to provide aged care services. They are a bloody insurance company. They see it as an opportunity to make some money – but they don't know how to do aged care. I recently wrote an email to the CEO. I was shocked by his ignorance about how his company treats its clients. I said: "If you treat educated well-connected people this way, how on earth do you treat those who are unable to protect themselves?" (Participant 9)*

> *The current provider seems just interested in making money. It's a business. For sure. (Participant 1)*

Participants were also concerned that some providers accepted too many clients without hiring enough staff. They were unable to deliver the services that participants expected.

> *Providers should only take on the number of clients they can properly manage. Provider M has far too many clients and far too few case managers and support workers. It was simply not possible for them to deliver services we expected in a Level 4 home care package. Their failure to deliver services has resulted in my partner moving into an aged care home (Participant 9)*

> *Provider P didn't have enough staff. They used an agency. There were several weeks when they didn't send someone to help me shower. They said they couldn't find staff. (Participant 12)*

Several participants expressed concern that their provider may be "*rorting*" the system. They worried about the impact this may have on an older person.

> *My concern is for the government. How do they make sure that providers don't behave illegally by rorting? That does worry me. I am concerned that the agent isn't honest. What would happen if they didn't pay the cleaner? There is a possibility of a confrontation with the older person. (Participant 7)*

Company takeovers

Some participants described a local provider being taken over by a large national company. They ended up with a provider they did not choose.

> *I started with a company but it has changed names. This is one thing that pisses me off a bit – they all keep changing names. I haven't changed providers but they were taken over by another company 12 months ago. They are now nationwide. If I have to phone after hours, Queensland answers the phone. (Participant 1)*

> *You could start with an honourable company. But it gets taken over by a dishonourable company. I started with the council. I am now dealing with a large company. I did not choose this. (Participant 7)*

Giving feedback to providers

Participants were disappointed by the manner in which some providers responded to their feedback.

> *My support lass has gone on holidays. They sent a new lass who was as thorough as the other girl is not as thorough. I mentioned this to the case manager. I said: "Could I change to the new lass?" But the answer was "no". (Participant 7)*

> *Twelve months ago, the case manager came here with Provider M's CEO. The CEO wanted to meet some consumers. The case manager encouraged us to tell him all the bad things that had happened. She had sympathy that we had been dudded all the way along. He was here for a couple of hours. I told him about the bad culture (you could tell there was no cohesion in the organisation). He seemed genuinely interested. So I thought: "Hang on. Things are going to improve." But nothing ever improved. It's gone from bad to worse. People keep leaving – they can't hold on to their staff. (Participant 9)*

Contracting an external provider

Some participants requested the services of a specific professional. They were surprised they were asked to pay a "*brokering fee*" to establish a contract – particularly when the service was provided by a government agency.

> *My mother's package is in surplus. So I asked for some dementia counselling support with Dementia Australia though Mum's package. Provider JJ agreed but said they would need to contract Dementia Australia. This would cost $500 to establish a*

contract. Once I told them Dementia Australia is a government organisation, they changed their mind. But it shows how they are looking for every cent. (Participant 37)

We had a great private gardener. We wanted her to continue as our gardener. It took four months for this to happen. They charged a set-up fee of $350 for the brokering. (Participant 9)

I suggested Mum see a physiotherapist but because they are not on Provider JJ's books as a contractor, they would charge Mum's package $500 to establish a contract with the physiotherapist. (Participant 37)

Some participants used external services. They believed this should be a financial arrangement between providers and the external service. They felt the external service should not contact the client about late payments.

The day care is $70 per day. They sometimes email me to say they have not been paid. However, this is a contractual agreement between the provider and the day care. They should be emailing the provider not the client. (Participant 22)

Provider profits

Participants commented on the "*big chunk of money*" some providers take from the home care package. Several participants described the taxpayer as being "ripped off".

The provider gets paid very well. They take a big chunk out of the money every month. Big chunk. And if my case manager has to do something else, like ring up the supplier for the stockings, that's another charge. (Participant 1)

I once asked Provider A how four hours of domestic assistance had cost me over $544.40. It was because they charge $136.10 per hour on public holidays. But that does not go to the worker. I phoned around and most agencies charge from $85 to around $99 for public holidays. My service is usually on Mondays so now I go without rather than give them this obscene amount. (Participant 17)

When I saw the hourly charges, they are very high. Are they allowed to charge this much? (Participant 13)

Several participants did not object to providers making profits when they provided a good service. However, one person was at her "*wits' end*" with the lack of quality services her partner received.

It wasn't fair on my partner and it wasn't fair on me. Meanwhile, Provider M is sitting back there raking in all this money. But everything we got was due to my persistence and determination. But it wears you down. Last year, I was at my wits' end. I told them: "I need more support." I didn't have anyone as a backup. I was so stressed out. And not knowing where to go for help. (Participant 9)

Another participant questioned whether her mother and the taxpayer were getting value for money.

Sometimes I think I should do Mum's shower myself. Mum pays a $10 per day fee ($300 a month) and we get 15 hours support per week. The provider gets around $4,600 a month and that buys us 15 hours support. That doesn't seem right. (Participant 25)

Consumer directed care

Several participants questioned why home care packages were described as consumer directed care when the consumer did not direct it.

> *They tell me that I direct the package. But they don't let me use our own gardener. It had to be their gardener. They use Jims Gardening. We had Jims Gardening once and I wasn't happy. So we pay our gardener out of our own pocket. (Participant 1)*

> *It was a fiasco from the beginning that it was a consumer directed care package. It was not consumer directed care – absolutely not. It has always felt like a service-directed package – and these are the restrictions and you just have to fit in with that. It has been the bane of my life from the word go. (Participant 9)*

Participants who had received in-home care for many years said the new system gave the 'consumer' more control than in the past. However, they did not have full control over how their home care package was spent.

> *We've had a package for about 15 years. We're finding consumer directed care better because we have more control over things but it is still not enough. I still have to deal with the Provider X who is still in control. I still have to ask them what I'm entitled to use the money for. (Participant 21)*

> *I didn't have any say in how the funds [in my home care package] were spent. They don't want to let you know very much. They don't sit down with you and explain what you're entitled to. They don't spell it out to you. A Public Guardian showed me a list of things I'm entitled to. But it was all airy-fairy stuff. You don't know if you're entitled to a printer cartridge because you keep printing off all these bills… My neighbour told me I could get vitamins. I've been with Provider A for over three years and I didn't know this. (Participant 17)*

> *Although I had about $12,000 in my package, I found it hard to get anything other than the shopping, cleaning and a taxi. Then suddenly the case manager was trying to get me to spend everything. I checked whether you lose your balance at the end of the year. You don't. (Participant 11)*

Home Care Agreement

Some participants signed the Home Care Agreement without reading it or without understanding what they were signing. A participant said she "*trusted*" the provider.

> *I read the contract – but at that stage I didn't have enough knowledge about average hourly rates for care. I didn't know what else was out there. I signed a contract. With the little I knew about the industry at the time, the fees and charges seemed pretty good. It looked like a good deal. But as I learnt more, I realised it so wasn't a good deal. (Participant 3)*

> *Who is going to sit down and read all this stuff? I just want some help. Not all the mumbo jumbo. (Participant 21)*

> *I just signed the contract without reading through it. I trusted them. I found out later they had an exit fee of $500. I also found the fees were very high. I agreed to it all – so there was nothing much I could do about it. (Participant 35)*

Length of contract

Several participants described the Home Care Agreement as "*too long and complicated*".

> *I can't even remember the contract – it was a mile long. Mostly looking after their tail – not much about what they are going to do for you. (Participant 1)*

> *When I got the Home Care Agreement, it was very long (29 pages). I asked some questions. They said: "Don't worry it's all fine. There is nothing here to worry about." They showed me the fees. It didn't mean anything to me. All I wanted was a good service. We had chosen the provider because we wanted the carers to be Jewish. They didn't tell me the carers would be from an agency. Maybe it was written somewhere in the contract. (Participant 16)*

Some participants wanted a hard copy of the Home Care Agreement.

> *They prefer to send the contract via email. Mum wanted a hard copy. Who could read 40 pages online? (Participant 13)*

Clarity

Some participants found the language of the contract "*legalistic*".

> *I'd prefer the home care agreement to be written in clearer English. It contained information about rights and responsibilities of the provider and clients, the financial arrangement, exit fees, notice to be given. The contractual agreement didn't contain any details about how it was going to be managed. So when we signed it, we didn't have in front of us a written agreement about what they were going to do for us. (Participant 15)*

Fees

Although all home care providers are now required to publish their existing pricing information on the My Aged Care Service Finder, several participants described the contract as having insufficient information about the fees.

> *You can't negotiate the fees in the home care agreement. This is not right. Also, the agreement should have the hourly rate, and the loading for public holidays. (Participant 16)*

Home Care Package entitlements

Participants described their home care package entitlements in terms of hours of personal support, transport and reimbursements for items they had purchased. Several described providers' policies around hours of support and reimbursements as being "*unclear*".

Hours of support

Participants wanted to know how many hours of support they would receive with their home care package. Staff at My Aged Care were unable to answer this question because each provider charges different rates for support workers.

> *In the beginning I used to ask: "How many hours am I entitled to each month?" No one could answer me. That's because of fees and charges but I was too ill to sort it out. My Aged Care were hopeless in explaining it. They gave me some convoluted answer that did not make a scrap of sense when I got off the phone (Participant 17)*

> *We could never understand the money. It was always: "How many hours of service will that give you?" (Participant 13)*

Participants on a Level 2 package described receiving personal/domestic support for approximately three to four hours per week.

> *Mum's on a Level 2 while waiting for a Level 4. The provider is getting $18,000 per year. They are giving Mum three hours support a week. (Participant 26)*

Participants on Level 4 described receiving a different number of hours of personal/domestic support per week – ranging from seven hours to around 25 hours for those who self-manage their home care package.

> *Mum is on a Level 4. In total, we get seven hours per week. We get a support worker for respite (five and a half) and domestic (one and a half). We also get podiatry once every six weeks. We occasionally need a registered nurse visit – whenever Mum goes to a home for respite, she comes home with a pressure sore. (Participant 30)*

> *On Level 4 with the Cognitive and Dementia Supplement, Mum will get $58,000. Provider BB has told us that will buy her 12 hours of personal care per week. I said: "You're kidding." If the government gave me $58,000, I could employ someone full time to live in our home to give us a hand. (Participant 26)*

For participants who did not self-manage their home care package, the average number of hours of personal/domestic support on the different levels of home care packages were:

- 2 hours per week on Level 1 package;
- 3 hours per week on a Level 2 package;
- 8 hours per week on a Level 3 package; and
- 14 hours per week on a Level 4 package.

Several participants were "*furious*" when they compared these hours with the funding the government provided annually for their care and support (Table 1). They described far too much money that was intended to support older people at home went "*into providers' pockets*".

Reimbursements

Several participants were unclear about the government's reimbursement policies.

> *Do you know what you can claim? I don't. The new provider told me about dental. The previous provider had not told us dental could be claimed from the package. (Participant 16)*

> *My agency didn't tell me what could be reimbursed. They bought me a new bed but won't pay for a doona and sheets. Yet they allowed me to buy a new stove. So it gets confusing. To be fair the government has not made this easy as it has so many grey areas. My neighbour's provider told her "if it will keep you in your home" it passes the test. (Participant 17)*

> *Nobody told me we could get reimbursed for equipment. I purchased Dad's wheelchair myself. It wasn't until later that I asked if we could be reimbursed. Now I don't rely on the provider for purchasing equipment. I find it myself and then ask for reimbursement. (Participant 19)*

Participants described the lack of guidelines about what items you can buy with your package.

> *People are not being given guidelines that tell you what you can and can't have from your home care package. The interesting thing is what you can't have is pretty much very clear – you can't get a gambling or footy membership. But under the guidelines of what you can have it is quite grey. (Participant 3)*

Participants expected case managers to tell them what they could purchase with their home care package. They were disappointed when this did not happen.

> *I didn't know there was a government reimbursement for continence products. I expected the Provider X to tell me these things. But they didn't. So things like that fall through the cracks. (Participant 35)*

> *I had an accumulation of money in my package. I didn't know I could spend it on equipment. (Participant 13)*

> *Mum burnt the stovetop. I asked if she could get a new one with some of the surplus in her package. I received no reply. (Participant 37)*

Some participants described the reimbursement policies as "*ad hoc*". Some providers reimburse items that other providers do not.

> *It's not clear what I can spend the package on. I bought a van to transport my husband. The package can be used to repair the hoist but not mechanical repairs on the van. That is so stupid. If the van doesn't work, he doesn't go anywhere. Another example is when our fridge died. Some of my husband's drugs have to be stored in the fridge. I asked if we could get a new fridge ($700) with the package – Provider X said "no" because I also use the fridge. A friend is with a different provider - they got a new fridge, cordless phone and a new TV. (Participant 21)*

Financial statements

Government-funded providers of home care packages are required to provide a transparent account of how money in the package is being spent. However, there is no requirement that these financial statements be easy to understand.

Difficult to understand

A common complaint about home care packages was that the monthly financial statements were "*difficult to understand*". A participant said: "*The statement is in code.*"

> *We didn't understand the statement. Nobody explained. We asked the case manager to explain. She couldn't understand it either. Our granddaughters who are studying at university couldn't even understand. It was very confusing. (Participant 12)*

> *Nothing much to do with my package or accounts has ever been explained to me. We were very confused about the invoice. My husband is an intelligent man - particularly with finance. He found all this overwhelming. He had to sort it all out himself. We could never make head or tail of the statement. You need to sit there for a few long hours to work out all the costs. (Participant 17)*

Even participants with business and accountancy experience found the financial statements "*bamboozling*".

> *We couldn't understand the invoicing. I phoned the regional manager to say I could not understand the invoices – I've been trying to understand them for two years. The invoices didn't match the hours the support workers came. How do they work that out? I've had a business and I know how to do accounts. These invoices are crap. (Participant 25)*

Participants said they should not need a university degree to understand their monthly statements.

> *I shouldn't have to be a qualified accountant to manage my Mum's aged care package. I shouldn't need that knowledge… Month after month my Mum's invoices would be incorrect. There was a specific agency (Provider E) that would phone to say the carer could not make it. I would reply: "That's fine, but please don't invoice my Mum." Sure enough, the invoice would come with this included. Luckily I was dating this and putting it in my calendar – "Carer didn't turn up on Sunday." Who else would be this detailed? They were also putting extra meals into the invoice that Mum never had. When Mum was in hospital, Provider B had "meal delivery" on the statement. Mum could not possibly have been having meals when she was in hospital. Anomaly after anomaly after anomaly. I think there are genuine mistakes and also greed. If you throw dementia into the mix, what hope do recipients have of being able to interpret their invoice? (3)*

Participants described older people, particularly those with dementia, having difficulties understanding the monthly financial statements.

> *How could my husband have managed on his own? How could he handle all these invoices that come in? I feel so sorry for so many of these people. (Participant 16)*

Some participants described not understanding the statements as causing recipients and their families "*stress*".

> *Mum does all her own finances. These statements have caused her so much distress. (Participant 13)*

Mistakes

Several participants noticed financial anomalies on their statements. A common anomaly was being charged for services they had not used.

> *I was getting all these crazy statements from Provider E. Last year they charged me for services when I was in hospital. My son has power of attorney. When I showed it to him, he was annoyed. I got in touch with them and complained. They rectified it. But what if I didn't have my brain working? How many get duped? It's the government paying these packages. And I am so grateful for it. I don't like to think they are being ripped off by a company charging for things the people didn't get. (Participant 18)*

> *They were charging quite a lot of money per kilometre to take my partner out. They used their phone to determine kilometres. They logged on at the start of their journey to our home, and would then take my partner to the supermarket to shop and afterwards come home. I was being charged for 30 kilometres even though the supermarket was only a couple of kilometres away. I phoned to complain. They agreed it was not right but they never put the money back in. I followed this up a few times but I gave up out of sheer exasperation. (Participant 9)*

> *I just wrote a complaint letter to Provider E because there were inconsistencies on the statements. In our last statement, Dad had over $2,000 listed as "Income Adjustment". What does that mean? They also double charged us for some services. They said it had been fixed, but it's not clear to me on the statement. (Participant 19)*

> *I arranged some extra support after Mum was discharged from hospital. I then cancelled it but they kept charging for it. They claimed I had not cancelled it. I sent the case manager the two emails. But I didn't have the energy to fight. I just gave up. Mum has so much in surplus that I didn't worry about it. (Participant 37)*

> *At the beginning Provider M charged $450 for a health and safety check. It was never done. Right from the word go, it's always felt as though they can charge for this and that – irrespective of whether they do it. I had so many arguments with these young case managers: "You can't charge for something that you haven't done." (Participant 9)*

One participant was fortunate to notice a provider withdrawing money from her bank account that the provider was not entitled to withdraw.

> *After I left Provider E, I noticed they were taking money out of my account. I had lots of phone calls with Provider E's accountant in Melbourne. What would have happened if I hadn't noticed? (Participant 18)*

Delayed statements

Some participants were concerned about the lack of real-time invoices.

> *My biggest beef is the lag time with the statements. They come about six weeks after the end of the month. Too long. I got a phone call that Mum had overspent her package. I had no idea. On our last account, they whacked on a $6,400 fee for pending services. When Provider S contract out this work to Provider L, there's a paperwork lag. This is July and they have services dating back to February that haven't been taken out of the package. They have taken away our gardening services and cut the support workers to nine hours per week on a Level 4. I'm furious about this. (Participant 14)*

Complaints about statements

A participant lodged a complaint with the Aged Care Complaints Commissioner about a provider charging her for services she had not used. She subsequently decided not to make a formal complaint.

> *I reported Provider E's accounting system to the complaints. It was wrong that they took money for services I didn't use. There was a very nice man there. He wanted me to follow it up. He told me there were several complaints about Provider E. He said: "You're not the only ones who has complained about them." It is shifty but I let it go. (Participant 18)*

Fees

Several participants stated it was reasonable for a provider to charge about 35 per cent in case management and administration fees to deliver a good service.

> *The provider I ended up with charges around 35 per cent of the package. I wouldn't mind paying this if they provided a good service. But Provider Y does not provide this. (Participant 22)*

Participant 24's daughter worked in the home care space - helping people find suitable providers. She shared her professional views of providers' fees. She also shared her experiences of finding suitable providers for her clients.

> *Providers have got superannuation, workers compensation, public liability and professional indemnity – looking at wages plus 15 per cent. You've got to give the agency something. So my view is about 20 per cent. So if they are charging any more than 35 per cent, I query it. Good quality carers would be earning $30-$35 per hour plus their on-costs. $55 per hour is not unreasonable. I've moved so many clients from faith-based providers to private providers because they were being gouged. For a Level 4 package they should be getting between 18-22 hours per week. This one client was getting around 10 hours. Provider I was sub-contracting to seven different providers. So each day, she had a different carer working with a different agency. (Participant 24)*

Participants agreed that providers were entitled to a percentage of the home care package for costs and profit. However, when a provider took a large percentage of the home care package funds, the recipient did not receive the support they needed – and the support the government intended them to receive.

> *The agency is entitled to a percentage – but it's not a specified percentage. The agency could take a large percentage and the older person may not be getting help the government intends. (Participant 7)*

> *They charge $110 per hour to have someone with Mum on a Saturday while I go to work. So that's $440. It's ridiculous. I earn $100. I accept Provider S has to make a profit – and they have payroll, insurance and running costs. But they shouldn't be charging double for their services. (Participant 14)*

Several participants were shocked when they calculated the percentage of their package spent on case management and administration fees. Some were charged more than 50 per cent of their home care package.

> *A woman went through my Mum's contract with me and said: "Do you realise your Mum's provider is taking 53 per cent of the package?" I was shocked, particularly because I had chosen a not-for-profit provider… I calculated that when the Level 4 package came in, they were going to be getting $26,000 per year out of my Mum's package. Given that Mum was going to need care twice per day (14 sessions per week), I calculated that with their case management and administration fees, the package would be in debt. And that is just from care costs. And that package is supposed to cover minor home renovations – everything. (Participant 3)*

> *I am currently getting nine hours of personal support on a Level 4 home care package. The package is mostly spent on fees. (Participant 14)*

> *About half of Mum's package is taken out in fees (Appendix 5, Example 4). That's before Mum gets any services. And then Provider G charges high*

rates for the services: $51 per hour on weekdays and $81 for a shower on weekends. The carers are with Mum for half an hour but they charge the full hour. (Participant 13)

Several participants said they were happy to pay case management fees if the case manager provided a worthwhile service.

They were taking over 50 per cent of my husband's package for case management and administration. I actually don't know what the case manager did apart from managing the funds and paying the bills. If I sent her our out of pocket, she would send it to admin… I wouldn't have minded paying case management fees if they provided a good service. (Participant 16)

They were charging us hours per week of case management at $91 per hour. But we don't get anything like that. I never saw the case manager. And I hardly ever spoke to her. I imagine some of the work is due to Provider S contracting out care work to Provider L. But at the most it would be one hour per month. (Participant 14)

Participants said it was wrong to be charged a fixed cost for case management irrespective of how much case management they used.

I didn't realise that case management was in the contract as a fixed four hours per month – no matter whether you used 10 minutes or four hours, you were charged $96 per hour for four hours… I used to think I didn't have a right to phone the case manager. I used to timidly phone – and think I should not take up much of their time. Until I realised that Mum was paying $400 per month for it. (Participant 3)

The invoice indicates that Provider L continues to charge $623.65 per month for case management irrespective of whether any case management services were used. (Participant 14)

A participant felt lower level packages might not require much case management.

A Level 2 package is about $1,200 per month. You cannot afford to lose $400 on case management fees and then on top of that another 23 per cent administration fee. Nor would you even need that much case management on Level 2. You get shopping, a bit of cleaning – you certainly don't need $400 worth of case management. (Participant 3)

Some participants questioned why they were charged case management fees when they received no case management.

It's how it is delivered that is the problem – and all the fees they charge. My husband doesn't use any personal services, so why does he pay for a case manager? (Participant 21)

I found out that Mum's package was being deducted by $400 per month for case management. So they are supposed to be doing all the work and yet I'm doing all the work. (Participant 3)

How do they work out the administration fees and the case management fees? I've had the same case manager for three years. She doesn't visit often, only when necessary. I haven't needed to contact her for a long time. Yet every month, I'm charged $400 for case management. (Participant 5)

I hate to think of the old people sitting alone in their homes too scared to phone anyone because it will cost them a bomb. (Participant 25)

A participant had no case manager allocated for 18 months. Yet they were charged $603.30 per month for case management. This participant was also charged $673.20 per month for administration (Appendix 5, Example 1).

Right from the beginning, I had my back up because I knew enough about packages to know the provider was creaming off a great deal in terms of management monthly fees and so on. And I never felt that we were getting any case management at all. There was an 18-month period when we did not even have a case manager allocated to us. We seriously had no case manager for 18 months. Yet they still charged us for case management. (Participant 9)

Fees for support workers

Participants were also alarmed at the disparity between what they paid the provider for support workers and what the support workers said they were paid. In some cases, the support workers told participants they were paid below the award rate.

> *The provider gets the funding from the government. They hand some of it out to Mum and keep the rest. They take a substantial amount of the package in fees. They also charge us twice or even three times what they pay the carers. (Participant 23)*

Costs for equipment and supplies

Participants expressed concern about the amount charged for equipment and supplies. Some participants questioned whether providers received a "*kickback*".

> *I asked for a new mattress. The case manager suggested I get an occupational therapist to assess my home. I said OK. She hadn't told me it would cost $250. The OT wrote a five-page letter with all these recommendations. And the case manager then wanted me to order all this stuff I didn't need. All I wanted was a new mattress but she wanted me to purchase a new bed that cost $4,000. She was pushing me to buy it. I did but I don't like it. It was not the right bed for me. I've turned off all the gadgets – so it's just a flat bed. All I wanted was a bloody mattress. There was nothing wrong with old bed. I concluded that someone must have got a kickback. (Participant 11)*

> *I've used most of the package for home modifications and some equipment. That is what my husband really needed. I told the care manager my husband was having trouble in shower. It took her about a month to send an OT to assess the house. She made a lot of suggestions. They then got quotes for equipment. The quote for the chair was $2,700. I could get the same chair from the same company for about $600 cheaper – but the supplier inflates price because it's on a package. The suppliers know the providers will pay for it so they inflate the price. There is lots of this nonsense going on. (Participant 16)*

> *I am concerned about the costs for items like the walker and wheelchair. It's hard to know if the providers are taking a cut. We don't know the arrangement the equipment supplier has with the providers. It's the same with physiotherapists and occupational therapists who come into the home. You'd like to think things are above board. But I just don't know. (Participant 5)*

Questioning fees

Participants wondered whether costs were inflated because home care packages were subsidised by the government.

> *We got gardening support – but I noticed we were being charged more than double what a gardener normally charges. As soon as you mention it's an aged care package, sub-contractors (e.g. gardeners) inflate their costs. Also, we were not able to continue with our gardener friend. And that was important to us – for social reasons. (Participant 15)*

Some participants said they did not have the energy to question the fees.

> *When you get elderly and have some sort of terminal illness like I have, it's just too overwhelming to get involved in questioning the fees. I am just trying to survive day to day. (Participant 5)*

Staff

Administration

Several participants described people who answer phones in the office as "*unhelpful*".

> *The people who answer the phones are just not well educated about the services. (Participant 27)*

> *I phoned and reception put me through to the case manager's voicemail. She didn't phone me back. I later found out she was on leave. But the receptionist didn't tell me this. (Participant 33)*

Some large providers have a centralised administration. Several participants said this made communication difficult for the older person and their family.

> *There have been so many small things. They changed over to a centralised system for answering the phone. There are always issues getting through to them. And then it takes time for the person to get back to you. There has been mistake after mistake after mistake. If you ask for an extra hour and give plenty of notice. And then it doesn't happen. Or someone doesn't turn up because the scheduling wasn't done properly. If anything gets a little bit out of the ordinary, it doesn't work smoothly at all. I can't leave Mum on her own. So if no one turns up, I can't go out. It is tearing-your-hair-out-stuff for me. I don't know how vulnerable people communicate well with them. (Participant 30)*

> *To speak to the case manager, I have to ring a 1300 number. Then a person in the head office looks up my husband's name on the computer and asks me what I want. Head office then phones the local office and asks the question. Head office then phones me back. It's ridiculous. Much better for me to email unless it's urgent. I keep a copy of my email and their reply. (Participant 21)*

A participant described administrative problems when ordering supplies.

> *But we seem to find lots of roadblocks. The office gives me the pip. For instance, I am incontinent and wear pads. I use different ones for night and day. If I ring up to order the pads, they say: "Yes we'll order them today." And sometimes they are quite quick off the mark and they arrive. And other times they don't. On one occasion, we ordered some pads and they sent the wrong ones. So I phoned and pointed out the mistake. And then they sent a different lot of wrong ones. It took a third phone call before they got it right. (Participant 1)*

Case manager

Some participants became aware they had a case manager when they saw the fees on their financial statement.

> *I didn't know what the case manager did. I became aware I had a case manager when I noticed a $270 core advisory fee each month on the statement. I thought: What's that? (Participant 13)*

Role

Participants expressed confusion about the role of the case manager.

> *I went to a carers' meeting once where people didn't know what was the role of a case manager. I was quite shocked at their level of knowledge. It showed me how deep this confusion runs – it runs down to the most basic. (Participant 3)*

> *I want to know what a case manager does? Given the fees, I thought a case manager would touch base once a month to see what's happening. I also thought the personal carers would report back to the case manager monthly on the state of the client. I never heard from the case manager unless I contacted her. And she was very difficult to contact. (Participant 16)*

A participant described a case manager's role as "*putting out fires*".

> *They spend their time putting out fires. That is obviously a priority. But she hasn't spent time with me to explain things with me. I've had to work things out for myself. (Participant 35)*

Several participants who were the primary carer of the older person described themselves as the "*real case manager*".

> *When I asked the case manager: "What is your role? What do you do different to me?" She replied: "I assist with the budget. I find services for you." But I found my own services. She couldn't articulate the difference between what she does and what I was doing. (Participant 19)*

> *I don't know why I get charged case management because I do almost everything myself. I plan everything. (Participant 30)*

Expertise

Some participants questioned the expertise of some case managers.

> *The expertise, skills and knowledge of case managers is questionable. (Participant 19)*

Contact

Several participants said they had rarely met their case manager. A participant explained that this was a problem when a recipient's health deteriorated. She was concerned how the case manager would know to arrange an assessment for a higher-level home care package.

> *I had to insist that the case manager organise another assessment for my Mum. The Level 2 package was not meeting her needs. If the case manager had been competent, she would have recognised this without me having to insist. What are we paying our case management fees for? It seems obvious that older people are going to deteriorate over time. They should not just deliver a Level 2 package and then keep it at Level 2 until the family brings it to the providers' attention that Level 2 is not enough. (Participant 36)*

Several participants said they had difficulty contacting their case manager.

> *A new case manager started about a year ago. I am still waiting to meet him so we can update my husband's care plan. I have spent the past few months sending emails reminding them that it has not been updated since June 2016. They do not reply. (Participant 21)*

> *I'm on the phone to them all the time. I phoned them three times yesterday because she didn't call me back and it was important. I then wrote an email. (Participant 26)*

> *My carer told me the biggest complaint is that the case managers don't respond. The phone doesn't answer. You leave a message and it takes them days to get back to you. (Participant 17)*

One participant waited six weeks for the case manager to respond. The receptionist failed to tell her the case manager was on holidays.

> *A couple of times I phoned reception who transferred me to the case manager. But no one answered the phone. I was later told this case manager was on holidays for a month. I had to wait until she came back. (Participant 12)*

A participant described why she did not phone the case manager.

> *I was told the mainstream provider charged $90 when you phoned the case manager. You wouldn't want to be charged that ridiculous amount. So you wouldn't phone. You'd go without. (Participant 41)*

Some participants decided to put "*everything in writing*". Even then, some case managers took a long time to reply.

> *I sent an email to the case manager in desperation about all the different support workers going into Mum's home. Everything was going really wrong. It took six days for the case manager to reply. (Participant 35)*

Communication

Some participants described communication with their case manager as "*unsatisfactory*".

> *I received minimal case management. And it wasn't satisfactory. When I phoned with queries, she was abrupt. She would always refer me to her manager. She wasn't informative. (Participant 19)*

> *I make one call a month at the most. And they hardly ever contact me. And they certainly take out a nice old swipe. (Participant 27)*

Some participants found it difficult to get information from the case manager about their entitlements.

> *I always have to drag information out of them about what we can and can't have. One recent example: I found out by accident Mum could have got taxi vouchers through the package. The case manager was very defensive. I asked if we could have them when I take Mum to the doctor. She ended up sending me four. When Mum ran out she said: "I can't keep just handing them out." But we are entitled to get them through the package. (Participant 30)*

A participant was frustrated when the case manager did not explain the provider's policies.

> *Once a carer arrived when Mum was on the floor. They are not allowed to help her up. You only find out about these rules after it happens. It's not explained. Most people would help someone up. They wanted to call an ambulance. I didn't let them. My brother came instead. We have now learnt that if they want to call an ambulance, the family can't override – and Mum can't override them. It's their duty of care. (Participant 13)*

Participants described poor handovers between case managers. They also described poor communication between case managers within different services.

The case manager texted to say he was going on holidays for six weeks. He said the replacement case manager would arrange a physiotherapist. I heard nothing. (Participant 22)

We've asked for the provider to phone a family member, not Dad. But they didn't pass this information on to the people coming to assess Dad's incontinence. They phoned Dad directly to arrange a continence assessment. I get the sense that there are lots of different groups involved but they don't share the relevant information. (Participant 39)

High turnover

A participant described the high turnover of case managers. She questioned the reasons so many case managers resigned.

The mainstream provider's case manager never came to my home. I was hardly ever able to even talk to them on the phone. If I phoned, I was told: "She's no longer here." They all left – and they never told you that the person was no longer your case manager. Nor introduce you to a new one. Why is there such a high turnover? What's behind that? (Participant 41)

Difficult to understand

Participants, particularly those with hearing impairments, found it difficult to understand case managers who spoke with strong accents.

She had a strong accent that I found hard to understand on the phone. She thought I was an idiot. She was condescending. I didn't like to contact her. I preferred to just leave a message with the receptionist. (Participant 13)

The new case manager was not easy to deal with. She was hard to understand – strong accent. She didn't seem relationship driven. She was operational – and I found that annoying. I've had lots of problems (Participant 35)

Authoritarian manner

Some participants said their case managers were poor listeners, thought they knew what was best and would tell them what to do.

My case manager thinks she knows best. She thinks I don't know what I need. I told them I wanted a desk chair but not one with arms – so it would fit under the desk. I was told: "No you can't have that, you've got to have the one specified by the OT." They say it's consumer directed care – but that's not how I was being treated. They were telling me what I could have, what I should do and when. (Participant 11)

I was 63 and my partner was 61 – younger than their other clients. They were used to telling older people what to do. They tried to tell us what to do. Of course, I got my back up. I didn't like their attitude at all. (Participant 9)

Inexperienced

Some participants had case managers who were inexperienced.

The first two case managers were 20-somethings who knew nothing about dementia – even less about early onset dementia. They also knew nothing about coming into a household of our age group. (Participant 9)

Lack of continuity

Participants said it was difficult forming relationships with case managers because some did not remain in the job for very long.

We got a new case manager who only lasted two weeks. And then I got another, then another and another one. I never have continuity… The staff changes are phenomenal. All the case managers leave. (Participant 17)

There have been three case managers in the last year. There was no case manager between December and April. They still charged. (Participant 14)

Too busy

Some case managers were too busy to provide the support required. Participants suggested this was because their caseloads were very high.

The case manager had so many people on her books – and she couldn't give us the time we needed. (Participant 9)

Case manager caseloads are very high, some as high as 100 and so they are unable to provide a quality service to clients. (Participant 19)

Support Workers

Participants did not want strangers working in their home.

> *Growing up, we were told not to let strangers into our homes. Now older people are being told to trust these strangers who come into our homes. (Participant 36)*

Unsuitable

Several participants suggested providers needed to be more selective about the people they employ as support workers.

> *They just employ ordinary people. I am not able to choose who comes… I've had some terrible ones – one was an IV drug user but I didn't know. She looked like she was going to drop dead. She was grey. What would I do if I had no husband and they were sending me this crap? (Participant 17)*

> *They just didn't have the right people. I had several mini meltdowns, and then I had a major meltdown. I had to get more help. (Participant 9)*

> *I once had a carer who told me she didn't like showering people. And I thought: "Bloody hell, what are you doing here then?" (Participant 1)*

> *The support worker was hopeless. She didn't come across as very caring or compassionate. Why do people like that work in aged care? (Participant 35)*

Participants were concerned about the lack of strict selection criteria when employing support workers. They said this meant providers had to keep a close eye on the support workers.

> *With Provider M, they know where staff are at all times. They are followed with GPS. They clock on and off with their phones. There is something about being watched and checked – it undermines relationships. With the charitable organisation that we used to have before the package, there was a level of trust with their staff. (Participant 9)*

When participants found a good support worker, they would request that person return to their home. However, this was not always possible.

> *When we find a good carer who has a rapport with Mum, it's a struggle to get her back again. I had to keep phoning and asking. I've also found when I compliment a carer, I never saw her again. I suspect they don't want clients and workers becoming too attached. (Participant 30)*

High turnover

Some providers were constantly understaffed. These providers also had a high turnover of support workers.

> *Provider M was always understaffed. If someone phoned in sick, they would send any Tom, Dick or Harry. Their staff turnover was also very high – churning different people through. It was extraordinary. Support workers would come and you wouldn't see them again. Last year, my partner had five different people in the first five months of the year – new person coming and going… I would get so sick of new people coming in to our home. So no wonder we were not able to spend our package because I did not want strangers coming into our house. With the local council, we'd had the same support workers for several years. (Participant 9)*

Several participants complained about the number of different support workers who were sent to work in their home.

> *Recently, we've had about 40 different support workers. Mum became very stressed by all these different people coming into her home. (Participant 35)*

> *My parents were both on a Level 4 package until Mum moved into a nursing home. They were initially very resistant to having people come into the home. At the beginning, Mum threw people out. One of the things that didn't help was the inconsistency of people. (Participant 40)*

> *The inconsistency in staff is a real problem. It's unmanageable with dementia. The consistency is critical. With one agency, there was a constant turnover. It took six months of emailing and phoning to get a roster. (Participant 3)*

> *Provider I is a big company. I had different people coming to my home. Someone came on Monday, a different person Wednesday and another person on Friday. I told the case manager I wanted to stick with one person. I don't have to explain everything – the mop is here, the detergent is here, the brush is here. If I had the same person, they would know what to do without me having to explain every time. I finish my shower, and then have breakfast. She replied: "Yes, of course." But it never happened. (Participant 4)*

Participants were upset when a stranger turned up at their door saying they were the support worker. A participant said this made him feel physically unsafe. Another participant was afraid of theft.

They used to send different people. Someone would knock on my door and I would say: "Who are you?" They would tell me they had been sent to help me shower. I would reply: "I can't accept you." No one phoned me to tell me anything about it. I needed to know who was coming into my home. I used to get very upset. One day a man turned up at my door. I asked: "Who are you?" He replied: "I'm the cleaner." I asked: "Who sent you?" He was agency. I said: "I don't know you. I don't want you in my home." I don't feel safe like that. I don't know his name, where he comes from. He could attack me. Who knows? I can't defend myself. I said to the case manager: "You have to stop this. It can't go on like that. I need to find someone who can take care of me." (Participant 4)

Provider AA promised the world but they were all over the shop. I ended up going off at the case manager because they kept sending different people every week. And they were never on time. I insisted on someone who knows us – and knows Mum. I can't keep having all these strangers in my house. I may as well be doing it myself because I had to keep explaining Mum's needs. (Participant 25)

It's important that support workers form relationships. You can't have strangers going into people's homes. Knowing that I have vulnerable parents on their own – you hear stories of people going in and robbing them blind and god knows what else. (Participant 40)

Although participants made it clear to the case manager they wanted support workers to be consistent, the high turnover of support workers remained a problem.

We were clear the staff coming to our home had to be consistent – so my partner could get to know them and vice versa. Nonetheless we were sent a whole ream of people. My partner refused some of them. (Participant 15)

I've told them numerous times: "If you can't send the girls we've approved to care for Mum, don't send anyone." These new girls stress Mum and cause more stress for my wife and me. With Mum's dementia, I don't want a different girl coming every day. It confuses Mum. Provider BB stuff it up. They keep sending new girls. (Participant 26)

Mum had short half-hour visits. They were different people all the time. She had 14 visits a week with around 10 different people. (Participant 23)

Participants suggested the problem is that some providers do not employ enough support workers. Agency staff were used to fulfill commitments.

There is a different person each day. They often change. It seems to me they don't have enough carers – not enough staff. Because when they can't fill the roster, they use an agency. (Participant 1)

Unreliable

Several participants said they never knew what time the support person would arrive at their home.

I never know when they are turning up. I knew when they were supposed to turn up. But one day I went to Mum's place at 3.30pm. Someone was in the kitchen and microwave was on. I asked what they were doing here. "Dinner. I came early." Fancy giving someone dinner at 3.30pm. It's wrong – and made me realise this type of thing is happening all the time. It's not fair because lots of people – with or without dementia – have trouble sleeping. And so they are up at 1am – and my Mum has no access to a stove – so she is going to be hungry if you feed her at 3.30pm. (Participant 3)

Participants said it was important to not only know who was coming, but also when. They were dissatisfied when support workers did not arrive on time or, in some cases, did not arrive at all.

Provider I was never on time. They were always phoning me to say they couldn't send someone today. Or they said they were coming at 10am and they would phone to say 11am. One day recently, I was still waiting at 1pm for a shower. I phoned the office and said: "What has happened? I need a shower." They told me they were short of staff and would send someone new from an agency. (Participant 4)

A carer was supposed to come at 7am but no one came. The carer who was rostered on was sick. Someone came at 10am. I was at work so I had no idea. When the carer arrived Mum was distressed–upset, hungry. I began to think Mum couldn't live alone if the service was not reliable. It was a difficult decision – she loves her neighbours, we are in the next street. Her geriatrician felt she needed proper care in an aged care home. (Participant 23)

A participant described feeling frustrated when a support worker did not turn up despite making the booking in advance for a special occasion.

I had asked Provider Q to have someone here at 1pm because I had an appointment. I had made the booking a long time in advance. The day came and the person never arrived. After half an hour, I phoned. The office people told me he should be there. And they phoned back to say they had made a mistake. On another occasion, I had cancelled but they forgot to tell him and he arrived. (Participant 16)

Communication

Participants expressed frustration when they were unable to communicate directly with their support worker.

The biggest frustration for me is that agencies don't want you to have contact with their staff/carers… Why are the agencies blocking family carers and professional carers from getting hold of each other? If I want the carer to get Mum milk, I have to phone the case manager and leave a message just to ask the evening carer to get some milk. (Participant 3)

The communication doesn't exist. It's hopeless. We had to phone a Melbourne number if we had to tell them we would not be home tomorrow so we don't need someone to come. Melbourne people would then phone local people. It was just hopeless. (Participant 9)

Having to go through a bureaucratic system to get a message to my carer is a stumbling block for me. If I want to say: "I don't need [Name] this week because I have a meeting somewhere," I can't say to [Name] – well I do say it anyway. But it has to go through the system. (Participant 41)

Participants also found it frustrating when they did not know the roster in advance.

I don't know who is coming tomorrow – but I have to trust that they will be OK. (Participant 1)

A participant was upset when the case manager did not inform her about a new support worker. Another participant said it was inappropriate to send "*anyone*".

They sent a woman who couldn't speak English. Mum was sitting in her chair. She cleaned but didn't give Mum anything to eat or drink. I would never have left Mum alone if I had known it would be a new person. Nobody told me. I think it is incompetence. (Participant 14)

If the regular workers were not available, they would send anyone in without telling me in advance. They learnt after a few discussions with me that this is not appropriate. (Participant 40)

Frequent staff changes made communication difficult.

I wasn't happy with the program because there was no connection. Staff changed so often. And you were never told who the new worker was. I would phone for something and I would be told: "No, she's not here any longer. Maybe you should speak with so-and-so." I just wasn't happy with it. Also she didn't try to match me with an Indigenous carer. That is an issue. (Participant 41)

Qualifications and experience

Many participants did not know whether the support workers were qualified.

How do you know if the carer is qualified? Are they nurses? Would they know what to do in a crisis. Do they have first aid or CPR? They once sent a support worker who was a student. I went out when he was here and told him not to let anyone into the apartment. He did and it caused a problem. (Participant 16)

Some participants were shocked to find that not all support workers were qualified. Provider O, for example, required only a police check.

Most care providers in an area advertise for staff with Certificate 3 or in the process of doing it. Little did I know that Provider O took anybody. Staff did not need to have any qualifications or experience. They literally employed anyone. They just needed a police check. They got staff from Centrelink - unemployed people who were told they had to get a job in aged care. These people didn't want to be there. (Participant 15)

Participants were concerned that inexperienced support workers might not know what they were doing.

A few have been quite inexperienced. They are tentative when they give me a shower. I'm quite sure one was still a schoolgirl – she didn't really know what she was doing. (Participant 13)

Training

Some support workers were insufficiently trained. Participants described new support workers as "*thrown in the deep end*".

> *I actually asked a carer one evening whether she had any training in dementia. Nope. Are you kidding me? University of Tasmania MOOC is free. There is no excuse for not having any training… You'd think a company as large as Provider G would have properly trained staff. (Participant 3)*

> *It is unacceptable that staff are not trained and they don't offer them any training. All the training has to be done out of hours under their own steam. Provider M needs to provide training about situations that their staff are going to face. (Participant 9)*

> *New staff were supposed to have two weeks buddying with experienced staff, but often they get none. They got thrown in the deep end. They sent staff who lacked experience and knowledge. They had no initiative – because they were so new. (Participant 15)*

Some support workers had not been trained how to safely use equipment such as a hoist. This put pressure on families to train the support worker.

> *I don't feel the carers are adequately trained. I had to teach them how to use the hoist. They didn't know how to do it. (Participant 19)*

> *I had to keep telling them what to do. They didn't even know how to use the hoist. It is easier for me just to do it myself. (Participant 21)*

Participants were annoyed when support workers without any experience came to their home. They were particularly concerned when support workers had not received any dementia training.

> *A few times, they have sent someone who is very young and inexperienced. My Mum is too high level. They need to train her before they send her out to someone who is Level 4 like my Mum. I end up having to show them what to do. That has been another struggle. (Participant 30)*

> *Provider K has sent me a lass who is only 20 years old. She is training in occupational therapy. I don't think she has ever cleaned a house in her life. My eyesight seems better than hers. I see all the dust. I see the rim in the bath. When she cleans the bathroom bench, she doesn't move things. She cleans around them. When she cleans the kitchen floor, she doesn't move the kitchen stools. The other day, she left a puddle of water on the floor. I could easily have slipped. (Participant 7)*

> *All the support workers with Provider M seemed to be casual – and they were very young. They knew nothing about dementia. (Participant 9)*

Competency

A participant was disappointed when a carer failed to call an ambulance when she was very sick.

> *I was very sick recently. My carer came to see me on Monday morning, but I don't recall her visit. I must have been very sick. I'm disappointed she didn't call an ambulance. Later that day, my friend called an ambulance and I was in hospital for a week. I phoned the case manager to ask why the carer didn't phone the ambulance. The carer had reported that I wasn't well. But she didn't do anything. (Participant 33)*

Another participant reported a support worker being unable to complete her tasks in a reasonable time. As a result, the older person was not able to go on her scheduled outing. The daughter expressed alarm that the support worker left her mother home alone.

> *On one occasion, Mum missed her outing because the support worker could not get her dressed and breakfast ready for her outing. They then left her alone at home. This could have been a disaster. (Participant 35)*

Manner

A participant described an episode of transphobia.

> *I had one woman come to my home, and she didn't speak. When she finished, I asked her whether she knew who I am. She replied: "Yes, I know who you are. I just don't approve of it." So she didn't come again. That's the only issue I've had with transphobia. (Participant 11)*

Another participant described a support worker making a decision without consulting her. Her daughter questioned whether the support worker's behaviour was ageist.

> *One woman was cleaning. She made it clear she didn't like cleaning. Two days later, two big parcels arrive – a mop and bucket. She had gone back to*

the office and told them my cleaning materials were not adequate. The cost came out of my package. And I had no idea. Surely I should have a choice of the type of mop used in my home. (Participant 13)

Remuneration

Participants said the support workers were underpaid. Several participants described support workers being paid below award wages. They also noted the difference between what the support workers were being paid and what the participants were being charged.

People working in sector are underpaid. Our carer has a Certificate IV and gets $27.17 per hour (the award). Provider E charges $48 per hour. So that's where they make some money along with their administration/ case management fee. (Participant 20)

The care workers at Provider O were being paid about $22 per hour. We were being charged $65 an hour. That's base rates – not overnights, weekends or public holidays. (Participant 15)

Gender

Several participants described preferring support workers to be female. They felt the case manager should have known their preference and not sent a male support worker.

Once a male turned up, and Dad would not let him in. Dad is obviously more comfortable with women. (Participant 39)

Travel

Participants noted the long distances some support workers travelled between client visits.

Some of the carers come all the way from Frankston. This is why they are often late. And their next client is in Frankston. It is not very efficient. (Participant 13)

I felt for the staff as well. They would ask whether we needed staff for half an hour. I said: "No, that's not fair on them." Provider N wouldn't let anyone come here for less than two hours. I think that's reasonable. Out of respect for the worker, they are driving from somewhere to our place. It needs to be worth their time. I think Provider N has always been the benchmark for me in terms of comparing with Provider M. (Participant 9)

A participant excused the support workers for being late due to the distances they travelled between jobs.

They are sometimes late. But the traffic is murder. They send them from here to Richmond – and expect them to get there in 10 minutes. It is impossible. So they are late. The other day, they sent a lass from Bulleen across to me. They gave her 15 minutes' travel time. (Participant 8)

Stress

Some participants described the support workers as "*stressed out*". One participant suggested staff receive training in meditation. Another suggested dementia training. They felt additional training might help reduce stress levels.

A lot of the carers are very stressed out. The agencies don't give a damn about them. They're not interested in helping their staff. I suggested to the state manager they could send out a CD for meditation for carers. "Oh fabulous idea" – but nothing gets done. (Participant 17)

Providers don't realise that by having dementia training you are bringing your own staff's stress levels down. For me, dementia is extremely stressful to deal with. By not training staff, you are contributing to workforce stress level and burnout. (Participant 3)

Time spent with care recipient

A participant questioned the amount of time support workers were spending with older people.

I'd be on the phone to Mum and hear the doorbell ring. I'd phone back 10 minutes later and say "Hi Mum. Is [Name] still there?" She would reply: "No, he has gone." They were paid for a 30- and 45-minute session. There is no way to confirm that the staff are in the home providing that care for the allocated time. For many isolated people, that 30-45 minutes is the only human contact they have all day. So to be ripping them off like that and just zipping in and out in 10 minutes – which is what they were doing – is terrible. (Participant 3)

Sub-contracting support workers

Several participants described providers hiring support workers from another provider. These providers either did not employ their own staff or employed an insufficient number of staff.

It is totally misleading for Provider Q to use another provider for carers. I came to Provider Q so that the carers would be from the same religious

group. But they are not. Provider Q is just the middle person providing no service. If I had gone directly to Provider R it would have been cheaper. (Participant 16)

Provider S gets carers from Provider C. Provider S doesn't have enough staff. The communication between agencies is terrible. If Mum has any problems, I phone the case manager at Provider S, who then phones the case manager at Provider C, who then informs the carer. It's very hard to change rosters. I can't speak directly to the carer. (Participant 14)

Agency staff

Some participants said they "*stumbled upon*" good agency staff. However, their case manager told them it was more expensive to hire agency staff. Other participants were dissatisfied when the provider sent agency staff.

I once stumbled upon a good agency person. I asked if I could keep him as a regular. But they said: "Agency are more expensive." They told me he would cost $140 per hour. (Participant 4)

If someone is sick, you have to take whoever. The problem with that is they don't know my mother, they don't where anything is in the house. I don't want some stranger working around the house, rooting through my cupboards. They often don't even tell me someone else is coming. It's wrong. They should have sent even an email or text or something to say: "Someone else is coming. Is that OK? Or do you want to change your booking?" (Participant 14)

A participant said support workers sourced from other providers were not flexible.

Provider S is not flexible – probably because they get their support workers from Provider L. (Participant 14)

Lack of respect

Some participants described support workers treating them disrespectfully.

Some of the workers treat me like a child… They don't always listen to me. They treat me like I'm a patient. They take control. (Participant 13)

A few weeks ago, when the lass came in I said: "I'm not getting out of bed." So she tried all sorts of ways to coerce me. But I insisted. I just wanted to stay in bed. (Participant 1)

There was a few hundred dollars missing. I couldn't say anything. With dementia it would have been Mum's word against the support worker's. (Participant 37)

Culturally and linguistically diverse

Some participants chose the provider specifically because they assumed the provider would provide support workers who could speak their language and/or share their culture or religion. They were disappointed when they discovered this was not the case.

It seemed sensible to choose one that suited our religion. I thought they would understand our religion and culture. I didn't know Provider Q does not employ carers. All their carers are sourced from another provider. They are taking over half the package in fees but not providing the service I expected… We had a family bar mitzvah in the synagogue. Men sit downstairs and women sit upstairs. I called the rostering people six weeks in advance. I wasn't sure how my husband would be on the day – but I arranged for a male carer to come with us, because I could not sit with him. They arranged for a young man from the Philippines. I needed someone who was Jewish. I was very unhappy. (Participant 16)

Mum preferred Greek-speaking support workers. As Mum's dementia has worsened, she has forgotten a lot of English. I chose this provider because they have Greek-speaking staff. Yet they sent Mum new support workers – none of whom spoke Greek. (Participant 35)

Although the following quote may be perceived as offensive, several participants expressed a preference for "*Anglo*" support workers.

Some care workers from different cultures don't understand our slang – they may not understand what my parents are saying. Dad is deaf and found their accents very difficult to understand. It was very important to get Anglo care workers. (Participant 40)

Food handling

Some participants were concerned about the level of training support workers received in food preparation. They questioned whether food handling in the home was regulated.

There is no regulation on food handling for people who come into the home. (Participant 29)

Cleaning

In many instances, the same support worker who provided personal care also cleaned the house. Some participants indicated they would have preferred a professional cleaner. Others suggested the support workers needed more time to clean.

> *I'd like proper cleaners. These women don't nearly do what I'd do. But I am not terribly assertive. When she comes out to say she is finished, I say "Good, thank you." And then I go into the bathroom and I see the cobwebs. I don't like to be picky. (Participant 1)*

> *They are restricted in what they can do. They can't move furniture. A professional cleaner would do a better job. (Participant 13)*

> *[The support workers] never have time to do a decent clean. They are in a rush to get to the next job. Also, they are restricted in what they can do. (Participant 17)*

Daily fee and means tested contribution

A provider was entitled to charge a daily fee for a home care package. As of September 2018, the daily fee was $146.02 per person per fortnight. Participants described several instances when providers did not charge this fee. However, it was not clear how providers chose who, and who not, to charge.

> *They said it was government recommended fees of $10 per day - $260 per month. My mum was on a full pension. The case manager told us they had some clients who were not paying anything at all. How is that fair? It is a big chunk out of her pension. (Participant 35)*

Participants were concerned about being charged a daily basic care fee for seven days when they received care on only one or two days per week.

> *Dad was approved for a Level 2. Once he was means tested, we were charged $20 per day. Our contribution was $20 a day for every day of the year – irrespective of how many days per week we used the service. But that didn't all come through until we were three months into the package… Prior to the package, I was paying the carer $25 an hour for seven hours per week. But on a Level 2 package we only got four hours. It worked out that Level 2 was not financially viable – so we stopped it. (Participant 20)*

Unspent package

As of 30 June 2017, providers who submitted their financial reports to the Department reported unspent funds of around $329 million (Aged Care Funding Authority, 2018). This equates to holding average unspent funds per 'consumer' of $4,613, an increase of 26 per cent from the previous year.

Participants described several reasons for having a large surplus in their package. One participant described her mother preferring her family over professionals to provide the support.

> *Mum is in a retirement village. Within a radius of about six kilometres is me, my brother, my son, and my daughter. We have a large surplus in our account because of the level of support Mum gets from family. (Participant 37)*

Several participants described being unable to spend their home care package because the provider did not supply the required services.

> *My partner couldn't spend her package because the provider did not provide services that we needed. It's morally wrong for Provider M to offer packages if they don't have the staff to give you the services to help you stay at home together. (Participant 9)*

Some participants described not using the services because they were unhappy with the quality of the services delivered.

> *We have a Level 4 but I cancelled the personal services because they were useless. I couldn't wait around until 2pm for my husband to have a shower. I also used to have a carer come in for some respite. But I need to be able to trust the person – especially when my husband is hoist lifted. The last one we had sat outside smoking and on her phone – leaving my husband alone inside. I also had a carer steal. So I don't use them. Our closing balance is $13,400 – because we are not spending it on services. (Participant 21)*

> *When we first signed up with Provider M, they gave us a list of their services – but a lot of these services were not of any interest… We just didn't fit in with how they wanted things to be. (Participant 9)*

> *We realised what is currently around does not suit us at all. Our early onset dementia group is aware that we will have to create what we need ourselves. (Participant 15)*

A participant had more than $30,000 surplus in her account. She was told she was not using enough of her package. Another who had $20,000 in her account said the provider was going to change her package from Level 4 to Level 3.

Our balance is simply because they haven't had the staff to deliver the service. We had over $30,000 unspent in our account. We would have spent it if they provided a service we could use. The regional manager came back one day – she said I was not using enough of the package. I said: "You give me decent staff and I will use it." She replied: "If you don't use it, we will give it to someone who will." I really flew off the handle. "How dare you say that? I am not the problem here. You're the problem. The organisation is the problem. You're not providing me with what I want and when I want it and how I want it… We've been trying to spend some money out of the package before my partner goes into residential care. Well, stuff you. You haven't looked after us for four years. You have to be prepared to compensate my partner for that." (Participant 9)

Provider O threatened to cut us back from a Level 4 to a Level 3 package "to share the money around to those who really need it". Bullying. Illegal. It still makes my blood boil, just thinking about it. (P 15)

Several participants were saving their money for a later date when they would require equipment or house renovations.

We had saved some money in our package for a rainy day. The house will need some modifications to be more accessible. These savings created further conflict with Provider O. This time last year, we had nearly $20,000. It has gone down to about $5,000. I suspect this may be financial fraud. (Participant 15)

A participant was saving the package because she anticipated her father would not be able to access a Level 4 home care package when it was required.

Level 3 is meeting his needs right now. In fact, we are not utilising the whole package. I'm accumulating on purpose because one expects if you're on Level 3 you are going to progress to Level 4. But the system doesn't allow for that. When you know things have deteriorated there are still huge hurdles to jump. You have to be reassessed by ACAS, you've got to be made high priority, you have to wait for someone to die or go into care. Only then do you get the next level package and can increase your hours. I'm accumulating on purpose because my father is now 95, his deterioration is significant but he is still holding himself together – just. This is a downfall of this system. (Participant 20)

Some participants had a temporary surplus because they used services from another provider. The surplus in their account was due to delays in the primary provider receiving the secondary provider's invoice.

The only problem now is Provider E is very slow sending their invoices to my new provider. Currently I have a large surplus because they haven't received invoices for the services I have used. (Participant 18)

Some participants expressed concern about the unspent money being taken back by the government.

I've heard rumours that the government is considering taking some of that back, to be seen to be injecting funds into more home care packages. (Participant 15)

I heard on the grapevine that a certain large care provider is telling their clients on packages they need to spend their package money or the government is going to take it off them and give it to the drought farmers. (Participant 21)

Complaints and advocacy

Complaints

Some participants made complaints directly to My Aged Care. Others contacted the Aged Care Complaints Commissioner. There was some confusion about whether the Aged Care Complaints Commissioner dealt with home care. When one participant contacted the commissioner, she reported being told the Aged Care Complaints Commissioner only deals with residential aged care. This was incorrect.

I used the complaints through My Aged Care. I spoke to someone on the phone and they wrote it all down. I asked to speak to someone, but was not allowed. I never heard anything back. (Participant 19)

I've found the Complaints' Commissioner useless. Not supportive at all. They just wanted to close the case without it being resolved. They were not prepared to put anything in writing to me. (Participant 35)

A participant relied on the Public Guardian to advocate on her behalf.

I had to get the Public Guardian on to them a couple of times. It was terrible. (Participant 17)

Moving into residential aged care prematurely

Although 22 participants were approved for a Level 4 home care package, five had been assigned a lower package. One participant approved for a Level 4 package had not yet been assigned a home care package.

> *Dad is still on the wait list. I think he will die before his funding comes through. (Participant 24)*

Some participants could not manage to remain at home on a lower home care package. Their families were forced to consider residential aged care.

> *Mum was approved for a Level 4 package two years ago. She was given Level 2. It was not enough. I was exhausted. So Mum went into respite. She had four falls in the first few days. I don't understand how she fell. She could walk with me to the local shops. She didn't even use a walking stick. She broke her hip and now can't walk at all. It is now not possible for me to look after her at home. (Participant 6)*

> *Mum was not ready for residential aged care. She was fully mobile, hadn't had any falls or anything else, but the system was going to put her there because we were still waiting for the Level 4. And she couldn't survive at home on Level 2. If the Level 4 package had not been assigned, Mum would have been another statistic in residential aged care ahead of time. (Participant 3)*

Ideas for improving in-home care

Participants made some practical suggestions about how the quality of in-home care could be improved. A number of these are being funded through the *More Choice for a Longer Life* budget measures.

In some cases the suggestion had already been implemented (e.g. interpreters). The fact that participants were unaware of interpreters suggests further communication about the National Translating and Interpreting Service may be warranted.

Participants' suggestions are discussed under the following headings:

- Make aged care system easier to navigate
- Legislative changes
- Improving My Aged Care
  - Better information
  - Website
- Reducing the queue
- Providers
  - Licences
  - Accountability
- Choosing a provider
- Schedule of fees
- Financial statements
  - Clarity
  - Explanations
  - Real-time statements
- Person-centred care
  - Culturally sensitive
- Case manager
- Support worker
  - Recruitment and training
  - Empathy
  - Consistency
  - Matching workers with clients
  - Information about outsourcing
  - Mentoring system
  - Roster
- Support for carers
- Purchasing private services
- Private health insurance
- Peer support
- Connecting care recipients
- Respite
- Advocacy

Make aged care system easier to navigate

Carers of older people are experiencing grief at the same time as they are trying to navigate a complex system. In some cases, it was "*all too much*". Participants said they would have benefited from assistance to navigate the system.

> *You can't be expected to do it on your own when you first start out. You need some guidance. (Participant 28)*

Legislative changes

A participant suggested legislation to ensure providers only charged a certain percentage in case management and administration fees.

> *It is open to abuse. More so because they are working with a group in society who are not able to monitor what is happening to them. An older person like my forgetful friend may not even to know to ask the question. I don't know what you do about it. Somehow they need legislation that locks the providers in to a certain percentage. No lower than, no higher than… The providers can then decide whether they can run a business on those margins. (Participant 7)*

Another participant recommended more government regulation.

> *It is not a very regulated service – there appear to be no client-centred frameworks, structures or adequate guidelines – they are different with each provider. A more consistent approach is needed. (Participant 19)*

Improving My Aged Care

A participant suggested a "*complete overhaul*" of My Aged Care.

> *I think this service needs a complete overhaul, with more qualified and trained staff who can offer families and clients more support and advice. (Participant 19)*

Better information

To make genuine choices, participants said they required more information.

> *We need more publicly available information that encourages people to be able to make those choices. Consumer directed care is ridiculous if the choices aren't real. (Participant 15)*

Participants also wanted more reliable information. They suggested staff at My Aged Care should be better informed. My Aged Care should be a "*one-stop-shop*" for information and advice.

> *We need one place where we can pick up the phone and find an answer to almost everything within aged care, including the legislation, parts of the Act – all of that stuff. You have to be prepared to make 20 phone calls. I have been – and that is the reason I know what I do (Participant 3)*

Website

Several participants were aware that the government had recently funded improvements to the My Aged Care website. They suggested the search engine that helps people find providers in their local area should be refined.

> *We went to the My Aged Care search engine and put in our postcode. It brought up hundreds of providers, many from miles away. I believe some of the money being thrown at the web page is to address this problem. The search function has to be more refined. (Participant 15)*

They also suggested the My Aged Care website should provide more detail about the different providers.

> *We need to be able to search for providers and see their reports – have they met standards, what is going on if they haven't? We also need to be able to see the basic costs – and for what. How do you know if you are getting value for money? (Participant 15)*

A participant suggested testing the website with 'consumers'.

> *They need to field-test the website with those of us who use it. (Participant 11)*

Reducing the queue

Participants suggested the government should increase funding so more home care packages can be released.

> *It is horrible for many people in queue. If they have been assessed as needing a Level 4, they need it now. Not in a year or two. And the government has all these ads on TV. It's ridiculous. They should have released a lot of packages instead. (Participant 27)*

Participants also suggested certain groups should be given priority in the queue.

> *People who are on pensions or don't have any family support need to be pushed up the queue. (Participant 24)*

Providers

Licences

To become a provider of home care packages, an application is submitted to the Commonwealth Department of Health. The department reviews suitability as per criteria stipulated in the *Aged Care Act 1997*. However, participants suggested the government restrict licences to only those companies that can demonstrate expertise in aged care. Only providers that employ qualified staff and deliver ongoing training should be given licences.

> *They need to give licences to providers who know about aged care not just companies that are interested in taking government money. (Participant 25)*

Accountability

Participants suggested providers needed to be transparent, accountable and financially audited.

> *There has to be accountability and transparency. You have to show that you have trained people, that you have an understanding of the area – and it's up to the Commonwealth Government to set the standards in both residential and home care*

that organisations have to sign up to. Why is an insurance company given a licence to deliver home care packages? (Participant 9)

It all depends on the integrity of the provider. There certainly needs to be a provision for more auditing. (Participant 5)

When we look at inefficiencies, and not having enough money in aged care, if they were to audit this entire industry with these invoices and everything else, there would be millions of dollars in either incorrect charges or unscrupulous charges that are going on to these invoices. (Participant 3)

Why didn't they include an audit when they set up My Aged Care? It just seems common sense – so government knows how providers are spending taxpayers' money… I just can't understand the government. It makes them look so weak when they don't have a built-in system where every provider is audited so many times a year. I just can't believe it. (Participant 5)

A participant suggested what providers paid their staff should be published.

Make the providers financially accountable. All salaries and fees must be published. And also made accountable for their duty of care. (Participant 29)

Several participants would prefer the government to give the home care package directly to the recipient so the family could employ professionals.

There are too many hands in the funding pie… It would work better if Mum received the funding directly and I hired the support workers. Mum would get more hours. Two hours a day is simply not enough for a person with dementia on a Level 4 package. (Participant 25)

My ultimate cry is: "Can't we please get the packages directly?" (Participant 15)

Choosing a provider

A participant suggested an innovative way to ensure recipients of home care packages chose a reputable provider.

How does an elderly person who has not had any experience with this system choose a provider who is going to do the right thing by them and the government? I was introduced to provider J by my GP. I wonder if it would help if the agent had to be introduced or recommended by the person's GP. Verified by the GP – so the older person knows they are honourable. And keeps on being honourable. (Participant 7)

Several participants would have preferred the government to give them a provider rather than require them to choose their own.

When the home care package was assigned, I immediately received phone calls from Providers M and O and others. They wanted me to sign papers. It was overwhelming. I was told later that I had to make the decision. I would have preferred to just be given a provider. So much was going on. My husband was very sick. It was hard to think about all this. (Participant 31)

Schedule of fees

Participants suggested it should mandatory to receive a schedule of fees before older people signed the Home Care Agreement.

Before you sign up for these packages, you should be sent a document with an average cost for the fees – like my private neurologist. She sent me a list of all her fees before my first appointment. We need the government to provide us with a schedule of fees. We need a schedule that everyone understands. For example, how do I know the charge for my walker was reasonable? Or the hourly rate the company charges? (Participant 5)

Home care providers must publish their existing pricing information on My Aged Care by 30 November 2018. This requirement was legislated in August 2018. However, on 22 January 2019, Provider B had not published its pricing information (Appendix 5, Example 6). A participant suggested there should be some penalty pricing information on My Aged Care.

What is the penalty for not publishing fees? Easy solution, their profile is removed from MAC!! (Participant 3)

Financial statements

Participants suggested improvements to the financial statements, which included improving clarity and providing explanations and real-time statements.

Clarity

The financial statements should be clear.

> *When we receive our invoice, we should know exactly what is going on. When they say "total expenditure", is that for the month? $1,344.50. That seems a lot for the three hours help that I get. (Participant 5)*

Explanations

Participants suggested the case manager explain the monthly statement to those who had trouble understanding it.

> *Many women my age did not do the family's finances. We haven't even got the language to check the statements. It's not a criticism, it's a fact of life. (Participant 7)*

Real-time statements

Participants described a need for real-time access to statements.

> *They should provide real-time accounting so we can know the balance of our accounts. (Participant 14)*

Person-centred care

Participants said listening to older people and their families – understanding their needs and matching them with compatible support workers – was an essential component of delivering person-centred care.

> *Overall, the idea of a package is a great idea and absolutely necessary. But there has to be a lot more professionalism. They have to take into account the family they are supporting. There has to be a culture at the top of person-centred care and listening to what clients want. (Participant 9)*

> *The service is very administratively driven with less focus on the client. Costing and budget is a priority to providers. A more personal approach is required. This could be achieved with more realistic caseloads and recruitment of more staff. (Participant 19)*

Culturally sensitive

A participant suggested a more culturally sensitive approach was needed. Although a national interpreting service is available, she also suggested there was a need for more interpreters. As stated earlier, this may indicate a need to further promote the Translating and Interpreting Service.

> *The language barrier inhibits quality of care and service provision and I think this needs to be incorporated in the clients' individual care plans and the system as a whole. More interpreters are required and need to be offered more readily. This is very hit and miss. Cultural training for case managers and personal carers is needed on a regular basis. (Participant 19)*

Case managers

Participants described what makes a good case manager.

> *A good case manager has an understanding of disabilities – in our case dementia, specifically younger onset dementia. A case manager needs to be a good listener. They don't come in with pre-set ideas of what it is that we may want or need but ask what you want/need. They then set about making sure that this happens. (Participant 9)*

Participants suggested recipients of home care packages should be given information about a case manager's role.

> *When you sign up with a provider, you need to be given a list of what the case manager is going to do. They need to be very clear about what the case manager does. (Participant 16)*

Participants also suggested providers give them a clear explanation about the different types of case management.

> *The different tiers of case management need to be clearly outlined. They are currently very ambiguous. There is no clear role differentiation provided between self-managed, partnership and fully managed. The agency needs to discuss differences with their clients and provide advice about which one to choose. (Participant 19)*

Some participants suggested case managers should receive specific training in consumer directed care.

> *They need better training of case managers so they understand customer directed care. (Participant 11)*

Support workers

Recruitment and training

Participants recommended more targeted recruitment and better training of support workers.

> *Regular training for staff needs to be incorporated. Also more targeted recruitment is required. (Participant 19)*

Although participants praised some online training courses (e.g. The University of Tasmania's Massive Open Online Course), face-to-face training was described as much better than online training.

An Indigenous elder suggested cross-cultural training.

> *It is important to train non-Aboriginal staff to be culturally aware. To make them find out what mission we come from, what country we come from, what tribe. So we can talk about our history. (Participant 41)*

Empathy

Participants said that support workers needed to be empathetic.

> *Hopefully people who work in people's homes have a degree of empathy. The biggest challenge we have is most people have never known anyone with Alzheimer's. So they don't know what it's like. They don't understand how long it may take to help someone bathe and get into bed – only to have them get up again. It's not a job for young people who have had no exposure to age or illness. (Participant 7)*

> *You have to be a kind, caring person. You can't just breeze into someone's home. (Participant 28)*

Consistency

As much as possible, providers should provide the same support worker.

> *I need the same person so I don't have to explain everything each time. I need someone who understands what I need. (Participant 4)*

Matching workers with clients

Several participants suggested in-home care would be improved if support workers were "*matched*" with the recipient.

> *I have said to them so many times: "I want you to match Mum with someone. Mum loves AFL footy, barracks for Hawthorn, loves to play cards, Scrabble and was an art teacher and artist. Surely you can do some sort of matching."*

> *When you're in a special group, you'd think they might consider sending us someone from our community. It was not necessary to send gay workers. But if there are members of staff who are gay, you'd think the case manager might ask us if we'd like to meet a worker who is a member of the LGBTI community. We were never asked. (Participant 9)*

Information about outsourcing

Participants suggested providers should be transparent about how they source their support workers. Do they employ them? Or do they use an agency?

> *You need to know about support workers – do they work for the company or are they contracted from elsewhere. (Participant 16)*

Mentoring system

Support workers would benefit from a mentoring system.

> *A new worker would benefit from going around with an experienced worker for a good deal of time. (30)*

Roster

Participants wanted to know in advance who would be working in their home.

> *I would like to have a weekly roster. I'd like to know who is coming every day before they arrive. I'd also like regular carers. (Participant 1)*

Some participants suggested local people should be responsible for preparing the weekly roster.

> *They needed to have local people rostering because they know the clients. Clients have to be matched with workers. (Participant 9)*

Support for carers

A participant suggested full-time family carers needed additional support.

> *I believe that more support for full-time carers is required in order to ensure continuous and consistency of care in the home. This can be in the form of regular respite in the home, counselling, or other offers of support as the carers needs. This should be provided as additional funds and not from the current funded packages. (Participant 19)*

Purchasing private services

A participant suggested families needed to be prepared to pay for private services.

This is where families really need to put their hand in their pocket. It doesn't cost an arm and a leg to pay someone to check on Mum or Dad a couple of hours three times a week. (Participant 24)

Some participants suggested all those who could afford to pay for in-home support should do so rather than depend on "*welfare*". Others felt they had paid taxes all their working lives and were entitled to access a "*public service*".

If I had money, I wouldn't have bothered. I'd just pay for it. But I can't afford it. (Participant 14)

Some people think people who can afford to pay for their own care should. I agree in a way. But Dad has paid his taxes all his life. (Participant 24)

I told my partner she had paid her taxes all her life and we could get some services for free. (Participant 15)

A participant predicted that future generations would not receive government support in their old age.

The younger generation with their superannuation will hopefully not be so dependent on the government's social service. My children don't anticipate they will need to use the government for support. But I didn't anticipate that I would live to my 80s. (Participant 7)

Private health insurance

Some participants suggested an older person's health insurance scheme should contribute to the costs of in-home care.

Mum's had private health insurance for years. Why aren't the private health funds covering some of this care? (Participant 25)

Peer support

A participant indicated a need for peer support. She suggested those who had cared for an elderly person in the home could be employed as peer support workers.

When an elderly person moves from a home care package to an aged care home or dies, family who have been the primary carer lose the carer's pension. People who have cared for a family member on a package could be employed as peer support for those of us who are currently in the system. (Participant 35)

Connecting care recipients

A participant suggested finding a way to connect care recipients. He suggested this might help to overcome his perception of the providers' "*divide and conquer mentality*".

The providers know we're all old and isolated in our own homes to a large extent. The divide and conquer mentality. If we could all get together somehow, we may understand how we are being exploited for their profit. (Participant 5)

Respite

There is widespread acknowledgment that family and others who care for older people in the home need a break from their caring duties. However, rather than place their parent/partner in an aged care home for respite, some participants suggested it would be better to have support workers stay with the older person at home. If this was not possible (due to the expense), they suggested support workers visit their parent/partner in the aged care home. Some providers allowed this while others did not.

I'd like someone to come to our home to stay with my husband for a week. They can do it but I'd need a lot of money to be accumulated. (Participant 28)

It would be valuable if one of the care workers could visit Mum for an hour a day when she is in respite – to check on her, give her a glass of water. She always comes home dehydrated – urine very smelly or left in soiled pads. A lot of things. I've asked Provider X if we could get this as part of the package. I've asked for that and have been told they don't do that. I am not sure if it's because of insurance. I am not sure if another provider would be able to do that. It would be most valuable – it would revolutionise our lives if we knew that was something we could have. (Participant 30)

Advocacy

A participant suggested an advocacy service to help people navigate the different home care services.

An advocacy service is definitely required to assist in navigating the aged care service as well as consultation and advice - perhaps it can be incorporated in My Aged Care or as a stand-alone service... Dad's case managers didn't do that. No one phones to check in – what are your issues this week/month? What do you think needs improvement? No one does that. (Participant 19)

Conclusion

The Commonwealth Home Support Programme and home care packages have been designed to help older Australians remain in their own homes for as long as they can and wish to do so. These programs delay the need for older people to move into an aged care home.

As part of the 2017-18 Federal Budget, the Federal Government committed to extend funding arrangements for the Commonwealth Home Support Programme to 30 June 2020. After that, who knows? Given such uncertainty, the conclusion focuses solely on home care packages.

The analysis of the data identified factors that are important to older people. These factors include:

- Access to a competently staffed My Aged Care information line/web page to provide accurate and consistent information and advice;
- A clear explanation of providers' services including their fees;
- Publication of providers' fees and charges on the My Aged Care website;
- Clear information about entitlements and reimbursements;
- Information on sub-contracted services, including rates and any additional charges;
- A home care agreement that is easy to understand;
- Reasonable fees for case management and administration;
- Reasonable charges for support workers;
- Support workers who are paid the award rate or above;
- Reasonable costs for equipment and home modifications;
- Reasonable charges for gardeners and other maintenance personnel;
- Clear financial statements that accurately reflect the services provided;
- Person-centred care delivered by a local provider;
- Support workers who are suitably trained[2], competent, trustworthy, punctual and empathetic;
- Knowledge about the qualifications and experience of staff;
- An option to choose support workers;
- Consistent support workers who work at regular and set times (e.g. 9am rather than sometime between 9am and 11am);
- Flexibility with times and changing needs;
- Access to service provision "on the spot" (i.e. same day) when a situation changes (e.g. transport to a doctor's appointment);
- Sufficient time allocated for support workers to undertake tasks required;
- Direct communication permitted between recipient and support workers for easier co-ordination;
- A weekly roster of support workers supplied in advance;
- Case managers who are experienced, qualified and easy to contact;
- Consistent use of mutually agreed means of communication with case managers (e.g. emails, messages, home phone or mobile);
- Information about how many older people case managers are overseeing;
- Forward-thinking case managers who seek to improve care and offer suggestions if new services become available;
- Regular mandatory visits by case managers to include health/welfare checks, face-to-face conversations and updates with the older person.
- Better-trained office staff (e.g. how to talk respectfully to older people, including older people with dementia);

2 Some suggested a mandated level of training be introduced for all support workers. Others suggested support workers without formal qualifications were sometimes better than qualified support workers.

- Options for different degrees of case management support/self-management;
- Involvement of family/advocates when issues arise;
- Ongoing professional development, including dementia training, for all staff;
- Access to affordable social activities inside and outside the home;
- Provision of information from case managers on other community resources (e.g. local services, volunteer groups etc.)
- Feedback from older people and their family/advocates welcomed by providers; and
- An effective complaints process.

On 30 June 2018, there were 869 approved home care providers. In this research, only 36 of these providers are represented. Fifteen were described as a "*good provider*". A "*good provider*" delivered a high quality service and charged reasonable fees and fair hourly rates for support workers.

Findings from this study suggest that some providers need to be more transparent and accountable. Providers also require regular financial audits. In this study, there were large differences among providers in both case management and administration fees and also hourly rates for support workers. How can these differences be justified? Some suggest it is a result of the market-based system that has been established explicitly to create competition, innovation and choice for the 'consumer'.

Questions must also be asked about unspent funds. How many older people are not spending their allocated home care package due to the poor quality of the services being provided? Or are they saving funds for a significant purchase (e.g. home modification).

Although an application to be a home care provider is submitted to the Commonwealth Department of Health to review suitability as per the criteria stipulated in the *Aged Care Act 1997*, participants described companies with limited or no expertise in the delivery of aged care services being given licences (e.g. insurance companies). It is not surprising that a company that specialises in insurance would deliver unsatisfactory aged care service. It is, however, surprising how many large established aged care providers were criticised for delivering an unsatisfactory service. The most common complaints were an insufficient number of staff and unqualified, inexperienced and untrained support workers.

Finally, participants described the negative impact of the policy of full cost recovery. In some cases, it prevented older people on higher-level home care packages from enjoying an active social life in their communities. Social isolation among older people is emerging as one of the major issues facing the industrialised world because of the adverse impact it can have on health and wellbeing (Cotterell et al., 2018; Landeiro et al., 2017; Commissioner for Senior Victorians, 2016; Aged and Community Services Australia, 2015; Pate, 2014).

When an older person transitions from the Commonwealth Home Support Programme and/or lower level home care package to a higher-level home care package, the cost of a bus trip or participation in an activity such as the Men's Shed significantly increases. This limits an older person's participation in local activities.

Participants also described the policy of full cost recovery as having a negative impact on people with chronic clinical needs who require daily nursing and/or allied health care. They are currently advised not to accept high-level packages due to the increased cost of delivering these health services.

Participants had high expectations for the services that would be provided by a home care package. Many participants described being disappointed. Those with the best outcomes had family and community support. Without this additional support, they acknowledged they would not have been able to remain at home.

References

Aged and Community Services Australia (2015) Social Isolation and Loneliness Among Seniors Australians: Issues Paper ACSA, Melbourne

Aged Care Financing Authority (2018) Sixth report on the funding and financing of the aged care sector, Department of Health, Canberra

Australian Government Department of Health (2018). Home Care Packages Data Report 4th Quarter 2017-18 1 April – 30 June 2018 (reissued 8 October 2018)

Australian Government Department of Health (2018). Home Care Package Research Report. Canberra: AMR

Commissioner for Senior Victorians (2016) Ageing is everyone's business: a report on social isolation and loneliness. State Government of Victoria, Melbourne

Cotterell N, Buffel T, Phillipson C. (2018) Preventing social isolation in older people. Maturitas Jul;113:80-84. doi: 10.1016/j.maturitas.2018.04.014. Epub 2018 Apr 30.

Coyle, J and Williams, B. (1999) Seeing the wood for the trees: defining the forgotten concept of patient dissatisfaction in the light of patient satisfaction research Leadership in Health Services 12 (4) 1-9

COTA (2018) FAQs – Home Care Package Services

https://www.cota.org.au/information/aged-care-for-consumers/home-care-today-consumers/frequently-asked-questions/faqs-home-care-package-services/

Day, J., Taylor, A. C. T., Summons, P., Van Der Riet, P., Hunter, S., Higgins, J. (2017). Home care packages: Insights into the experiences of older people leading up to the introduction of Consumer Directed Care in Australia Australian Journal of Primary Health, 23, 162-169

Department of Health (2018) 2017-18 Report on the Operation of the Aged Care Act 1997, Department of Health, Canberra

Denniss, R (2018) Dead right: how neoliberalism ate itself and what comes next elderly Quarterly Essay Issue 70 June

Gill, L., McCaffrey, N., Cameron, I. D., Ratcliffe, J., Kaambwa, B., Corlis, M., Fiebig, B., Gresham, M. (2017) Consumer Directed Care in Australia: early perceptions and experiences of staff, clients and carers Health and Social Care in the Community, 25(2), 478-491

Gilling J (2018) Understanding Consumer Directed Care (CDC) and the changes to Government Funded Home Care Packages Presentation 20 September, Sydney

Haggerty JL. (2010) Are measures of patient satisfaction hopelessly flawed? BMJ. 341 (7777) 790-791

Hitchcock K (2015) Dear life: on caring for the elderly Quarterly Essay Issue 57 March

Kaambwa, B., Lancsar, E., McCaffrey, N., Chen, G., Gill, L., Cameron, I., Crotty, M. Ratcliffe, J. (2015). Investigating consumers' and informal carers' views and preferences for consumer directed care: A discrete choice experiment Social Science and Medicine, 140, 81-94

Kalucy L, Katterl R, Jackson-Bowers E. (2009). Patient Experience of health care performance. PHC RIS Policy Issue Review Primary Health Care Research and Information Service. Adelaide

Landeiro F, Barrows P, Nuttall Musson E, et al. (2017) Reducing social isolation and loneliness in older people: a systematic review protocol BMJ Open; 7:e013778. doi: 10.1136/bmjopen-2016-013778

LASA (2017) Media Release 21 June 2017

McCallum, J., Rees, K. and Maccora, J. (2018). Accentuating the positive: Consumer experiences of aged care at home. Brisbane: National Seniors

McCaffrey, N., Gill, L., Kaambwa, B., Cameron, I. D., Patterson, J., Crotty, M., & Ratcliffe, J. (2015). Important features of home- based support services for older Australians and their informal carers. Health and Social Care in the Community, 23(6), 654-664

Mold J, Lawler F, Schauf K, Aspy C (2012) Does patient assessment of the quality of the primary care they receive predict subsequent outcomes? (2011) An Oklahoma Physicians Resource/Research Network (OKPRN) study. Journal of the American Board of Family Medicine: JABFM. 24(5): 511-23

Moore, L and McAuliffe E. (2012) To report or not to report? Why some nurses are reluctant to whistleblow Clinical Governance: An International Journal 17 (4), 332-342

Nous Group (2018) Wellness and Reablement: A summary of consultations across the home care sector

Ottmann, G., Allen, J., & Feldman, P. (2013). A systematic narrative review of consumer- directed care for older people: implications for model development. Health and Social Care in the Community, 21(6), 563-581

Pate, A. (2014) 'Social Isolation: Its impact on the mental health of older Victorians', COTA Victoria, Working Paper No. 1. COTA Vic, Melbourne

Russell, S. (2018) Resident-centred care webinar AAG (in production)

Simons, B., Kimberley, H., & McColl Jones, N. (2016). Adjusting to Consumer Directed Care: The experience of Brotherhood of St Laurence community aged care service users. Melbourne, Australia: Brotherhood of St Laurence

Watts, R. (2018) What's wrong with privatisation? Presentation at Does Darebin Care: community forum on aged care 14 August (unpublished) http://www.agedcarematters.net.au/wp-content/uploads/2018/08/RobWatts.pdf

Wessel M, Lynøe N, Juth N, et al. (2012) The tip of an iceberg? A cross-sectional study of the general public's experiences of reporting healthcare complaints in Stockholm, Sweden. BMJ Open doi:10.1136/ bmjopen-2011-000489

World Health Organisation (2002) Active Ageing: A Policy Framework WHO, Geneva.

Worth T. (2012) Practicing in a world of transparency. Online scores and comments about you can be painful, but they also provide an opportunity for improvement Medical Economics 89 (21): 52, 54, 57-8

Appendix 1: Invitation letter

Date

Name
Address

Dear [Name]

I am writing to invite you to take part in a research project called "Consumer views of aged care in-home support services". Your contact details were obtained from Community Health at Peninsula Health.

You have been invited because you receive a Home Care Package. Dr Sarah Russell (Research Fellow, Peninsula Health) would like to hear what's good about the Home Care Package you receive and what you think would make it better. We are inviting you on Sarah's behalf.

The Participant Information Sheet enclosed tells you about the research project. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. You may want to talk about it with a relative, friend or local health worker before deciding whether to take part. All information will be confidential. Sarah will have no access to your personal files.

Please contact Sarah if you have questions or want more information. Sarah's phone number is 9489 5604 or mobile 0435 268 357. My email is sarahrussell@comcen.com.au

Yours sincerely,

Iain Edwards
Community Health

Appendix 2: Flyer

Peninsula Health

Research Matters
researching issues of health and illness

Would you like to participate in a research project?

Do you receive in-home care?

My name is Dr Sarah Russell. I am the Principal Researcher at Research Matters and a Research Fellow at Peninsula Health.

I would like to talk with people who have been approved for a Home Care Package, irrespective of whether this package has been assigned.

* Are you getting the support you need?
* Do you have suggestions to improve the program?

I would like to come to your home to talk with you in person, or talk with you on the phone. Our conversation will take about 30-45 minutes. You are welcome to have a family member or friend with you.

If you would like to take part in this useful project please contact me before 30 October 2018 so I can send you further information.

My phone number is 03 9489 5604 or mobile 0435 268 357.
My email is sarahrussell@comcen.com.au

Your name will be kept confidential and no identifying information about you will be used.

The Commonwealth Department of Health has funded this project.
The ethical aspects of this research project have been approved by Peninsula Health's Human Research Ethics Committee.

T: 03 9489 5604 (B) or 0435 268 357 (M)
E: sarahrussell@comcen.com.au
www.research-matters.com.au
www.agedcarematters.net.au

Appendix 3: Participant Information Sheet / Consent Form

Peninsula Health

Participant Information Sheet/Consent Form

Title	Consumer views of aged care in-home support services
Principal Investigator	Dr Sarah Russell
Associate Investigator(s)	Professor Velandai Srikanth, Dr Kristy Siostrom, Mr Iain Edwards

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Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called Consumer views of aged care in-home support services. You have been invited because you have been approved for a Home Care Package. Your contact details were obtained Community Health at Peninsula Health.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:
• Understand what you have read
• Consent to take part in the research project
• Consent to be involved in the research described
• Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

The aim of the study is to investigate firsthand experiences of in-home care for older people who have a Home Care Package or use Commonwealth Home Support Program. We want to know what is working well, and what is not working well. We also want to hear your suggestions about how home care services can be improved. This information will help Home Care Packages and Commonwealth Home Support Program to better meet people's needs.

3 What does participation in this research involve?

If you decide to take part in our study, you will be asked to participate in a face-to-face interview in your own home. The interview will last about 30-45 minutes. The interview will take place at a time that suits you.

Peninsula Health

During this interview, you will be asked to talk about your experiences of home care. With your consent, the interview will be tape-recorded so that we can ensure what you say is recorded accurately.

You will be asked to reflect on both positive and negative aspects of home care. What do you like about home care? What don't you like? How could things be done better?

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way. There are no costs associated with participating in this research project, nor will you be paid.

4 Other relevant information about the research project

There will be 40 people participating in this study.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with Peninsula Health.

6 What are the possible benefits of taking part?

We cannot guarantee that you will personally benefit from this research; however, a potential benefit is you will be contributing to research that may help to improve the future delivery of Home Care Packages and Commonwealth Home Support Program.

7 What are the possible risks and disadvantages of taking part?

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

8 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team.

9 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as the principal researcher becoming unwell.

Peninsula Health

10 What happens when the research project ends?

A copy of the final report will be mailed to you in January 2019.

Part 2 How is the research project being conducted?

11 What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. The personal information that the research team collect and use will be the transcript from the recorded interview.

Any information obtained in connection with this research project that can identify you will remain confidential and be securely stored. Your contact details will only be kept with your permission so we can send you a copy of the final report about the project.

Your information will only be used for the purpose of this research project. The data you provide will be permanently de-identified; this means that it will not be possible for the researcher to match recorded interviews to particular individuals.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, you will be referred to by a pseudonym.

In accordance with relevant Australian and/or Victorian State privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

12 Complaints and compensation

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact: Ms Lee-Anne Clavarino from the Research Office at Peninsula Health. Ms Clavarino's contact details are: Phone 9784 2679 or Email: LClavarino@phcn.vic.gov.au

13 Who is organising and funding the research?

This project has been funded by a grant from the Commonwealth Department of Health. The researcher is independent. She has no affiliation with the government or any provider of home care services.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the HREC of Peninsula Health.

Peninsula Health

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

If you would like further information, please do not hesitate to contact Dr Russell by phone or email.

Research contact person

Name	Dr Sarah Russell
Position	Principal Researcher
Telephone	9489 5604 or 0435 268 357
Email	sarahrussell@comcen.com.au

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	Peninsula Health
HREC Executive Officer	*[Name]*
Telephone	*[HREC Executive Officer Phone number]*
Email	*[HREC Executive Officer Email address]*

Local HREC Office contact

Name	Ms Lee-Anne Clavarino
Position	Manager, Office of Research
Telephone	9784 2679
Email	LClavarino@phcn.vic.gov.au

Appendix 4: Interview Schedule

1. What made you realise you needed support in the home?
    - Did someone suggest you may be eligible (e.g. family, friends, GP or other health care professional?
2. Tell me how you went about getting the services you needed?
    - Did you do it yourself? Did others help you (e.g. family, friends, GP or other health care professional?)
    - Tell me about your experiences with myagedcare?
        - Information
            - How did you get? (e.g. phone, internet)
            - Was it helpful?)
        - Screening questions (e.g. relevant?)
3. Tell me about your assessment
    - What prompted you to have an assessment? Who instigated it?
    - Did you have services in mind?
    - Did you want a HCP or CHSP?
    - How long did you have to wait for the assessment?
    - Were questions asked during the assessment
        - Relevant to you and your situation?
        - Repetitive (e.g. did you have to re-tell the story you told at screening)?
4. Do you have any comments about the approval letter? (e.g. Did you understand what you were required to do?)
5. Tell me about your experiences whilst you waited to receive your package?
    - What is your understanding of the queue? How long have you been on it?
    - Did you need support during this period? Who provided the support you needed?
    - What services did you receive while you were waiting for your package?
        - Did you receive a lower level package/CSHP?
6. What type of services are you receiving while you wait for your package?

Question 7 only for those who are using CHSP (while waiting for HCP)

7. Tell me about your experiences of CHSP.
    - Are you receiving the help you need?
    - Do these services meet your needs?

(Question 8 only for those who have transitioned from CHSP to HCPs)

8. What was it like to move from CHSP to HCP?
    - Tell me about the transition?
    - What differences have you noticed between the 2 different programs

9. How did you go about identifying and choosing your provider?
    - What support did you receive from family or others to choose a provider?
    - Was information you needed to easily available?
        - Overwhelmed by choice? Feel pressured by any service provider?
    - Were the costs explained to you?
        - Did you understand how much you would be required to contribute to your services?
        - Did you ask how much your service provider would access from your package?
10. Tell me about your experiences with your chosen provider.
    - Your views about your Home Care Agreement
        - Do you understand what the provider is contracted to do?
    - Your understanding of the monthly statement/fees.
        - Was the statement explained to you?
    - Communication with provider (e.g. understanding what you're entitled to, what you need to do?)
    - Tell me about your relationship with your case manager
        - Continuity?
        - Do you feel you can contact them if something is going wrong?
            - How do you contact them? (phone, email?)
                - Answer their phone?
                - Is the response timely?
            - How often does the case manager visit your home?
    - How did you go about choosing and planning actual services with your case manager?
        - Are the services meeting your needs?
    - Did you feel that you had a say in how the funds in your package were directed?
        - Did you have enough money in your package to get everything you need?
            - Are there any services that you need but can't afford?

Question 10 only for CALD participants

11. How did you go about finding a case manager that spoke your language and understood your cultural needs?

For those who did not find a case manager that spoke their language

- Do you have difficulty communicating with your provider and case manager?

12. Tell me about staff who come to your home:
    - How did you choose them?
    - Same people?
    - Skills/qualifications/experience/competency?

- Do you make decisions about:
  - Time the staff come?
  - How long they stay with you?
  - What staff do when they are in your home?
  - Flexibility (can you change arrangements according to your needs?)
  - Are staff reliable (arrive on time? Inform you if late/sick?)
- Tell me how staff show their respect towards your particular needs/circumstances.
  - Do you feel staff listen to your needs?

13. How has your quality of life changed since commencing your HCP?
    - Confidence living at home
    - Relationships with family and friends

Question 13 and 14 only for those who are dissatisfied with provider

14. Do you intend to change providers?
    - What is the process for changing your providers

Question 14 only for those who changed providers

15. Tell me about the process of changing providers
    - How did it go? (i.e. was it straightforward or complex)
    - Did you understand the exit fees?
16. What is the best thing about the HCP?
    - What are your suggestions for how HCP could be improved?

Appendix 5: Examples of financial statements

Example 1:

On this financial statement, Provider M charged Participant 9 $25.04 more for case management and administration ($1,276.50) than was charged for services ($1,251.46). During an 18-month period in which Provider M did not provide any case management, they charged over $600 per month for case management.

SERVICE DETAILS

Home Care Package	HCP Level 4
Active Package Days	30

Date	Transaction Type	Amount $
Section 1 - Invoice		
	Consumer Contribution for June	$0.00
Section 2 - Home Care Package Budget Statement		
	Opening Budget Balance	$31,837.42
	Funding Allocation	$4,483.80
	Consumer Contribution	$0.00
	Contingency Allocation	$0.00
	Administration Fees	$-673.20
	Care Advisory Fees	$-603.30
	Total Available Budget	**$35,044.72**
	Total Budget Expenditure - see Section 3	**$-1,251.46**
	Total Budget Adjustments - see Section 4	**$0.00**
	Budget Balance Available	$33,793.26
	Contingency balance Available	$0.00
	Total Closing Budget Balance	**$33,793.26**

Expenditure Date	Type of Service	Units (Hrs)	Rate ($)	Amount $
Section 3 - Home Care Package Budget Expenditure				
05/06/2018	Cancellation Fee: Peri: Escort Shopping	2.00	$47.50	$95.00
05/06/2018	Mileage: In Service Travel-In Service KMs	0.90	$1.15	$1.04

Example 2:

Provider Z takes 9.1 per cent of the home care package in case management and administration fees.

Statement Period: 01 July 2018 to 31 July 2018

Home Care Package Summary	
Package Opening Balance for Period	$399.46
Package Government Funding Allocation for Period	$4698.05
Package Client Contribution for Period	$313.10
Package Administration Charges	($128.34)
Package Case Management Charges	($299.15)
Total Available Budget	**$4983.12**
Total Package Charges in Period	($5032.00)
Package Closing Balance Including Contingency	**($48.88)**
Available Contingency in Period	**$0.00**

Example 3:

Participant 22 receives a Level 2 home care package. Provider Y takes 35 per cent of a Level 2 home care package in case management and administration fees.

from 01-August-2018 to 31-August-2018

		Debit	Credit
Opening Balance at 1/08/2018			**$2,328.92**
Income			
Subsidy - Government Subsidy			$1,277.82
Total Income			**$1,277.82**
Expenditure			
Administration costs			
Administration costs - Administration Fee		$191.58	
Core advisory & case management services			
Core advisory & case management services - Case Management Fee		$255.44	
Service and Support	**Total Hours/Quantity**		
Visit: Transport	5:00	$240.00	
Total Expenditure		**$687.02**	
Closing Balance at 31/08/2018			**$2,919.72**

Example 4:

Participant 13 receives a Level 2 home care package. A personal support worker helps her to shower 3 mornings a week and once a fortnight the support worker also cleans. Provider G takes 41 per cent of her Level 2 home care package in case management and administration fees.

Monthly funds for my care			
Government Funding		$1,277.82	
Customer Contribution		$53.13	
Total Funds available this month			$1,330.95
Fixed Costs			
Administration Fee		$250.00	
Core Advisory Fee		$270.00	
Total Fixed Costs			-$520.00
Services			
Cleaning 60 minutes	(7.5 hours)	$382.50	
Personal Care	(9 hours)	$459.00	
Personal Care 30 minutes	(4 hours)	$324.00	
Miscellaneous - Mop & Bucket		$79.16	
Total Services			-$1,244.66

Example 5: Provider A's hourly rates.

Home Care Services										
	Low Needs Care Support with housework, companionship		Standard Care		Complex Care Support from higher skilled staff		Nursing Services Enrolled Nurse (EN) and Registered Nurse (RN)			
Duration / Time/Day	30 mins	Hourly	30 mins	Hourly	30 mins	Hourly	EN 30 mins	EN Hourly	RN 30 mins	RN Hourly
Weekday	$37.20	$57.20	$39.20	$60.30	$39.90	$61.40	$49.70	$76.50	$70.70	$108.70
Weeknight	$41.10	$63.20	$43.20	$66.50	$44.00	$67.70	$54.90	$84.40	$78.00	$120.00
Saturday	$43.40	$66.80	$45.70	$70.30	$46.60	$71.60	$58.00	$89.30	$82.50	$126.90
Sunday	$55.40	$85.30	$58.40	$89.80	$59.50	$91.40	$74.10	$114.00	$105.30	$162.00
Public Holiday	$82.50	$126.90	$86.90	$133.60	$88.50	$136.10	$110.30	$169.70	$156.80	$241.20

Example 6: Provider KK charged $607.56 in case management and administration fees (51.6 percent of a Level 2 package) to supply an outing valued at $130.22.

General Funds	
Balance carried forward from previous month	$0.00
Package Income	
Government Funding	$1,177.83
Client Contribution	$219.34
Total Income	$1,397.17
Package Expenditure	
Administration Fee	$258.75
Case Management	$348.81
Service and Support Provision	$130.22
Total Expenditure	$737.78
Balance carried forward to next month	$659.39
Pending Charges	$0.00
Net Available Balance	$659.39

Net Available Balance is estimated taking into account pending charges.

Appendix 6: My Aged Care Service Finder

Appendix 6: My Aged Care Service Finder
At the time of publication (March 2019), Provider B had not published its fees on the My Aged Care website.

There are no notices of non-compliance or sanctions for this service

Overview | Services | Costs

Average percentage of package available for services	
Maximum exit amount	$500
Provider pricing	
Provider website	
Average surcharge for evenings	
Average surcharge for weekends	
Average surcharge for public holidays	
Average surcharge for 24/7 care (incl. overnight stays)	

Older People Living Well with In-Home Support

Sarah Russell

March 2019