



Healthdirect Australia

Carer Service Development Research

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Executive Summary

In May 2015, the Assistant Minister for Social Services, the Hon. Mitch Fifield announced the Government’s commitment of \$33.7 million to establish a national carer gateway. The national carer gateway will be implemented to help carers access information and support which will assist them in maintain their caring role.

This research was commissioned by Healthdirect Australia to consult with Australia’s carer population, service providers and peak bodies to inform the development of the national carer gateway. The research utilised the following definition published by the Australian Bureau of Statistics (ABS) and Carers Australia¹: *“Carers are people who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged.”*

Research objectives and design

The overarching objective of the research was to: Understand the needs of carers in order to inform the development and design of a carer information and support service delivered via contact centre and website, supported by service finder functionality.

The research comprised both qualitative and quantitative methods and included over 1300 carers. In addition to carers, ten service providers and peak bodies were consulted. The qualitative research included over 130 carers across a range of different research methods (focus groups, telephone interviews and in-home immersions). The quantitative research included a nationally representative survey of 1,205 carers aged 18-65. The survey was conducted online and the following sources of sample were used: Research Now Online Panel and contacts via Department of Social Services, service providers and peak bodies.

Research findings

The research findings to follow are organised around five key areas, which are related to the research objectives:

Theme	Research Objective
Understanding Australia’s carers	<ul style="list-style-type: none"> Explore the different types of carers and their experience accessing information and support services
Size of the ‘hidden carer’ population	<ul style="list-style-type: none"> Assist in understanding the ‘hidden carer’ population, who they are, and how they can be reached
Access to information, support and services	<ul style="list-style-type: none"> Explore the different types of carers and their experience accessing information and support services Scope existing information for carers assessing what is currently available
Developing the national carer gateway	<ul style="list-style-type: none"> Understand and capture carer information and support wants, needs and expectations Gather feedback on the national carer gateway concept
Marketing the national carer gateway	<ul style="list-style-type: none"> Determine the most effective communication channels for reaching carers
Future Research	

¹ <http://www.carersaustralia.com.au/about-carers/statistics/>

Understanding Australia's carers

Australia's carers are a diverse group, evidenced by differences across demographics, culture, caring responsibilities and experiences. Demographically, there are as many male carers as female carers. Carers can be of any age with the largest proportion falling into the 40-54 age bracket (31%) and 12% of carers are aged 18-25.

In terms of location the majority (64%) are living within a capital city, however a large proportion (36%) live outside of capital cities. Income levels and sources are varied, the majority are in paid employment (full-time 35%, part-time 16%, casual 7%) and 35% rely on government benefits and allowances, with an average annual household income among all carers of \$74,754. Culturally, 14% of carers speak a language other than English at home and 3% are from Aboriginal or Torres Strait Islander descent.

In terms of caring responsibilities the majority of carers (54%) are the only person providing care and 74% of carers consider themselves the main carer. The care recipients are typically a parent/grandparent (38%), spouse or partner (33%) or child (16%). Carers are caring for primarily one person (78%), with 21% caring for two or more people. On average, carers spend 4.4 hours per day in the caring role, this is significantly higher among carers of someone with a disability (6 hours per day).

The research confirms the anecdotal feedback that Australia's carers face a number of challenges. Across 13 attributes measuring satisfaction with a range of lifestyle, personal and family factors, *'how well you are supported by family and friends'* is the only attribute where more than 50% of carers are satisfied. Carers indicate the following challenges:

- Caring responsibilities lead to isolation, which leaves little personal time.
- Difficulty watching the care recipient deteriorate and in pain.
- Stress placed on the carer and care recipient's relationship.
- Navigating and accessing government services.
- Living outside of capital cities and gaining access to services.
- Carer's confidence in their own skills and ability to satisfy the care recipient's needs.

Despite these challenges, **carers take pride in their caring responsibilities** which are viewed as an opportunity to give back to the care recipient and provide them with care to improve quality of life and life expectancy. Caring also brings the carer close to the care recipient and for Aboriginal and Torres Strait Islander carers specifically, the knowledge that their family members are safe and the family unit is maintained is a key reward.

Generally those caring for someone with a disability or mental illness are under more personal pressure than any other group. These carers have the lowest satisfaction with their current situation, particularly how well they are coping and their financial situation.

Size of 'hidden carer' population

The term 'carer' is well understood but the majority do not necessarily see caring as their primary responsibility or association with the care recipient. The research shows that **the hidden carer group is large, the majority of carers (79%) did not see themselves as a carer** (either part-time or full-time) opting for other things such as employment (51%), keeping house (16%) and retirement (20%).

Executive Summary

Access to information, support and services

The research shows that generally, carers are accessing limited services for themselves. Main barriers for accessing services are:

- Seeking help and support is viewed as a sign of not coping, failure or 'admitting defeat'.
- Carers feel that there is a lack of support services available specifically for them.
- Carers are reluctant to go outside the immediate support network.
- Challenges associated with identifying the support needed and how this can be accessed.

Google is the starting point for many carers when accessing information, support and services (70%). The most effective support is accessed through the immediate support network which includes family (72%), friends (62%) and the doctor (71%). Carers are comfortable relying on their immediate network for key things such as financial assistance, emotional support and part-time respite.

Aboriginal and Torres Strait Islander carers refer to a 'trusted contact person' who explains systems, reasons for practices, terminology and other issues affecting the care recipient. Among Culturally and Linguistically Diverse (CALD) carers there is a strong family focus towards providing care and this is highly valued by the carers interviewed.

A key trend across all the specific services measures was that **awareness was very high (over 50% for most services) however actual usage of services was very low.** Access to services included in the research is highest for the following helplines: Carer State and Territory Associations (13%), Lifeline (12%) and Commonwealth Respite and Carelink Centres (CRCC) (12%). Among websites, the Department of Human Services (46%), Carers Australia (13%), State health departments (13%), and CRCC (13%) are the most frequently used.

Support groups are widely accessed by carers with views and experiences mixed, some carers find making connections through carer support groups very helpful whereas others feel that support groups are 'not for them'. Respite was discussed widely, some carers are positive about respite whereas others struggle to see how respite can help given the high dependency placed on them by the care recipient.

Developing the national carer gateway

The research found overwhelming support for the introduction of a tailored carer service which provides access to relevant information, support and services. Carers need a central service which provides them with information on what services are available. The main findings validating the need for a service are:

- Access to services is currently difficult for carers to navigate and access.
- Carers know there are services available and have heard support can be provided, but are not sure how to gain access.
- Carers are struggling to cope with the significant pressure placed on them and their caring role.

Executive Summary

The national carer gateway concept was well received, with most carers in the research indicating they would either definitely or be very likely to access the service, via the website (57%) or service finder (51%). There is lower likelihood of carers accessing the phone line (27%). Specific feedback and expectations on the services were as follows:

- Carers seek both emotional and practical support to assist them in providing ongoing quality care.
- Carers require a service that addresses both their needs and the needs of the care recipient.
- There is a strong need for expert guidance to navigate the national carer gateway and the information, support and services available.
- Carers need a tailored service that contains information relevant to them and their caring responsibilities.
- Carers view the phone line as critical, however there are concerns that the customer experience may follow other government managed helplines such as Centrelink (i.e. long wait times). These concerns need to be addressed to ensure the phone line is accessed.

Reactions to the national carer gateway concept among Aboriginal and Torres Strait Islander carers is not positive. This is primarily a result of disillusionment with multiple “government” actions and programs over their lives that are not aimed at Aboriginal and Torres Strait Islander people nor have any element addressing the needs of Aboriginal and Torres Strait Islander people.

CALD carers follow a similar trend to mainstream carers with high support and interest in all aspects of the service. Given most of these carers feel ill-informed, ‘experts’ providing authoritative information on help and support available is viewed positively.

Marketing the national carer gateway

From a branding perspective, out of the names tested in the research **Carer Network and Care for Carers are the two preferred names**. Carer Network has strong appeal, particularly among those who are looking for a service that would bring together all of the support and services available. Care for Carers is popular among those looking for emotional support and counselling, however it does not encompass the other information, support and services due to the ‘counselling’ implications of the name.

The other names tested were Carer Access, YouCare and Carer Central. Carer Access received mostly positive reactions, although not as strong as the reactions to Carer Network or Care for Carers. Carer Central received mixed reactions and YouCare was the least appealing of the names tested.

Executive Summary

The research identified a number of key selling points and barriers to accessing the service, summarised in the table below.

Selling Points	Barriers
The national carer gateway can ease the significant burden associated with accessing information, support and services simply and efficiently.	Carers are time poor, are very busy looking after the care recipient and would not have time to access the service.
Assistance and guidance in navigating the various government and other services care recipients and carers need.	Carers view their individual situations as complex, unique and very different to other carers. Carers are concerned that the service would not offer anything specific to their situation.
One stop shop for all information, support and services for carers and care recipients.	Given the challenges most carers face when accessing and navigating government services there is hesitation that the national carer gateway would offer a similar experience, particularly the phone service.
Service built specifically for carers and their requirements for information, support and services.	Some carers question whether or not the service would be delivered by inexperienced people or experts in care.
Delivered by professional people who can discuss their situation and provide advice on the best course of action.	The national carer gateway would refer carers to many services without providing a direct linkage (warm referral) or follow up.

In terms of promotion of the service, carers suggest multiple sources: **a Google search is seen as the main channel (56%), followed by health professionals (55%)**. Given the critical role the GP plays, their recommendation would be highly valued. Hospitals create an environment where carers would be most receptive to the national carer gateway. Mass media (TV, radio) exposure would be beneficial, ensuring a broad group of carers could be reached as carers spend a significant amount of time in the house. Other suggestions include targeted approaches through government carer pathways such as through the carer payment information or other pensions or allowances.

Future research

The Carer Service Development research provides a basis for future research. Key metrics measured across life satisfaction and access to information, support and services should be included in future research to evaluate the impact of the national carer gateway. The research methods used have delivered statistically reliable data representing the carer population adequately, within time and resource constraints, and should be replicated for future research.

1. Research background and objectives

In May 2015, the Assistant Minister for Social Services, the Hon. Mitch Fifield announced the Government's commitment of \$33.7 million to establish a national carer gateway. The national carer gateway will comprise a national telephone contact centre and a website to help carers find support and services, regardless of the need or the age of the person they care for. The national carer gateway will be implemented to help carers access information and support to help them maintain their caring role. This is the first step in a longer term plan to better support carers.

From December 2015, the national carer gateway will be the front door to existing services and will provide quick and relevant information about the supports and services available to them. The Department of Social Services (DSS) in partnership with Healthdirect Australia are responsible for developing and implementing the national carer gateway. An Expert Advisory Group is assisting with development of the national carer gateway with membership drawn from service providers, peak bodies and individuals who have carer-specific expertise, along with Department of Social Services representatives.

Anecdotal information and research suggests that carers currently access services through pathways across disability, community mental health, and aged care sectors, which leads to fragmented delivery of information. This fragmentation can also lead to confusion among carers about where to go to get the support they need to sustain their caring role. There is potential to offer a more streamlined service to carers by providing accurate and timely carer related information that increases equitable access and support.

This research was commissioned by Healthdirect Australia to consult with a representative sample of Australia's carer population. In addition to discussions with key service providers and peak bodies to inform the development of the national carer gateway.

1.1 Research scope

The scope of the study was to conduct research among Australia's caring population utilising the definition published by the Australian Bureau of Statistics (ABS) and Carers Australia²: *"Carers are people who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged."* Key considerations which informed the scope of the research are outlined below:

- The inclusion of 'hidden carers' in the research who do not consider themselves carers but fit the definition of a carer. This group of carers was viewed as critical as they were potentially less likely to access information, support and services.
- Representation across the main care recipient conditions which included:
 - Disability
 - Mental illness
 - Substance abuse (alcohol and drug related)
 - Aged and Frail
 - Terminally and chronically ill
- Representation across the following key groups in the community
 - Carers which identify as Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI)
 - Aboriginal and Torres Strait Islander carers
 - Culturally and Linguistically Diverse (CALD) carers (Lebanese, Vietnamese, Chinese, Greek and Italian)

² <http://www.carersaustralia.com.au/about-carers/statistics/>

Research background and objectives

- Nationally representative sample covering all States and Territories in Australia.
- Inclusion of young carers aged 18-25. Carers below the age of 18 were not included in the research due to the requirement for parental consent for research with children.
- Inclusion of key service providers and peak bodies to inform the development of the research.

A full description of the research methodology is provided in section two of the report.

1.2 Research objectives

The overarching objective of the research was to: **Understand the needs of carers in order to inform the development and design of a carer information and support service delivered via contact centre and website, supported by service finder functionality.** The specific research objectives are outlined below:

- Explore the different types of carers and their experience accessing information and support services.
- Assist in understanding the 'hidden carer' population, who they are, and how they can be reached.
- Scope existing information for carers assessing what is currently available.
- Understand and capture carer information and support wants, needs and expectations.
- Gather feedback on the national carer gateway concept.
- Canvass views of key stakeholders on the current situation with carers and response to the development of a carer service (contact centre, website and service finder).
- Determine the most effective communication channels for reaching carers.

2. Research design and methodology

The research comprised both qualitative and quantitative methods and included over 1339 carers. In addition to carers ten service providers and peak bodies were consulted. This section outlines the research design and data collection methods utilised for the qualitative and quantitative research.

2.1 Qualitative

2.1.1 Carers

Three data collection approaches were utilised with carers:

- **Mini-focus groups (90 minutes):** Created a forum for open discussion and interaction between carers with similar circumstances. This was an effective forum for reviewing, discussing and co-designing the service concept.
- **In-home immersions (60 minutes):** Flexible approach that was conducted in the convenience of the carer's home. Used for carers in more difficult circumstances (e.g. caring for long-term or critically ill) who found it difficult to attend a focus group or central venue. In situ settings provide an appropriate environment to uncover the carer's personal situation and experiences.
- **In-depth phone interviews (45 minutes):** Efficient approach that facilitated understanding of carer's personal situation and identified individual needs for information, advice and support. Provided capacity to reach carers across Australia in capital cities, regional and remote areas.

The discussion guide is provided in Appendix A of the report, with the broad outline of the discussions summarised below.

Table 1: Carer Research Qualitative Discussion Guide

Section
Getting to know the carer
<ul style="list-style-type: none"> • Get to know the carers • Understand personal situation • Explore the challenges and rewards of being a carer
Awareness and current use of support, information, services
<ul style="list-style-type: none"> • Awareness of support, information and services carers are aware. • Access and experience with information, support and services
Needs at different stages of the carer lifecycle
<ul style="list-style-type: none"> • Identify the wants and needs of carers at different stages of the caring lifecycle. • Ideal information, support and service for carers.
Reaction to carers service concept and service name testing
<ul style="list-style-type: none"> • To explore reactions to the national carer gateway concept, capture language used to describe the service and test service name concepts to inform brand development.
Communication channels
<ul style="list-style-type: none"> • To explore the most effective communication channels to reach carers

Research design and methodology

The research design with carers is summarised below.

	West Sydney	West Sydney	Dubbo	Dubbo	Melbourne	Melbourne	Ballarat	Ballarat	Townsville	Townsville	Perth	Perth	Phone
G = Mini-groups	G	IH	G	IH	G	IH	G	IH	G	IH	G	IH	
IH = In-home interviews													
Care recipient condition													
Disability	2	1	1	1	2	1	1		1	1	2		3
Mental illness				1				1					3
Substance abuse		1											3
Aged and frail	1	2	1		1	2	1		1		1		5
Terminally ill		1											2
Chronically ill		1		1									1
Carers identify as LGBTI													3
Aboriginal and Torres Strait Island carers		4											
CALD carers													
Lebanese		2											
Asian (Vietnamese & Chinese)		3											
Greek		2											
Italian		3											
Young carers (18-25)		1						1				1	8
Total no.	15	21	10	3	15	3	10	2	10	1	15	1	28

Grand total	134
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2.1.2 Recruiting carers for the qualitative research

Carers were recruited to participate in the Qualitative research by our recruitment partner Qualitative Recruitment Australia (QRA). QRA has databases and networks Australia-wide and recruited research participants via a number of different methods including from their own database/panel of respondents, via business and personal networks, referrals, social media and advertising. Using these methods, contacts were taken through a recruitment screener provided by AMR and recruited to the relevant carer category and research methodology.

Aboriginal and Torres Strait Islander carers and CALD carers were recruited by our research partner Cultural Partners, who also conducted the Aboriginal and Torres Strait Islander and CALD interviewing. Cultural Partners are industry leaders with hands on experience and depth of knowledge, specialising in hard to reach audiences, specifically CALD and Aboriginal and Torres Strait Islander communities.

The methods of recruitment for Aboriginal and Torres Strait Islander carers included through non-government organisation connections working with the Aboriginal and Torres Strait Islander community in service delivery and via a Carer Network associated with the NSW Carers Strategy component for Aboriginal and Torres Strait Islander carers.

The CALD recruitment involved referrals through third party ethno-specific agencies working directly with carers in the health and disability sector.

2.1.3 Other audiences

The methods used for the other audiences consulted are outlined below:

- Health professionals (4 General Practitioners and 2 Social Workers) were interviewed face to face in Sydney and Melbourne and by phone for other locations including regional and remote areas. The discussion with health professionals covered their experience treating carers and their care recipients.
- Service providers and peak bodies were also interviewed via telephone: The discussion with service providers and peak bodies covered the following:
 - The services the organisation provides, and how they are delivered
 - Perceptions of the needs and requirements of the carers that they interact with
 - Views on the opportunities to improve the services provided to carers
 - Anything other additional relevant information
- The peak bodies and services providers included in the research are listed below:
 - Carers Australia
 - Carers NSW
 - Carers NT
 - National Respite Association
 - Association of Relatives and Friends of the Mentally Ill (ARAFMI)
 - Council of the Ageing (COTA)
 - Alzheimer's Australia
 - Loddon Mallee Commonwealth Respite and Carelink Centre
 - Mind Australia
 - Pilbara Commonwealth Respite and Carelink Centre
 - South East Country Commonwealth Respite and Carelink Centre

2.2 Quantitative

A nationally representative survey was conducted to measure key characteristics, experiences, needs and requirements of carers. The survey was conducted online with a length of interview of 20 minutes. There were two sources of sample for the study, an online research panel and distribution to carer contacts via key stakeholders.

2.2.1 Research Now online panel

Surveys were distributed to an online access panel utilised by AMR for social research projects. The panel contains over 150,000 active panellists who volunteer to participate in market and social research studies. Panel members have signed up with these research panel organisations specifically to complete online surveys in return for compensation (incentive). The incentive systems used for both panels are in line with ISO 26362 and industry requirements. Types of incentives include; bi-monthly \$5,000 cash draw prizes, bi-monthly \$2,000 voucher prize draws, vouchers, direct incentives, charitable donations and sharing of results with respondents. Incentives are used as a token of appreciation and to stimulate participation.

2.2.2 DSS, service provider and peak body contacts

In addition to the Research Now panel, key stakeholders for the research were provided with an 'open link' to distribute among their carer contacts. The link was distributed via email to carers associated with the service providers and peak bodies. The Department of Social Services (DSS) also posted the survey link on their website.

2.2.3 Sample size and representation

In total 1,205 surveys were completed by carers which gives a margin of error of +/- 3%. The majority of the sample came via the Research Now Panel (1,000 completes) with the remaining 205 coming via the stakeholder channels.

The carers completing the survey met the following criteria:

- Aged 18-65
- Providing unpaid care and support to a family member or friend with at least one of the following conditions:
 - Disability
 - Chronic illness
 - Terminal illness
 - Mental health condition
 - Alcohol or other drug dependency
 - Frailty due to age
- Paid carers were excluded, defined as people paid by either a support agency, a home care service provider or some other organisation to provide care in the home or residential facility.

Specific details of the sample characteristics and demographics are outlined in the sections to follow. The full questionnaire is provided in Appendix A and a summary of the sections within the questionnaire is outlined below.

Table 2: Quantitative questionnaire outline

Section
Profile of carers
<ul style="list-style-type: none"> • Key demographics include age, gender • Time spent caring, details of the care recipient • Help and support provided • Length of time caring
Awareness and sources of information
<ul style="list-style-type: none"> • Awareness, access and preference of information, support and services
Needs for information, support and services
<ul style="list-style-type: none"> • Participation in leisure, social and community activities • Satisfaction with current life situation
Experience accessing information, support and services
<ul style="list-style-type: none"> • Awareness and usage of respite • Importance of different information, support and services
Communication channels
<ul style="list-style-type: none"> • Internet and device access • Preferred channels for receiving information
National carer gateway concept feedback
<ul style="list-style-type: none"> • Likelihood to use national carer gateway (website, service finder and phone line)
Demographics
<ul style="list-style-type: none"> • Work situation, income • Education • Language spoken at home

Comparisons have been made between different groups of carers in the survey using tests of statistical significance. Differences between groups in the tables of results have been highlighted:

Higher	Lower
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2.3 Desktop research

The objective of this literature review was to identify carer information, support and services which align with the needs identified in the research. The desktop research were used to inform the development of the research. The findings from the desktop research are shown in Appendix B.

3. Understanding Australia's carers

Key insights

- Carers in the research were evenly split on gender with 47% male and 53% female. This differs only slightly from ABS findings, where females are slightly more likely to be carers (56% females vs 44% males in the ABS findings³) The average age of all carers was 47 with the largest proportion falling into the 40-54 age bracket.
- Just over one-half (54%) of carers were the only person providing care. This proportion increased with age with 67% of those 65+ being the only person providing care.
- Average annual household income was \$74,754. Over 50% of carers were in some form of paid employment, with 35% in full-time employment.
- Most carers' (52%) income source was from paid employment, however over one-third (35%) were reliant on government benefits or allowances.
- The research shows that over one-third of carers also have a health condition which in some cases was the same condition as the care recipient.
- The majority of care recipients (68%) were either a parent, parent in-law, spouse or partner.
- On average carers spent 4.4 hours per day caring, which was significantly higher among those caring for someone with a disability (6 hours per day on average).
- Key **benefits** raised by carers in the qualitative research:
 - Being given the opportunity to give back to the care recipient.
 - Carers took full responsibility for their caring role and treated their responsibilities with the utmost importance.
 - Ability to improve the care recipient's quality of life and enable them to develop and live beyond expectations.
 - Caring for someone brought the carer closer to the care recipient.
- Key **challenges** raised by carers in the qualitative research:
 - Caring responsibilities consume the carer and lead to isolation.
 - Having to watch the care recipient deteriorate and be in pain.
 - Stress placed on the carer and care recipients relationship.
 - Caring is a full-time commitment, which leaves little personal time for carers.
 - Living outside of capital cities and gaining access to services.
 - Navigating and accessing relevant government services.
 - The financial burden associated with providing adequate care.
 - Carer's confidence in their own skills and ability to satisfy the care recipient's needs.
- The majority of carers (79%) did not see themselves as a carer (either part-time or full-time) opting for other roles such as employment (51%), keeping house (16%) and retirement (20%).

Generally speaking those caring for someone with a disability or mental illness were under

³ Disability, Ageing and Carers, Australia: Summary of Findings 2012

3.1 Characteristics of carers and the people they care for

3.1.1 Carer demographics

Table 3 below outlines demographic characteristics of the carers in the research, broken down by the condition of the care recipient. A slightly greater proportion of carers were female, while the average age of carers was 47, with half of all carers falling into the 40-64 age bracket. Those who cared for someone with a mental health conditions or (especially) an alcohol or drug dependency were younger on average, while those who provided care to an older person or care to someone with a terminal or other condition were older themselves.

Table 3: Basic carer demographics

	Condition of Care Recipient:	Total %	Disability %	Mental illness %	Alcohol/drug %	Chronic illness %	Aged and frail %	Terminal/Other %
Gender	Male	47	51	47	46	50	44	37
	Female	53	49	53	54	50	56	63
Age of carer	18-25	12	14	13	25	7	8	9
	26-39	22	21	28	36	28	14	17
	40-54	31	29	30	23	30	37	23
	55-64	19	20	15	9	16	22	23
	65-74	9	10	10	5	9	9	17
	75 and over	7	6	4	1	11	10	11
	Average	47	47	45	38	49	51	52
Location	Capital city	64	62	61	66	59	64	65
	Rest of state	36	38	39	34	41	36	35
CALD/ ATSI status	Neither	84	82	84	82	84	85	87
	CALD	14	14	13	17	14	13	11
	ATSI	3	5	4	3	2	2	4
	Sample size	1205	403	374	98	316	430	144

Base: All carers, n=1205

Table 4 shows that over one-half (54%) of carers were the only person providing care. Carers aged 65+ were significantly more likely to be the only person providing care due to the higher proportion of this group caring for a partner. Close to three-quarters (74%) of carers considered themselves the main carer this trend was the same across age and gender.

Table 4: Main carer

	Age:	Total %	18-39 %	40-64 %	65+ %	Gender:	Male %	Female %
Multiple carers	Sole carer	54	48	54	67		55	53
	Other carers supporting	46	52	46	33		45	47
	Sample size	1205	298	609	298		486	718
<i>Base: All carers, n=1205</i>								
Main carer	Yes	74	69	75	81		75	73
	No	26	31	25	19		25	27
	Sample size	553	165	282	106		216	337

Base: Carer of a multiple carer care recipient, n=553

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Table 5 shows the household income and education levels for Australia's carers. Carers of someone with a disability had a significantly lower average household income than other carers. Highest education attainment was consistent across all the groups with 48% of carers having tertiary education.

Table 5: Carer income and education

	Condition of Care Recipient:	Total %	Disability %	Mental illness %	Alcohol/drug %	Chronic illness %	Aged and frail %	Terminal/Other %
Household income	Under \$10k	2	3	1	4	1	1	0
	\$10k to \$30k	14	20	14	14	15	14	22
	\$30k to \$50k	18	20	17	13	17	18	21
	\$50k to \$75k	18	17	20	14	18	17	19
	\$75k to \$100k	16	13	20	24	16	17	11
	Over \$100k	20	15	16	19	22	21	12
	Unsure	3	4	2	6	3	2	5
	Prefer not to say	10	8	9	5	9	11	10
	Average	\$74,754	\$64,218	\$72,283	\$75,641	\$75,882	\$76,688	\$61,375
Education	Below high school	7	8	8	4	7	7	5
	High school	23	26	23	27	21	20	28
	Trade qualification	10	10	10	15	7	10	11
	Vocational certificate	10	11	10	7	8	10	12
	Tertiary education	48	40	47	43	54	50	41
	Some other level	2	2	1	0	2	1	3
	Prefer not to say	2	2	1	4	1	1	0
	Sample size	1205	403	374	98	316	430	144

Base: All carers, n=1205

3.1.2 Carer situation

Over 50% of carers were in some form of paid employment, with 35% in full-time employment. Carers less likely to be in paid employment were those caring for someone with a disability or someone nearing the end of their life which was indicative of the significant time commitment allocated by these carers.

Most carers' (52%) income source was from paid employment, however over one-third (35%) were reliant on government benefits or allowances. Those caring for someone with disability were more likely to rely on government benefit or allowances than any other group of carers.

Previous anecdotal information has suggested that carers themselves also have their own personal and health concerns. The research showed that over one-third of carers also had a health condition which in some cases was the same condition as the care recipient, for example:

- 23% of those caring for someone with a disability also have a disability
- 26% of those caring for someone with a mental illness also have mental illness
- 22% of those caring for someone with a chronic illness also have a chronic illness

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Table 6: Carer situation

	Condition of Care Recipient:	Total %	Disability %	Mental illness %	Alcohol/drug %	Chronic illness %	Aged and frail %	Terminal/Other %
Working status	Full-time	35	28	35	47	32	35	23
	Part-time	16	14	16	17	17	14	15
	Casual	7	7	9	7	9	8	8
	Unpaid voluntary work	7	8	8	4	7	6	13
	Student Full-time	5	6	8	11	5	3	7
	Student Part-time	5	5	7	7	8	2	5
	Unemployed	4	5	4	11	4	5	4
	Keeping house	16	16	16	11	19	17	22
	Age pension	7	7	6	3	9	8	12
	Carers payment/allowance	11	18	11	2	16	8	15
	Disability pension	5	10	6	9	5	5	3
	Other pension	3	3	3	1	4	3	2
	Retired	17	17	14	6	19	22	29
	Other	1	2	1	0	1	2	4
	Rather not say	1	1	1	0	1	0	0
	Income source	Income from employment	52	43	53	64	50	54
Government benefit or allowance		35	46	40	33	42	31	40
Superannuation/self-funded retirement		12	9	10	5	12	16	17
Other self-funded living (e.g. savings)		12	11	12	10	14	15	16
Income from another person		8	7	11	5	6	8	3
A pension from another person		2	3	1	1	4	1	1
Another source of income		5	4	3	0	5	5	10
I prefer not to answer		5	8	4	5	5	3	3
Condition of carer		A disability	12	23	14	8	9	12
	A mental health condition	13	15	26	23	11	10	13
	Alcohol/drug dependency	3	3	5	18	3	4	1
	Chronic or terminal illness	10	9	10	4	22	10	6
	Frailty due to age	5	5	4	2	5	9	3
	Other	4	5	3	3	5	4	11
	Unsure	2	2	2	3	2	1	0
	None of the above	62	55	54	58	57	64	64
	<i>Sample size</i>	<i>1205</i>	<i>403</i>	<i>374</i>	<i>98</i>	<i>316</i>	<i>430</i>	<i>144</i>

Base: All carers, n=1205

3.1.3 Caring profile

Table 7 shows the profile of the care recipient, the majority of care recipients (68%) were either a parent, parent in-law, spouse or partner. As expected those caring for someone who is aged were more likely to be caring for a parent or parent in-law. The majority of carers were living with the care recipient. This proportion was higher where the care recipient had a disability (56%), mental illness (54%) or chronic illness (58%). Over half (52%) of carers caring for someone aged were not living with the care recipient.

Table 7: Caring profile

Condition of Care Recipient:		Total %	Disability %	Mental illness %	Alcohol/ drug %	Chronic illness %	Aged and frail %	Terminal/ Other %
Who is cared for	My parent or parent in law	38	26	28	33	37	70	44
	My spouse, partner or de-facto	33	34	38	34	46	18	36
	My child or step child	16	26	28	17	11	7	13
	Another relative	12	12	16	23	12	12	9
	My friend	8	10	7	13	7	4	11
	Another person (please specify)	3	5	2	3	3	2	4
	My neighbour	2	2	2	3	2	5	6
	My grandchild	2	3	2	4	2	2	2
	I prefer not to answer	1	3	0	1	2	0	1
Care recipient age	Average age of care recipient(s)	57	50	45	44	58	77	62
Live-in status	Yes	50	56	54	37	58	30	46
	Some of them	6	9	7	10	8	8	9
	Some of the time	9	7	9	8	9	9	11
	No	35	28	31	44	25	52	34
<i>Sample size</i>		1205	403	374	98	316	430	144

Base: All carers, n=1205

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Table 8 shows metrics related to carer workloads, the majority (78%) of carers were caring for only one person with close to one-fifth (21%) caring for two or more people. The time allocated to caring was significant, on average carers spent 4.4 hours per day caring, which was significantly higher among those caring for someone with a disability (6 hours per day on average).

Table 8: Caring commitments

	Condition of Care Recipient:	Total	Disability	Mental illness	Alcohol/drug	Chronic illness	Aged and frail	Terminal/Other
No. cared for	Only one person	78	74	73	75	75	69	71
	2 people	17	19	19	16	19	24	23
	More than 2 people	4	7	7	8	6	7	7
	I prefer not to answer	0	0	1	1	1	0	0
Daily hours caring	Up to 1 hour	36	26	33	32	23	40	33
	2-3 hours	32	29	31	37	39	36	28
	4 or more hours	33	46	36	30	37	24	39
	Average hours	4.4	6.0	4.8	4.2	4.9	3.8	5.4
Duration as carer	Less than 6 months	6	5	4	8	3	5	9
	6 months to 2 years	26	17	23	18	24	31	38
	3 to 5 years	29	29	25	38	35	32	22
	6 to 10 years	18	20	17	12	19	17	20
	11 to 15 years	8	10	14	10	10	7	3
	16 to 20 years	4	6	7	3	3	3	5
	More than 20 years	7	12	10	7	5	4	3
	I prefer not to answer	1	1	0	3	0	0	0
Sample size	1205	403	374	98	316	430	144	

Base: All carers, n=1205

3.1.4 Help provided by carers

The main tasks undertaken by carers for the care recipient were domestic duties, for example shopping (71%), housework (63%), transport (59%) and meal preparation (55%). There were a number of significant differences driven by condition of the care recipient, carers of someone with disability were significantly more likely to play an active role all activities. The main areas were healthcare (47%), help moving around the house (40%) and personal care (40%).

Table 9: Help provided

Condition of Care Recipient:		Total %	Disability %	Mental illness %	Alcohol/ drug %	Chronic illness %	Aged and frail %	Terminal/ Other %
Help provided	Shopping	71	74	64	67	81	80	76
	Housework	63	67	61	63	75	64	63
	Transport	59	68	50	47	67	72	67
	Meal preparation	55	60	56	44	60	50	64
	Maintenance around the home	54	54	51	48	61	64	52
	Guidance in decision making	50	48	60	50	47	56	50
	Health care	39	47	43	25	48	39	43
	Financial assistance	34	34	47	53	33	30	26
	Coordination of services and support	31	38	32	21	36	39	35
	Assistance with social participation	30	37	40	27	31	27	32
	Help moving around the house or outside	29	40	20	17	38	36	29
	Supervision for safety reasons	27	39	27	25	26	33	36
	Advocacy for their rights and support	24	31	26	18	27	28	38
	Personal care, such as showering, bathing, dressing, eating, or toileting	23	40	21	21	29	23	30
	Supervising & preventing certain behaviours	21	28	38	35	16	16	20
	Reading & writing	17	26	18	8	15	13	21
	Communication (such as translating into the persons native language)	11	16	10	7	11	14	11
	<i>Sample size</i>	<i>1205</i>	<i>403</i>	<i>374</i>	<i>98</i>	<i>316</i>	<i>430</i>	<i>144</i>

Base: All carers, n=1205

Q. What help and support do you provide?

3.2 What are the lifestyles and interests of carers?

3.2.1 Hobbies and interests

Table 10 shows the activities carers engaged in more than once per week with the majority undertaking common activities such as watching television (76%), listening to music (60%) and reading (59%).

Table 10: Activities engaged in more than once a week

Age of Carer:	Total %	18-39 %	40-64 %	65+ %
Watching TV or movies	76	64	79	90
Listening to music	60	59	60	64
Reading	59	46	62	76
Shopping	37	24	40	51
Other indoor hobbies	34	33	32	43
Other activities involving exercise such as walking, jogging, swimming or dancing	32	24	37	38
Online forums or social media	19	29	15	9
Social activities at home, such as visits from family or friends	17	20	15	18
Social activities away from home, such as visiting friends, or going to a restaurant or club	13	15	12	14
Visiting places of interest	9	11	10	5
Other outdoor hobbies	9	7	9	12
Playing sport	7	9	6	7
Travelling	6	6	6	4
Religious activities	4	4	4	4
Cultural activities	2	4	1	0
Support group meeting	2	3	1	1
Sample size	1205	298	609	298

Base: All carers, n=1205

Q. How often do you engage in the following?

3.2.2 Internet access

The majority of carers were using multiple devices to access the internet (Table 11). Younger carers were most likely to use a smartphone (86%) or laptop computer (80%) to access the internet. CALD carers were also more likely to access the internet using a laptop (84%), smartphone (73%) or tablet (68%).

Table 11: Devices used to access internet

Age of Carer:	Total %	18-39 %	40-64 %	65+ %	CALD status:	No	CALD
Laptop computer	72	80	76	44		71	84
Desktop computer	64	57	64	76		64	63
Smartphone	61	86	58	23		59	73
Tablet	53	63	54	29		50	68
Other mobile phone	18	18	16	21		16	25
Other device	6	10	5	2		4	18
Sample size	1205	298	609	298		1037	150

Base: All carers, n=1205

Q. Which of the following devices do you use to access the internet?

Carers used the internet regularly for communicating with others (44%), searching for information (44%) and social media (39%). Daily usage of the internet was high among younger carers aged 18-39 and carers in capital cities (Table 12).

Table 12: Everyday online activities

Age of Carer:	Total %	18-39 %	40-64 %	65+ %	Location	Capital city %	Rest of state %
Communicating with others	44	52	41	35		48	36
Searching for information	44	55	40	30		45	41
Social media	39	58	33	19		41	36
Entertainment	28	44	21	15		31	21
Other reasons	20	29	16	13		22	17
Shopping	7	11	6	2		8	5
Sample size	1205	298	609	298		790	415

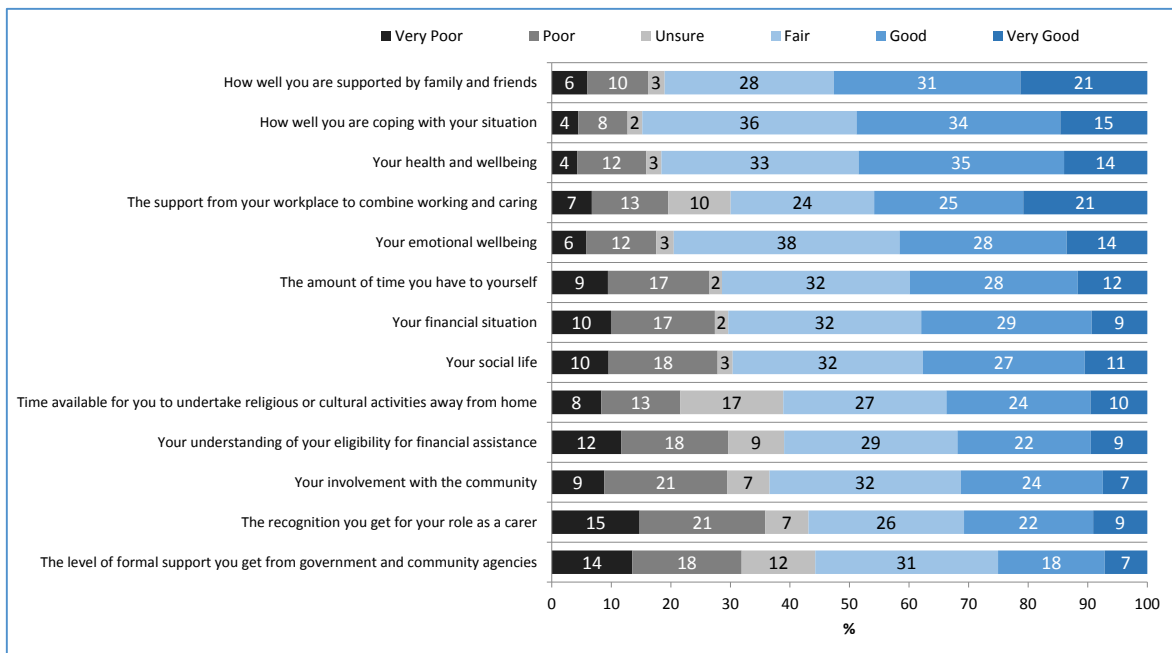
Base: All carers, n=1205

Q. How often do you use the internet for each of the following?

3.3 What are the benefits and challenges of caring?

Carers were asked to rate their level of satisfaction across 13 attributes which measured satisfaction with a range of lifestyle, personal and family factors (Figure 1). One attribute, 'how well you are supported by family and friends' was the only attribute where more than 50% of carers were satisfied. The next highest attribute was 'how well you are coping with your situation', (49% satisfied) followed by 'your health and well-being' (48% satisfied). Carers were least satisfied with 'the level of support from government and community agencies' (25% satisfied), the 'recognition you get for your role as a carer' (31%) and 'your involvement in the community' (31%).

Figure 1: Carer satisfaction with situation and sources of support



Base: All carers, n=1205

Q. Please rate how satisfied you are with each of the following:

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Carers of someone with a mental illness were significantly less satisfied than any other group across three out of the 13 attributes indicating the significant impact of caring for people with mental illness (Table 13). Those caring for people with a disability were significantly less satisfied than other groups across two of the 13 attributes, most notably 'your financial situation' (29%) which was also shared with those caring for someone with a chronic illness.

Table 13: Satisfaction ratings of good + very good

Condition of Care Recipient	Total %	Disability %	Mental illness %	Alcohol/ drug %	Chronic illness %	Aged and frail %	Terminal/ Other %
How well you are supported by family and friends	53	51	50	43	50	52	56
How well you are coping with your situation	49	47	39	34	47	52	53
Your health and wellbeing	48	41	40	42	47	54	51
The support from your workplace to combine working and caring	46	45	48	37	45	46	48
Your emotional wellbeing	42	39	31	35	35	50	44
The amount of time you have to yourself	40	37	34	36	34	43	43
Your financial situation	38	29	36	38	29	43	45
Your social life	38	37	31	34	27	43	38
Time available for you to undertake religious or cultural activities away from home	34	31	33	29	29	36	31
Your understanding of your eligibility for financial assistance	32	32	32	37	39	30	30
Your involvement with the community	31	29	30	29	28	36	36
The recognition you get for your role as a carer	31	30	25	27	28	35	39
The level of formal support you get from government and community agencies	25	24	24	21	23	27	27
Sample size	1205	403	374	98	316	430	144

Base: All carers, n=1205

Q. Please rate how satisfied you are with each of the following:

3.3.1 Benefits of caring

There were a number of benefits mentioned by carers in the qualitative research which are summarised below.

Being given the opportunity to give back to the care recipient.

The opportunity to give back was mentioned spontaneously as one of the key rewards of caring. This was particularly evident among carers of the aged and frail, for these carers they felt a sense of obligation to give back to the care recipient for the role they played in the carer's life. Carers also felt that caring gave them a sense of purpose and additional meaning in their lives.

- "It's rewarding that I'm helping somebody in my family." (Aged and Frail)
- "The good thing about it is you feel useful, you're giving something back" (Aged and Frail)

Carers take full responsibility for their caring role and treat their responsibilities with the utmost importance.

Carers in the research viewed their role as critical given its impact on the care recipient. Carers wanted to care for as long as possible to ensure they could stay in the home with the family where high quality and loving care could be provided.

- "Knowing that it's going to get done properly. You hear stories in aged care of the elderlies getting abused or treated like a number there, it's not an ordeal for him". (Substance Abuse and Chronic Illness)

Ability to improve the care recipient's quality of life and enable them to develop and live beyond expectations.

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Carers derived satisfaction from ensuring the care recipient received the best possible treatment and assistance. Being able to see the impact of caring while not always immediate was very satisfying when it did occur. Particularly those caring for people with a disability or long-term illness, being able watch the care recipient develop or live beyond what is expected was a key reward.

- *"Caring is extraordinarily rewarding. It is all about being able to do something for somebody else. If you do it well and make a difference to their life, what more reward can you get out of anything?" (Disability, Aged and Mental Illness)*
- *"Rewards comes from our love for our daughter, the way we have improved her quality of life and help her surpass all expectations in terms of her development and life expectancy." (Disability)*
- *"I think it's really good when you can see they have come from a place which is really dark and hard and harsh and they've come to a place where they're now able to do things autonomously and you can see they are on an even keel and going well." (Mental Illness)*

Caring for someone brings the carer closer to the care recipient.

The opportunity to build a closer relationship with the care recipient was a key reward for those caring for parents and grandparents. For many of these carers they had drifted apart from their parents and their caring role enabled them to reconnect. This went beyond the immediate carer and also impacted the extended family as they (in some instances) were living together.

- *"Having everyone together [is the reward], the whole family is together. My mother is here, my children are here, so we are all together" (Aged and Frail)*

A key reward for Aboriginal and Torres Strait Islander carers was the knowledge that their family members were safe and the family unit was maintained.

There was a fear of being viewed as incompetent or not appropriate, with the associated fear of child removal or government intervention in family matters. Aboriginal and Torres Strait Islander carers wanted to take full responsibility gaining satisfaction from being able to see family members who needed care were alive or happy, and seeing them *"get in a better place"*.

- *"Just look at them smiles. Nothin' compares to that little one... If they weren't with me who knows who'd be takin' care of them." (Aboriginal carer, Disability)*

3.3.2 Challenges of caring

There were a number of challenges mentioned by carers in the qualitative research which are summarised below.

Caring responsibilities consumed the carer and led to isolation.

Caring responsibilities were significant for the majority of carers in the research which led to putting their own needs second. Carers managing complex disabilities and conditions such as mental illness or substance abuse were constantly focused on the care recipient and their issues. Care recipients often added to this isolation as they were uncomfortable with outside assistance. These responsibilities left carers isolated from the outside world and they failed to see how this could be improved or how a change in situation was possible.

- *"It's like being trapped and I know there is help out there, you can get respite, but she doesn't want anyone else coming into the house and she still wants to be independent." (Terminal Illness)*
- *"Because I'm her carer sometimes I feel like I'm her slave." (Terminal Illness)*

Within CALD communities isolation is exasperated by cultural stigmas towards disability, addictions and illnesses. This caused CALD carers to be less likely to seek support, services and advice.

- *"At first, it took me a long time to be keen to get help and that it was a shame in our community to tell people that my son was a drug addict." (Vietnamese carer, substance abuse)*

Having to watch the care recipient deteriorate and be in pain.

The severity of the care recipient's condition had a significant impact on the carer. As most carers were immediate family such as parents and grandchildren they were heavily impacted by watching the care recipient in pain or watching their condition deteriorate. Carers experienced the deterioration of the care recipient and were acutely aware that the chance of significant improvement is unlikely.

- *"Seeing someone who's so strong, and then basically all his privilege is taken away from him. That's the hardest thing." (Aged and Frail)*
- *"I think it sucks, my child didn't ask for this. He suffers from pain all day long. It's not fair." (Disability)*

Stress placed on the carer and care recipients' relationship.

Some carers in the research raised the difficulties faced maintaining a productive and healthy relationship with the care recipient. Caring responsibilities placed significant burden on relationships because the carer was required to keep the care recipient on track with things such as medication, hygiene and social activities. Care recipients' reluctance to cooperate led to stress in the relationship and in more severe situations, violence and physical harm towards the carer.

- *"99% of my time I have to walk on eggshells. I still have a lot of trouble coping with that. I don't know what her mood swing's going to be from one minute to the next and that's exacerbated when she starts using drugs. She is often suicidal, and does not take her medication unless I make her. She has been extremely violent towards me in the past." (Mental Illness and Substance Abuse)*

Caring is a full-time commitment, which leaves little personal time for carers.

One of the primary challenges faced by the carer was the significant time and emotional commitment required to provide adequate care. This often left carers sacrificing their own needs such as socialising, education, employment and their own health. Carers that were isolated and were not fulfilling their own personal needs were often dissatisfied with their own personal situation, some described being on the 'edge' of giving up. However they were aware this was not an option given the importance of their role.

- *"We are glad that she is still with us, but my life is in chaos 24/7." (Terminal Illness)*
- *"It's taken a lot of my time, money and energy to care for a loved one... Other family members try to help out, but always rely on me as his best mate" (Italian carer, Substance abuse)*
- *"Being a carer is a job that never ends" (GP, Sydney)*
- *"Often carers don't have medical care that is as good as the person they are looking after and can't or don't look after themselves as well as they should" (GP, Sydney)*

Living outside of capital cities and gaining access to services.

Living in small rural or remote areas was a key challenge faced by these carers when accessing support, as the availability of services in their local area was limited. To ensure the care recipient received adequate support travelling long distances became a necessity which led to additional financial burden. In some instances carers were receiving subsidies and while helpful, there was often a gap which the carer paid for. Travelling long distances wore carers down and led them to not take up services such as respite.

- *"We live in a rural town; there is no services. We are so far away from everything, we are so isolated and cut off." (Disability)*
- *"It was taking us an hour to drive there (to respite). And then you'd drop her off, and you'd come home one day and you've got to back the next day, so it was like an hour there, an hour back; you had a day; and then you're an hour there and an hour back. So you had four hours of driving for one day of respite. It was just too much driving and that." (Disability)*

Navigating and accessing relevant government services.

One of the key challenges faced by carers in the research was gaining access to the support and services required for the care recipient. Carers described undertaking extensive research in order to understand what was available. These struggles led to some carers avoiding assistance or support, and as a result care recipients missed out on potential key services.

- *"I've found that I have a real difficulty asking for support and assistance, and all you need is somebody to knock you back once or twice and you don't ask again." (Disability, Aged and Mental Illness)*

Aboriginal and Torres Strait Islander carers were faced with multiple referral pathways which were difficult to navigate and information was not shared between pathways or services.

- *"If I piled up all the pamphlets and papers and stuff from all the people who are supposed to help out people like me I'd have one huge bonfire!" (Aboriginal carer, Disability)*

Understanding Australia's carers

CALD carers faced significant language and communication barriers to access information, support and services. The limited English skills resulted in lack of confidence and greater isolation.

- *"I don't have the research skills to find out what services are available"*
(Lebanese carer, Aged and frail)
- *"I received information from hospital advising us of programs for people with Downs Syndrome. I never followed it through. I guess I didn't have the confidence in the system at the time."* (Chinese carer, Disability)

The financial burden associated with providing adequate care.

Cares were acutely aware of the financial pressures they were under. Carers in the research with full-time caring responsibilities were unable to work. This loss of income was compounded by the costs associated with the care recipient's condition such as medication, equipment, transport, professional care and medical expenses. Financial support from government while available was viewed as difficult to access as often the care recipients' conditions did not fit with the requirements of the benefit.

- *"She has no diagnosis. So she falls through any loop there is for any funding for anything, so she gets nothing."* (Disability)
- *"The most frustrating thing is that she's struggling really bad to get any sort of financial assistance from any departments, especially disability pension, because apparently she's not disabled enough...so for us its very financially stressful, for our family, and it's changed everything."* (Disability)

Among Aboriginal and Torres Strait Islander carers there was reliance on limited financial resources to support multiple chronic and acute needs. Carers were required to take on these responsibilities single handed as there were no options for shared carer roles or respite.

- *"It is world war three here most days. But it's home"* (Aboriginal carer, Disability)

Carer's confidence in their own skills and ability to satisfy the care recipient's needs.

Some carers reported being unsure of their own skills and abilities to provide the right care for the care recipient. Carers were looking for reassurance that what they are doing is the right thing and not limiting the development of comfort of the care recipient. Younger carers needed direction and guidance on how they should care, particularly for more difficult tasks such as showering.

- *"I need a well-trained supervisor to guide me through...having someone letting you know you are doing the right thing."* (Young Carer)

3.4 What is the size of the 'hidden carer' population?

The research showed that while the term 'carer' was well understood and something that carers associated themselves with, the majority did not necessarily see caring as their primary responsibility. The 'carer' role was most commonly viewed as "just looking after my kids" or "it's what we all do" and was generally seen as a role that family members fulfilled as "caring for your family".

Carers primarily saw themselves fulfilling their traditional role (i.e. partner, friend, parent or grandparent) rather than as the 'carer'

Carers preferred to maintain their traditional role rather than being seen as the carer. While carers generally agreed this term was widely accepted as who they are, there was a preference to be seen as the partner, friend, parent or grandparent.

- *"So, I don't identify strongly with a carer role. I really try and stick to being a mother for my children. And, so I mean, I believe I get the same sense of satisfaction as any other parent." (Disability)*

The term 'carer' was associated with being a professional or paid carer

Some carers felt the term 'carer' referred to paid or professional care, someone with a qualification to give care. This reluctance to associate with the term carer was driven by a belief they did not have the appropriate skills to be considered a professional carer.

Aboriginal and Torres Strait Islander communities viewed the term 'carer' differently.

This difference was due to the historical association with foster 'care' or alternate care arrangements. Aboriginal and Torres Strait Islander carers in the research were also either fulfilling a paid foster carer role or unpaid kinship carer role for younger generations in their family. For this reason all discussion in the research was clearly differentiated between 'care for family' versus 'foster care'.

Looking after the needs of loved ones who may be frail or sick in CALD communities was often an 'underground' issue with many carers not readily identifying as 'carers'.

The circumstances under which care was required (e.g. family crisis, injury, illness) often 'forced' or 'entrapped' CALD carers into arrangements where they were the only frontline and consistent option for care.

- *"I have my parents and brother and sister living in China... I have been mostly responsible for the care of my son and his welfare" (Chinese carer, Disability)*
- *"Other family members try to help out, but always rely on me to do the majority of the workload" (Italian carer, Aged)*

Offering regular care and support did not qualify the provider (in their eyes) as a 'carer'. Moreover, it was often stated that they were simply doing 'what was expected' of them.

- *"In our Greek culture and going back to old traditional ways, it was seen as a shame to show you had a child with a disability...For a very long time, my parent isolated themselves from society and was embarrassed to say they had a kid with a mental illness. They slowly but surely opened up and got matters back on track and accepted this to be a part of life" (Greek carer, Mental Illness)*

This was validated by the survey findings (Table 14) that the majority of carers (79%) did not see themselves as a carer (either part-time or full-time) opting for other things such as employment (51%), keeping house (16%) and retirement (20%).

Understanding Australia's carers

Table 14: Carer situation

Condition of Care Recipient:		Total %	Disability %	Mental illness %	Alcohol/drug %	Chronic illness %	Aged and frail %	Terminal/Other %
Carer Situation	Full-time or part-time paid employment	51	41	53	59	50	52	42
	Part-time or full-time student	10	9	12	16	11	6	11
	Unpaid voluntary work	8	9	10	4	9	10	15
	Keeping house	16	16	15	10	19	20	18
	A part time carer	11	10	12	12	14	14	14
	A full time carer	10	18	11	3	15	7	11
	Receiving a pension	12	19	12	9	18	14	20
	Retired	20	18	15	7	21	24	32
	Unemployed	4	8	4	9	4	4	4
	Other situation	2	2	1	2	2	1	2
	Prefer not to answer	0	1	0	0	1	0	0
	<i>Sample size</i>	<i>1205</i>	<i>403</i>	<i>374</i>	<i>98</i>	<i>316</i>	<i>430</i>	<i>144</i>

Base: All carers, n=1205

4. Current access to information, services and support

Key insights

- Carers in the research viewed their caring role as the most important thing they did and for some, seeking help and support was a sign of not coping.
- Carers felt there was a lack of support services available specifically for them.
- There were groups of carers who were well informed and were accessing information, support and services.
- Carers relied heavily on the immediate support network, which includes family, friends and health professionals.
- Around 7 in 10 carers had sought information and advice from family, their doctor or via an online search in the past 12 months.
- Along with medical specialists/healthcare professionals these were also the most preferred sources of support.
- Younger carers and those caring for someone with a mental illness were more likely than average to seek information and advice online.
- Carers in Victoria were more likely than average to have used local council or community centres.
- Recognition of telephone helplines was relatively high compared to usage which was very low, though higher amongst carers of people with a mental illness and/or alcohol/drug dependency.
- The Department of Human Services (formerly Centrelink) website had the highest awareness and usage of a range of prompted web offerings for carers.
- Although more than half of all respondents had heard of respite services, just over 1 in 10 had used any in the past 12 months.

Amongst those respite services used home care/help was the most popular, especially amongst those caring for someone with a chronic illness.

4.1 What services are carers currently accessing?

4.1.1 Sources of information and advice used

Carers in the research viewed their caring role as the most important thing they did and for some **seeking help and support was a sign of not coping**. Accessing support and services was seen by some carers as 'admitting defeat' and a failure to provide adequate care. These carers preferred to persist with the current situation rather than seek external help and support.

- *"You've just got to keep dragging yourself, keep travelling. That's what you've got to do." (Disability)*
- *"I think people don't go looking for it so much out of guilt, they just feel like if they complain they shouldn't be because it is their family members so they just put their head down and get on." (Aged and Frail)*
- *"I was scared to ask people or the government in case I get humiliated for my bad raising of my child." (Vietnamese carer, Substance abuse)*

Carers felt there was a lack of support services available specifically for them. Carers in the research viewed the information, services and support tailored specifically to carers as limited which was compounded by an unwillingness to search or access help and assistance.

- *"There's a lot out there for the people we care for...but I don't think there's anything for carers...Not that you expect anything." (Aged and Frail)*
- *"Who are you supposed to find out from in your local community? (Local Service Provider) sends out their info in the mail but it's either already over or you get it the day before." (Aboriginal carer, Aged)*
- *"Carers just don't know what is available to them. We do a lot of work just to make people aware of what is available to them and what they can access" (Social worker, Regional Western Australia)*

There were groups of carers who were well informed and were accessing information, support and services. Throughout the research there were examples of carers who were accessing information, support and services, these carers were typically experienced carers who had positive experiences finding tailored information and support. These carers were accessing services through a range of sources including peak bodies (e.g. Carers Australia), charities (e.g. Red Cross), community organisations and government.

- *"I have been able to find day respite which gives me a few hours to clean or work in the garden. If I can get him minded it is my little holiday, I can finally relax. If he is home I have to watch him constantly." (Aged and Frail)*

These carers also had the assistance of experience health professionals. Health professionals included in the research agreed that their role was critical in providing carers with access.

- *"When I'm trying to link them in to other services, I do the phoning myself, because I'm better at it basically. I've had more experience." (Social worker, Perth & Sydney)*
- *"For us as professionals I don't think it's very difficult at all. We can ring around, look online, get the nurse to chase it up... But from their point of view sometimes might be difficult for them, they don't have the same resources... know what to look for, exactly where to look." (GP, Melbourne)*

Current access to information, services and support

Many carers from CALD backgrounds had little or no understanding of the service systems (health, aged care, disability, mental health) that they could access.

- *"I really don't know what services are out there and how they can be a benefit to me. I do need assistance." (Lebanese carer, Chronic illness)*
- *"I have a patient who is a Filipino carer and her understanding of the Australian system is not great and it often falls on the GP to direct carers to services" (GP, Sydney)*

Carers relied heavily on the immediate support network, which included family, friends and health professionals. Across the research carers tended to rely primarily on an immediate support network. The immediate support network did differ depending on the care recipient condition and the level of support provided by family and friends. However a health professional was typically included e.g. General Practitioners, Health Specialists and Psychologists. Carers were comfortable relying on their immediate network for key things such as financial assistance, emotional support and part-time respite.

- *"You get a good GP, who's onto it, then things can go well. But if you're not au fait with how things work, well good luck" (Social worker, Perth & Sydney)*
- *"Thank heaven for families, that's all you can say, because if you really get stuck." (Disability)*
- *"My sister is finding it more and more taxing as my mum gets older...so I looked into getting some help to clean Mum's room. I looked up the My Aged Care website." (Aged and Frail)*

Service providers were unwilling to take ownership for the carer's issues. Carers experienced being sent to numerous service providers before their issue was resolved and some never received what they needed. There was a tendency from service providers (e.g. Disability Services) to refer carers to numerous services which resulted in carers having to spend significant time navigating the system. To be successful carers required service providers to take ownership of their recommendations and assist them in making linkages to services which make a difference.

- *"He emailed me a list and then I just started crying, and said, "I'm calling you because I don't actually even have time to make a phone call. There's no way I can call every agency to find out who can do this for us...so I now make them work for me, and at the moment, the social worker I just call her every week and say, 'where are we up to? What are you finding out?'" (Disability)*

Aboriginal and Torres Strait Islander carers – trusted contact person

This person was generally referred to as a worker (usually an Aboriginal worker) who was able to explain systems, reasons for practices, terminology and other issues affecting the care for the person's family member. Examples of this were: Community Worker (generic position but happened to be filled by an Aboriginal woman), Aboriginal Mental Health Worker in the hospital setting, other family members who had older children (and were seen as knowledgeable and experienced) or local worker at the school (relied on by one participant to "explain all them big terms"). This trusted individual had typically come into their lives through some other aspect and developed a trusting and regular connection.

- *"She (Service Provider) wasn't even supposed to cover my area. But she followed up for me and came out for a cuppa and we just, you know, got on. Doesn't matter what it is I know she'll help me day or night." (Aboriginal carer, Aged and frail)*

Culturally and Linguistically Diverse carers – family focussed care

There was a strong family focus towards providing care amongst CALD communities and this was highly valued by the carers interviewed. Larger families enable the care recipient to be cared for solely by the family.

- *“We did not get any other help, information or support for many years as we felt at the time that a big family like ours we could manage our brother’s affairs appropriately” (Greek carer, Mental illness)*

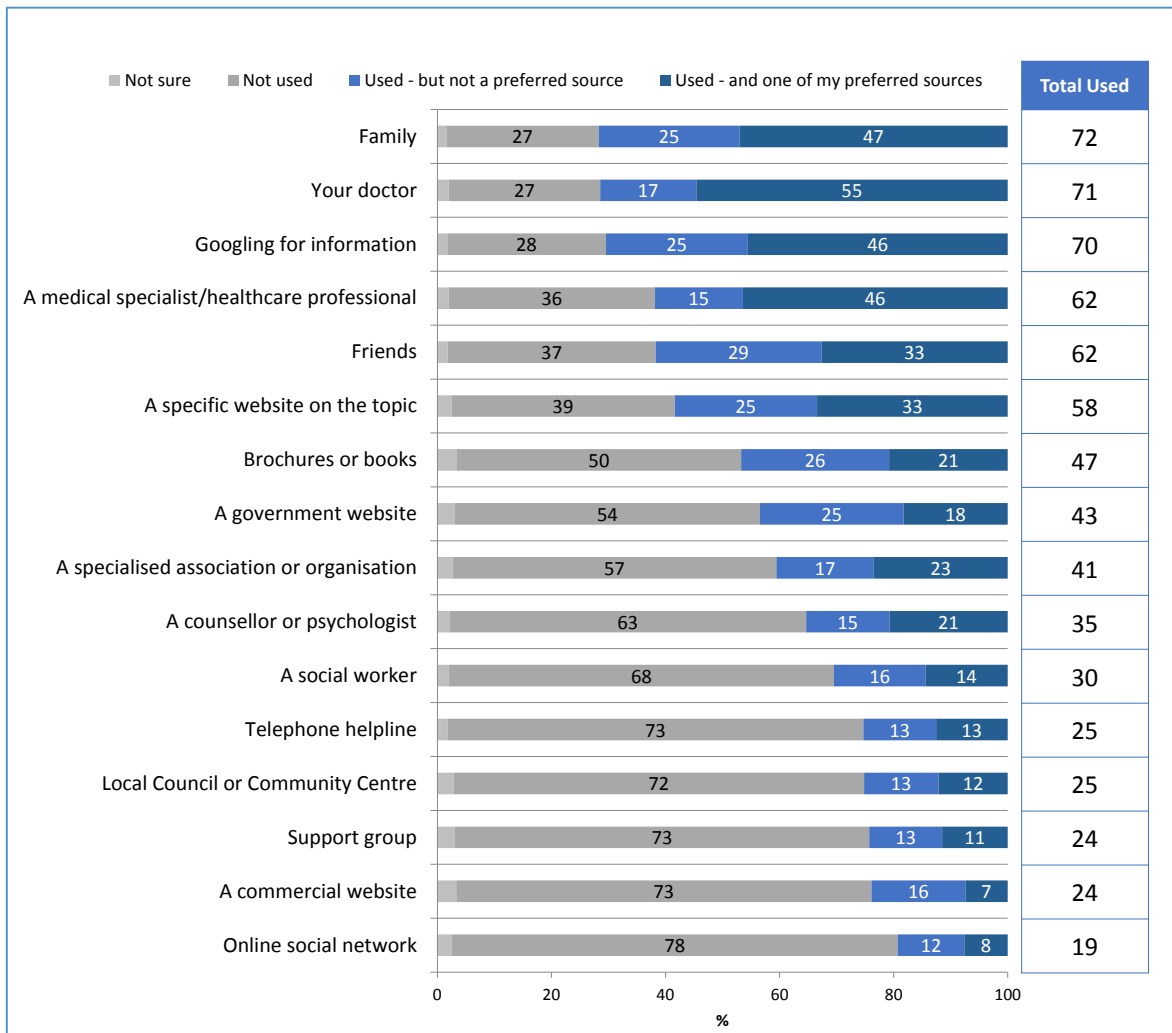
In many CALD families, irrespective of ethnicity or length of residence in Australia, there was often an expectation that the family would look after its own. Feelings of pride, protection, concern and guilt were highlighted as some reasons to keep the responsibility of care within the family

- *“I can research for service if I need to, but we as a family just didn’t go through with it as pride had stopped us from proceeding” (Greek carer, Aged and Terminally Ill)*

Respondents were presented with a list of options incorporating a variety of sources of information and advice for carers they may have used in the past 12 months, and asked to select which they had accessed and which were amongst their preferred sources. As shown in Figure 2 below around 7 in 10 respondents had sought information and advice from members of their family, their doctor or via an online web search. These three options along with medical specialists/healthcare professionals also proved to be the most preferred sources. By contrast, online social networks, commercial websites and support groups were the least accessed and least preferred sources.

Current access to information, services and support

Figure 2: Sources of Information and Advice used



Base: All carers, n=1205

Q. Which of the following sources have you used for information or advice in the last 12 months?

Current access to information, services and support

General Practitioners were mentioned as a key source of support for carers. The GP provided a wide range of support from counselling to information and diagnosis relevant to the care recipient. GPs were also critical in referring carers to relevant services and were viewed by many as the central point for information, support and services. In some instances the GP had become a dedicated support for the carers, the relationship often started with the care recipient but the GP recognised the carer themselves required support.

- *"I don't tend to talk to people very much about my own problems, so the (GP) is someone I... trust." (Disability)*
- *"I would say more than anything, it's my GP. He's probably my main support when I feel like I've really had enough." (Disability)*
- *"We do rely on information received from our family doctor and they are good on any information they feel would be of assistance to my parents." (Italian carer, Long term illness)*

Nurses were also mentioned by some as being very helpful, providing a lot of information about the various services available that the carer would have not known about otherwise.

- *"I didn't know mum could have a yearly health check, so (the Nurse) went through all that with me. She checked that I had her booked in for hearing tests, eyesight tests, checked what mobility aids we needed for her...this has all come from our clinic nurse." (Aged and Frail)*

Access to government services was difficult, the main challenge faced by carers was eligibility for the care recipient and themselves with many discussed being passed from department to department because their situation did not fit with the requirements for the benefits or services offered.

- *"I tend to find it's very difficult about what you are and aren't eligible for...It took me years before we actually got any financial assistance because it was so hard." (Disability)*

Government websites, such as the Department of Social Services and Centrelink, were viewed in a negative light amongst the entire group. It was difficult for carers to find what they were looking for on these websites.

- *"I got disheartened and one point and decided that the whole purpose for the way it was written up was so you walk away." (Disability)*

My Aged Care was mentioned by some carers in the research.

- *"When I need to take a break from the stress of full-time caring, you need someone to help out a bit I call the myagedcare service provider and they assist me with bringing out someone to help with house duties, transport, personal care and respite care when I can't handle the stress of being a carer... I found the services to be great and helpful and really supportive" (Vietnamese carer, Aged and frail)*

Table 15 displays the varying usage of the prompted sources of information and advice according to the condition of the care recipient as well as the age of carer. A clear trend can be seen with the use of the internet to seek support: a significantly higher than average proportion of carers in the 18-39 age bracket looked for information via a web search, on a specific website, or via an online social network. For the first two options, the same was the case for those caring for someone with a mental illness, likely a function of the lower average age for this type of carer.

Current access to information, services and support

Those caring for someone with a mental illness or alcohol/drug dependency were also more likely than average to have accessed a counsellor or psychologist. This may, in part, be due to the fact that carers for people with these conditions had a higher rate of mental illness and drug/alcohol dependency themselves. Close to double the proportion of younger carers (aged 18-39) compared to older carers (aged 65+) accessed a counsellor or psychologist.

Finally, carers of those with a drug and/or alcohol dependency were significantly more likely to have used a telephone helpline in the last 12 months.

Table 15: Sources of information used in last 12 months

Condition of Care Recipient:	Total %	Disability %	Mental illness %	Alcohol/drug %	Chronic illness %	Aged and frail %	Terminal/Other %	Age of Carer	18-39 %	40-64 %	65+ %
Family	72	72	76	77	70	73	70		73	71	73
Your doctor	71	77	74	68	79	67	76		74	68	77
Googling for information	70	70	79	74	73	68	74		77	69	61
A medical specialist or healthcare professional	62	68	65	56	69	60	71		59	64	63
Friends	62	62	67	74	58	61	67		63	61	62
A specific website on the topic	58	58	65	62	59	54	64		66	57	48
Brochures or books	47	50	51	56	47	48	58		45	48	47
A government website	43	50	45	61	41	48	41		47	46	30
A specialised association or organisation	41	48	48	40	43	39	48		41	41	40
A counsellor or psychologist	35	38	61	53	35	23	24		44	34	23
A social worker	30	32	34	36	30	32	37		37	28	26
Telephone helpline	25	29	29	39	21	28	22		32	24	18
Local Council or Community Centre	25	29	24	29	24	28	28		25	26	25
Support group	24	30	30	34	23	23	25		28	22	25
A commercial website	24	30	24	40	22	26	25		29	23	15
Online social network	19	22	23	31	20	18	17		30	16	8
Sample size	1205	403	374	98	316	430	144		298	609	298

Base: All carers, n=1205

Q. Which of the following sources have you used for information or advice in the last 12 months?

Current access to information, services and support

Usage of the various sources of information and advice across the jurisdictions was fairly uniform (Table 16): one exception was Victoria which had a significantly higher than average prevalence of usage of local council or community centres (40% vs. 25% on average). Another was the relatively low usage of online social networks in South Australia (6% vs. 19% average), likely due at least in part to the higher than average number of respondents over the age of 65 in that state (18% vs. 7% on average).

Table 16: Sources of information and advice used across States and Territories

States and Regions:	Total %	NSW %	Victoria %	Queensland %	South Australia %	Western Australia %	Tasmania* %	ACT* %
Family	72	68	70	73	75	81	82	66
Your doctor	71	70	69	68	86	75	75	69
Googling for information	70	72	73	67	66	67	70	74
A medical specialist or healthcare professional	62	61	65	57	57	67	66	60
Friends	62	60	62	61	61	64	69	57
A specific website on the topic	58	59	61	54	50	64	59	73
Brochures or books	47	46	45	47	40	55	58	41
A government website	43	45	43	45	36	40	43	45
A specialised association or organisation	41	39	41	42	42	45	37	42
A counsellor or psychologist	35	34	35	34	33	41	31	43
A social worker	30	32	27	30	29	35	35	22
Telephone helpline	25	25	26	24	22	24	33	32
Local Council or Community Centre	25	21	40	17	24	23	19	26
Support group	24	25	19	26	21	34	21	31
A commercial website	24	22	24	26	15	28	30	32
Online social network	19	19	18	20	6	30	24	32
Sample size	1205	364	277	313	82	93	39	31

Base: All carers, n=1205

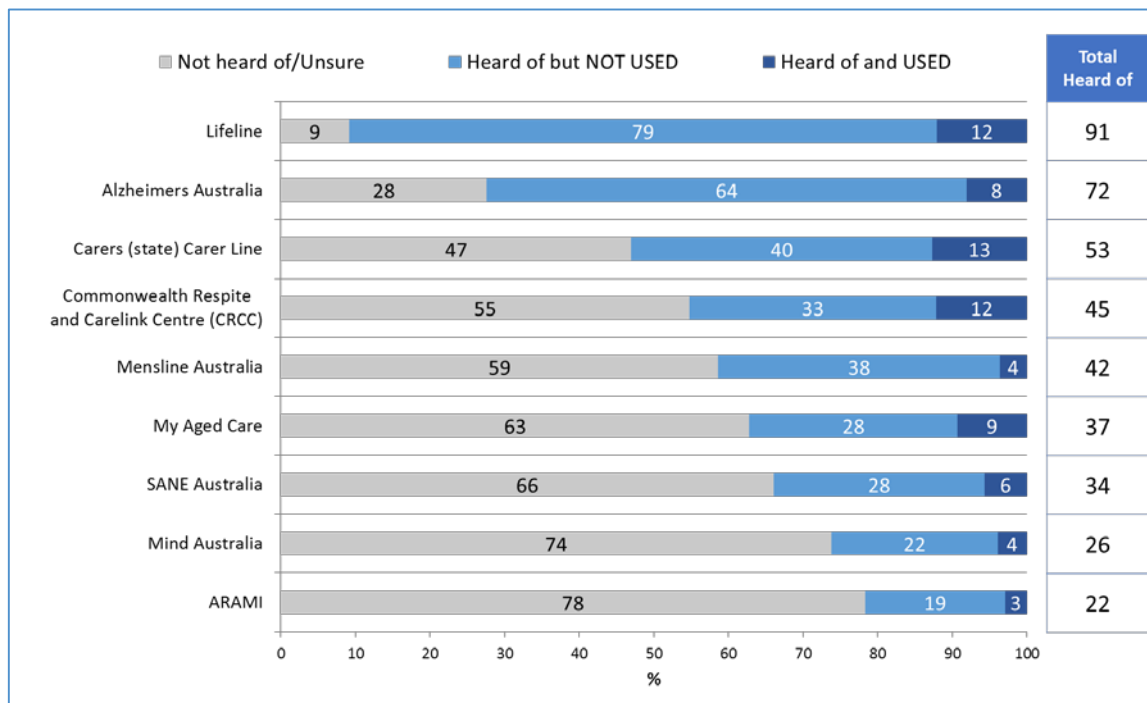
Q. Which of the following sources have you used for information or advice in the last 12 months?

*Low base size interpret with caution

4.1.2 Helplines

From a range of prompted helplines, the three with the greatest amount of recognition (over 50%) amongst carers were Lifeline, Alzheimer’s Australia and the Carer State and Territory Association in each state (Figure 3). Actual usage of these services was low, with several garnering a maximum proportion of recent users of around 10%.

Figure 3: Helplines heard of and used by carers



Base: All carers, n=1205

Q. Have you heard / used of any of the following helplines which provide support for carers?

Current access to information, services and support

As seen in Table 17, respondents caring for someone with an alcohol and/or drug dependency were more likely to have accessed a helpline overall recently. When looking at specific helplines it is clear that a greater than average proportion of these carers (along with to a lesser degree carers of those with mental illness) have accessed a range of nominated helplines. This was particularly evident for Lifeline, which almost three times the proportion of these carers had accessed compared to the carer sample as a whole (34% vs. 12%).

Table 17: Helplines used by carers

Condition of Care Recipient:	Total %	Disability %	Mental illness %	Alcohol/ drug %	Chronic illness %	Aged and frail %	Terminal/ Other %	Age of Carer	18-39 %	40-64 %	65+ %
Lifeline	12	13	23	34	12	10	11		19	10	4
Alzheimers Australia	8	8	11	11	7	10	10		9	8	8
Carers (state) Carer Line	13	16	17	16	17	12	13		14	12	11
Commonwealth Respite and Carelink Centre (CRCC)	12	16	15	19	15	15	12		12	13	12
Mensline Australia	4	5	7	14	5	4	2		6	3	2
My Aged Care	9	11	11	17	12	15	14		8	10	9
SANE Australia	6	6	12	16	6	5	6		7	6	3
Mind Australia	4	4	7	13	5	3	4		7	2	3
ARAMI	3	4	6	13	4	4	2		3	3	3
Sample size	1205	403	374	98	316	430	144		298	609	298

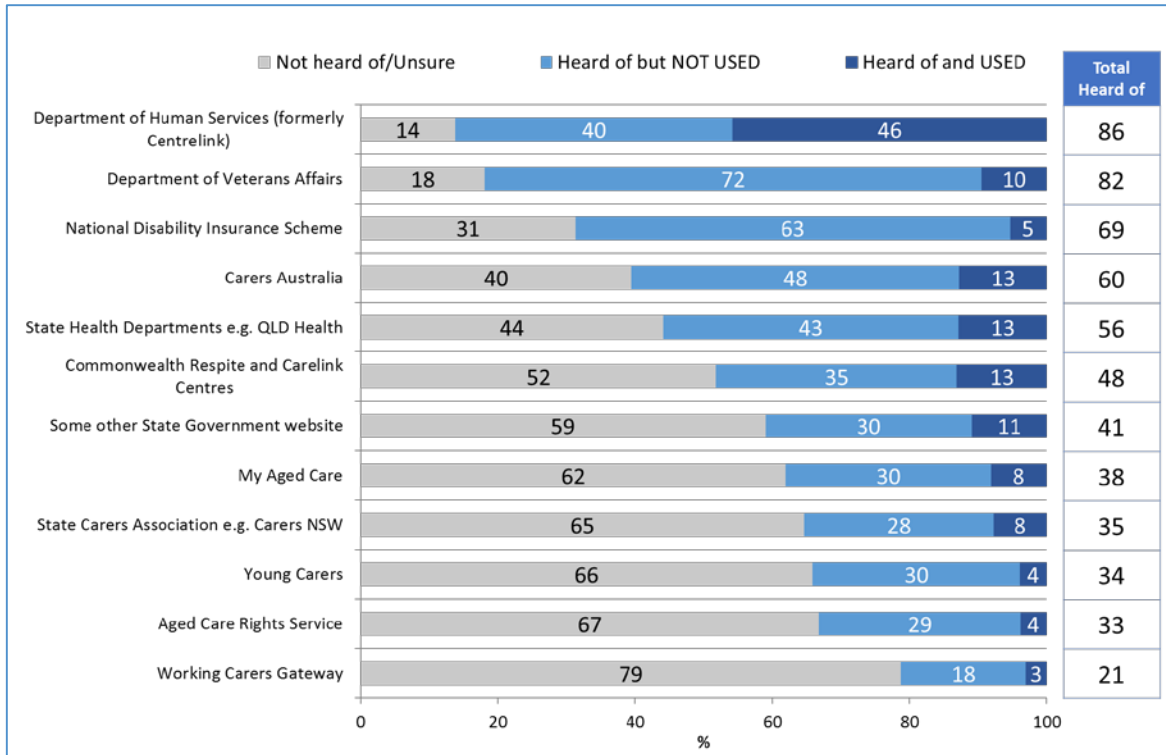
Base: All carers, n=1205

Q. Have you heard/used of any of the following helplines which provide support for carers?

4.1.3 Websites

Figure 4 below displays the level of awareness and usage for a range of carer-focused websites. Overall cut-through for websites was slightly higher than telephone helplines: the Department of Human Services (formerly Centrelink) website dominates both awareness (86%) and recent usage (46%). In spite of the fact that it was still in the piloting phase and awaiting full national rollout, more than two thirds of respondents had heard of the National Disability Insurance Scheme website (or potentially the Scheme more generally).

Figure 4: Websites heard of and used by carers



Base: All carers, n=1205

Q. Have you heard / used any of the following websites that have information, services or support for carers?

Current access to information, services and support

When broken down by condition of care recipient (Table 18), the level of usage of the DHS website was higher amongst those providing care to people with a disability, mental illness and chronic illness. A range of websites was more likely to be used by those caring for someone with a mental illness.

Table 18: Websites used by carers

Condition of Care Recipient:	Total %	Disability %	Mental illness %	Alcohol/drug %	Chronic illness %	Aged and frail %	Terminal/Other %	Age of Carer	18-39 %	40-64 %	65+ %
Department of Human Services (formerly Centrelink)	46	54	53	39	54	44	46		45	46	47
Department of Veterans Affairs	10	8	8	12	7	14	9		8	10	12
National Disability Insurance Scheme	5	8	8	7	5	4	5		8	4	3
Carers Australia	13	16	20	18	17	11	14		14	12	11
State Health Departments e.g. QLD Health	13	13	14	15	17	15	16		15	12	11
Commonwealth Respite and Carelink Centres	13	16	19	16	15	16	15		13	15	10
Some other State Government website	11	9	15	14	13	10	14		14	11	6
My Aged Care	8	8	10	11	10	15	14		6	10	8
State Carers Association e.g. Carers NSW	8	9	14	16	11	7	7		9	8	6
Young Carers	4	5	6	9	4	4	6		8	2	1
Aged Care Rights Service	4	4	6	11	7	5	9		3	4	3
Working Carers Gateway	3	3	6	6	3	3	5		6	2	1
Sample size	1205	403	374	98	316	430	144		298	609	298

Base: All carers, n=1205

Q. Have you heard/used of any of the following websites that have information, services or support for carers?

Current access to information, services and support

Support groups were widely accessed by carers with views and experiences mixed, some carers found making connections through support groups with other carers as very helpful. Others felt that support groups were 'not for them' because of the stigma and the negativity around 'group therapy'. Carers who found a support group which was relevant to them and the condition of their care recipient were very positive.

- "It's nice to know other people are going through the same thing and not only happening to yourself." (Young Carer)
- "A carer support group is something that I would participate in, not on a weekly basis, but if it was once a month or an online forum then definitely. Especially because I am young as well, like I am 23, there are not many people my age that can empathise with my family situation." (Young Carer)
- "Just helps come to grips with what is happening and again feel like you are not on your own and other people who have gone through those issues that you've had being able to help you see a way through it." (Disability)
- "Carer support groups are full of parents who have quite a victim kind of, "The world's against us," and, you know, "My life's been ruined by caring responsibilities," and that kind of stuff turns me off, and having morning teas with carers, or having a ladies day out is just (not right for me)." (Disability)

Awareness of other carer support services was varied amongst carers, from 7 in 10 being aware of respite care down to only 1 in 4 indicating recognition of employment support for carers (Table 19). Although awareness of this last support channel was even lower amongst the oldest carers (aged 65+), they demonstrated a higher than average recognition for the top three services: respite care (84% vs. 70% overall), home help or domestic assistance for carers (80% vs. 63% overall) and personal/nursing care (74% vs. 64% overall).

Table 19: Awareness of other carer support services

Condition of Care Recipient:	Total %	Disability %	Mental illness %	Alcohol/ drug %	Chronic illness %	Aged and frail %	Terminal/ Other %	Age of Carer	18-39 %	40-64 %	65+ %
Respite care [^]	70	69	68	54	72	79	76		53	76	84
Personal/Nursing care	64	64	57	57	65	76	81		51	70	74
Home help or domestic assistance for carers	63	61	55	50	64	72	74		52	65	80
Support from other carers or other social groups	47	46	53	36	44	43	54		48	47	45
Counselling services for carers	46	48	53	43	46	46	48		44	48	47
Meal services for carers	45	42	41	43	41	53	54		39	47	51
Training and education for carers	31	32	35	32	29	32	40		35	29	28
Support to keep carers employed	25	26	25	27	26	22	28		32	23	17
Sample size	1205	403	374	98	316	430	144		298	609	298

Base: All carers, n=1205

Q. What other carer support services are you aware of to help you in your caring role?

[^]Respite care - also known as 'short-term care' - is a form of support for carers. It gives carers the opportunity to attend to everyday activities and have a break from the caring role. Respite care may be given informally by friends, family or neighbours, or by formal respite services.

Current access to information, services and support

Some carers were positive about respite whereas others struggled to see how respite would help given the high dependency placed on them by the care recipient. Requirements to obtain respite were often impractical, particularly given the significant planning required, which on occasion deterred carers. Some carers in the research found it challenging to identify nearby respite facilities and were required to contact numerous services and undergo multiple assessments in order to find an appropriate facility.

- *"You have to put in notice three months in advance for respite...I mean how do you know you're going to stub your toe and have to go to the doctors or you're in hospital three months in advance?" (Disability)*

For some carers respite services had proven valuable as it offered the carer a break and an opportunity for the care recipient to engage with other people. Respite was most effective when the objective went beyond 'having a break', there were examples where peak bodies (such as Alzheimer's Association) delivered weekend retreats for couples to learn about managing Alzheimer's.

- *"The week away was fabulous, a change of scene in a nice location...but one that is safe for my husband to walk around...he can't walk off and it is set-up so it is safe for him. They provided you with a room and you still cared for your husband but the meals were all done and they provided lots of information sessions...one was on the law and guardianship, one was on the services that are available and one was on the equipment that can help you." (Aged and Frail)*

Accessing respite services also proved challenging due to variability in the quality of the respite provided.

- *"We were also betrayed by one of them. She told us lies. She claimed she'd spent the entire day at the local playground when it was raining. You are putting your faith in someone you don't know." (Long-Term Illness)*

Carers from CALD backgrounds stated that they relied mostly on other family members rather than formal respite services to give them a break from the daily grind. This was partly due to the lack of awareness of suitable respite options, the lack of 'cultural competence' in the service system (e.g. carers from same cultural and language backgrounds not available) and partly due to the stigma attached with accessing external (to the family) support services. In other cases, the shame and guilt associated with disability meant that such respite services were not sought after at all.

- *"My two sisters share the weekend care to give me a break to be with my family" (Greek carer, Mental Illness)*
- *"I think there are a lot of families that are suffering significantly because they are too worried about the rejection from society of being bad parents" (Vietnamese carer, Substance abuse)*

Current access to information, services and support

With regards to awareness of particular respite services (Table 20), more than half the sample (52%) had heard of residential respite care in an aged care home; not surprisingly this rose to 64% amongst providers of aged care and to 69% for carers over the age of 65. A similar overall proportion of just under 1 in 2 respondents (46%) had heard of in-home respite care, while recognition of weekend and holiday programs and opportunities was higher amongst mental illness care providers (33%) than average (26%).

Table 20: Respite services carers have heard of

Condition of Care Recipient:	Total %	Disability %	Mental illness %	Alcohol/drug %	Chronic illness %	Aged and frail %	Terminal/Other %	Age of Carer	18-39 %	40-64 %	65+ %
Residential respite care in an aged care home	52	48	51	45	54	64	59		38	56	69
In-home respite care	46	47	47	42	54	49	53		42	47	54
Recreation activities in the community	39	38	40	31	41	45	43		37	38	50
Residential respite care for younger people with an illness or a disability	36	36	37	33	35	37	41		26	41	39
Types of respite that may be available in your area	32	33	34	32	31	39	43		27	34	41
Day care programs for carers	28	24	32	28	26	32	34		24	29	35
Weekend and holiday programs and opportunities	26	25	33	26	20	27	29		25	27	24
Sample size	1205	403	374	98	316	430	144		298	609	298

Base: All carers, n=1205

Q. Have you heard of any of the following respite services for carers?

Although more than half of all respondents had heard of respite services, just over 1 in 10 (11%) had used any in the past 12 months (Table 21).

Table 21: Use of respite services in the last 12 months

Condition of Care Recipient:	Total %	Disability %	Mental illness %	Alcohol/drug %	Chronic illness %	Aged and frail %	Terminal/Other %	Age of Carer	18-39 %	40-64 %	65+ %
Used respite services	11	16	13	16	12	14	10		12	11	8
Sample size	1205	403	374	98	316	430	144		298	609	298

Base: All carers, n=1205

Q. Have you used any respite services in the last 12 months?

Current access to information, services and support

Of those who had used such services (Table 22), the most popular was home care or help, with just over a quarter (27%) having accessed this type of support. This proportion was 61% amongst the n=41 carers providing care to someone with a chronic illness.

Table 22: Respite services used *in the last 12 months*

Condition of Care Recipient:	Total %	Disability %	Mental illness %	Alcohol/drug %	Chronic illness %	Aged and frail %	Terminal/Other %	Age of Carer	18-39 %	40-64 %	65+ %
Home care/help e.g with housework, cleaning	27	29	23	34	61	22	28		35	26	9
Other home specified e.g Montefiore, Sunnyfield	10	5	18	4	6	14	2		0	12	35
Respite Care (general)	7	9	8	0	0	10	5		9	6	6
Aged care respite/respite at an aged care facility/home	6	1	4	9	2	9	2		3	8	4
Commonwealth/Commonwealth Care respite	5	2	6	11	4	6	6		8	4	3
Time in respite specified e.g 4 hours fortnightly	5	7	10	0	6	5	15		5	4	12
Disability respite	3	8	1	0	0	1	4		0	7	0
Local council/council respite	3	4	4	1	5	4	0		0	6	2
Day care	3	0	5	0	2	3	9		2	1	12
Anglicare	2	0	1	0	2	3	3		0	2	4
Silver Chain Respite home	2	3	0	0	0	0	19		3	0	4
Sample size	152	72	62	12	41	63	23		30	93	29

Base: Those who have used respite services n=152

Q. What respite services have you used?

*Caution: Small sample sizes

5. Developing and marketing the national carer gateway

Key insights

- Carers were seeking both **emotional** and **practical** support to assist them in providing ongoing quality care.
- Carers described **emotional support** as being able to talk to someone who could reassure them that they were doing the right thing or offer suggestions on how to approach the provision of care.
- **Practical support** involves relief from household and other duties that prevent the carers from fulfilling their caring responsibilities.
- Carers required a service that addressed both their needs and the needs of the care recipient.
- There were different needs depending on where carers were in the caring journey. At the beginning of the caring journey, the focus was usually on organising and getting key aspects in place. Carers recognised that different or additional support would be needed in the future, particularly as circumstances change (e.g. care recipients growing up and leaving school, aged and frail care recipients becoming less mobile).
- Findings from the survey among carers showed that support from family and friends will continue to be a key requirement for carers (83%), the second most important aspect was better services for the care recipient (82%) followed by planning ahead to make sure they are covered in an emergency (80%).
- Most carers would either definitely or be very likely to access the national carer gateway, via the website (57%) or service finder (51%). There was lower likelihood of carers accessing the phone line.
- The research identified the following **key selling points of the national carer gateway**:
 - Ease burden of accessing information, support and services simply and efficiently.
 - Assistance and guidance in navigating the government services.
 - One stop shop for all information, support and services for carers and care recipients.
 - Service built specifically for carers
 - Delivered by professionals.
- The research identified the following **barriers to accessing the national carer gateway**:
 - Carers are busy and have no time to access the service.
 - Concerned that the service would not offer anything specific to their situation.
 - Given the challenges most carers faced when accessing and navigating government services there was hesitation that the national carer gateway would follow a similar experience.
 - Service would be delivered by inexperienced people.
 - The national carer gateway would refer carers to many services without providing a direct linkage
- Google search (56%) and health professionals (55%) were considered the most preferred channel for information about the national carer gateway.

Based on the Qualitative feedback, appeal and preference were strongest for two of the names; Carer Network and Care for Carers.

5.1 What information, support and services do carers need?

Carers were seeking a central service which could provide them with all the information about what services were available for the care recipient and themselves. Carers in the research knew there were services available or had heard support could be provided but were not sure how to gain access.

- *"Going to one place where you can get all the information rather than getting all different types of reports." (Disability)*
- *"What would be nice to know is just what was available, what was out there, what information was out there, I didn't know what questions to ask, I still don't really probably know what questions to ask." (Disability)*

Carers were asked the research to indicate the information, support and services they needed to fulfil their caring responsibilities. Generally, carers struggled to articulate their needs primarily due to their focus on the care recipient and their view that there was minimal tailored carer support available. Following prompting and further discussion, the following needs were identified.

Carers were seeking both emotional and practical support to assist them in providing ongoing quality care.

For carers, **emotional support** consisted of guidance around the approach to their caring role. Carers described this as being able to talk to someone who could reassure them that they were doing the right thing or offer suggestions on how to approach the provision of care. This was particularly important if the caring role came about due to a sudden event or change.

- *"Someone to go and talk to at first, because if you start at that base you can deal with things emotionally. Because your world comes crashing down. I didn't have family here, my ex-husband was gone, I was on my own, so it was hard - and I found there wasn't any help." (Disability)*
- *"Give them as much support as we can, with counselling, and then tell them what other services they could source. Basically help for their personal health and help for them to look after and care for someone else." (GP, Melbourne)*

Practical support involved relief from household and other duties that prevent the carers from fulfilling their caring responsibilities. Most often, this consisted of cleaning, cooking and assistance with transporting the care recipient to specialist appointments.

- *"It sounds funny, but things like food, meals, so that your attention could be focused on the hospital, the caring." (Disability)*
- *"Things like transport, doctors' appointments from time to time. I can do that now but there are times when it would be good if that could be incorporated." (Aged and Frail)*
- *I try to help them as much as I can by reducing their workload" (GP, Regional Victoria)*

Developing and marketing the national carer gateway

Carers required a service that addressed both their needs and the needs of the care recipient.

Help for the care recipient and easy access of services are integral to supporting the carer, as this was key to relieving the pressure and stress of caring. The different types of services and support required for the **carer** were:

- **Advice about what to expect in the caring journey**, for example a 'road map' to help them understand what to expect in the future.
 - *"When I was looking for early intervention, you're getting stuff that was for adulthood when you're looking up stuff. Yeah I need that but in 20 years time"* (Disability)
 - *"Nobody sort of said anything about you have now a different role in life"* (Aged and Frail)
 - *"You could put in age groups, you could put in even the individual types of disabilities too so they can identify and find, from a database, pull up everything and give you what's relevant"* (Disability)
- **Practical advice and training on key caring tasks** and how to approach certain situations. This included specific information and training related to the care of an individual (e.g. showering and lifting).
 - *"When I first took over I needed help in what to do, like how to bath him, how to feed him, how to dress him. He's a grown man it's not like he's a little baby."* (Disability)
- **Respite services** and options that allow the carer to have some time out.
 - *"Someone to change her bed and clean the room. Somebody to sit with her for a couple of hours and keep her company. Maybe someone who had Mum as a particular part of their case load and would come once a week just to check up and see how everything is going...It would take a little bit of that pressure off...all that responsibility is on you."* (Aged and Frail)
- **Considering the carers own health** both from a mental and physical health perspective. This may involve, potentially seeing a counsellor if needed or seeking professional counselling to discuss experiences and bounce around ideas:
 - *"I just think that I might need someone that I can go and see if I'm having a hard time and just go 'okay, you know, can I bounce some ideas off you, what do you think, where do you think we should go?'"* (Mental Illness)
- Listings of service providers in local area
 - *"I'd love to have an accessible carer centre, that I know when I walk in that door and ask for something that I require for the caring role ...I will get it."* (Disability, Mental Illness, Aged and Frail)

Developing and marketing the national carer gateway

The support required for the carer directly related to the **care recipient** are:

- **Condition specific information** is important, particularly immediately following diagnosis and also to increase the carer's knowledge about the condition of the care recipient.
 - *"Being a condition we have never ever heard of before, just even information on that condition." (Disability)*
 - *"With mental health, they are wanting to understand the illness and ways of responding. Is the behaviour the illness? Or drug and alcohol related?" (Social worker, Regional Western Australia)*
- **Access to the best services available for the care recipient** from service providers, peak bodies and charities, to know what services are available for different stages and age groups.
 - *"It would have been good if everything had actually connected up...there was the early intervention and that was going to go up to a certain age, and then after that it dropped out and I was like who do I talk to now?" (Disability)*
 - *"Today, I still don't know what is out there and how I can get information." (Chinese carer, Disability)*
- Government information (e.g. Centrelink, National Disability Insurance Scheme, My Aged Care) was required to understand what benefits, allowances and services can be provided and how these can be accessed.
- Recreational activities to assist with the care recipient socialising and also relieving burden on the carer.
 - *"If we could go to a swimming lesson, and someone got in the pool with my son, so that I could sit there and have a cup of coffee like all the other parents are doing, just sitting on the edge, cheering on your kid and taking photos, and being like, 'Yeah, you had a good swimming lesson'." (Disability)*
- Education around early intervention and information as the care recipient is going through a transition such as moving into school.
 - *"For me, I just think if we could have someone that is there to help us around the issue of the transition from school to work for my son. What are we going to do to help you progress into that next stage of life? Because for me the level of caring could go up, especially if he cannot transition into the workforce, he will be at home 24/7 and the level of care will go up." (Mental Illness)*

There were different needs depending on where carers were in the caring journey.

At the beginning of the caring journey, the focus was usually on organising and assistance with this would be helpful. This assistance would come in the form of someone who can direct carers quickly and efficiently towards all of the support that the care recipient and carer need.

- *"I was working too it was like getting him to counselling and basically getting him organised. When he first moved in and all organised I was so used to just coming and going and now I had to think about my son" (Disability)*

Developing and marketing the national carer gateway

There was also a recognition around a future need for information and support particularly as the condition of the care recipient changes or deteriorates. These changes may require different types of support and assistance that potentially the carer was unable to provide and external support may be required.

- *"I'm pretty new at it so I'm going to assume that in the next couple of years I might need that support...he will be with me forever, so that's a big learning curve for me" (Disability)*
- *"They finish school...what do we do then? I guess it's just a bit scary... what will they do next?" (Disability)*
- *"At the time I was relieved to think that wow, there is a reason for this, it's not us, it's not bad parenting or anything we've done, I felt relieved at the beginning but I still feel very sad now though because I feel I don't know what the future holds." (Mental Illness)*

Furthermore, some carers realised that in the future they may be **unable to continue with full time care** particularly as they themselves were ageing and becoming less capable of caring. However, for the most part, they tended to avoid thinking about it and also found it hard to predict what might be needed until an unexpected change in circumstance occurs.

- *"I have no idea...I'm very much a day by day person. I don't know what will happen." (Terminal Illness)*
- *"What if something happens to me? What if I have a heart attack? What is going to happen to her... Something saying if something happens to me, that is what will happen to my recipient. Some plan or something." (Aged and Frail)*
- *"As my mother gets older and requires help in later life, I am already planning to use government agencies that can assist us with ongoing care in the home environment." (Greek carer, Terminally ill)*

Future **financial concerns** were a key focus for carers particularly for carers who were limiting their paid work to provide care.

- *"Takes time away from earning money and I have to get someone to look after my wife if I have to go to an interview. The red tape, it just kills you. The system sucks. They just let you down." (Disability)*
- *"I would like assistance with greater financial support, respite care, community organisations and other services that may be of assistance to me to help offload the stress of caring for my son for such a long time." (Italian carer, Disability)*
- *"Because you have to work less and less to help them." (Aged)*

Developing and marketing the national carer gateway

Aboriginal and Torres Strait Islander carer needs

Aboriginal and Torres Strait Islander carers viewed their caring role as differently. All the carers interviewed had caring roles that were relentless and continual across multiple family members of different ages and with different needs.

- *“It’s just what I always been doing. Who else would look after this mob? Just when you think ‘maybe, just maybe it’s easing off a bit’, slam! Another scam and back into rehab. And who looks after the grannies then? ‘Course we do. It’s just never ending but” (Aboriginal carer, Disability)*

A major concern for the future was fear for younger children as no alternate caring option was known or in place. This also highlights the difficulty in Aboriginal carers accessing support services when they feel that there is an attendant risk in being viewed as incompetent or not appropriate (with the associated fear of child removal or government intervention in family matters). This was typified by the following comment from one carer:

- *“I don’t know what I’d do if the DoCS took the kids! I just gotta keep strong for them.” (Aboriginal carer, Disability)*

Culturally and Linguistically Diverse carer needs

The needs for information, support and services among CALD carers were similar to the mainstream carers consulted. One key difference however is the evolution of caring responsibilities in CALD families. The first generation carers believe that the Australian-born second generation may have a different approach to the nature and extent of care they are willing to provide. Some CALD carers (Lebanese, Italian and in the future Greek) stated that their own children may not be prepared to make the same sacrifices that they themselves did. They also stated that these same children having been raised in Australia would have a greater level of understanding of the health service system and be able to navigate it more effectively with respect to accessing suitable services to suit the family’s care needs.

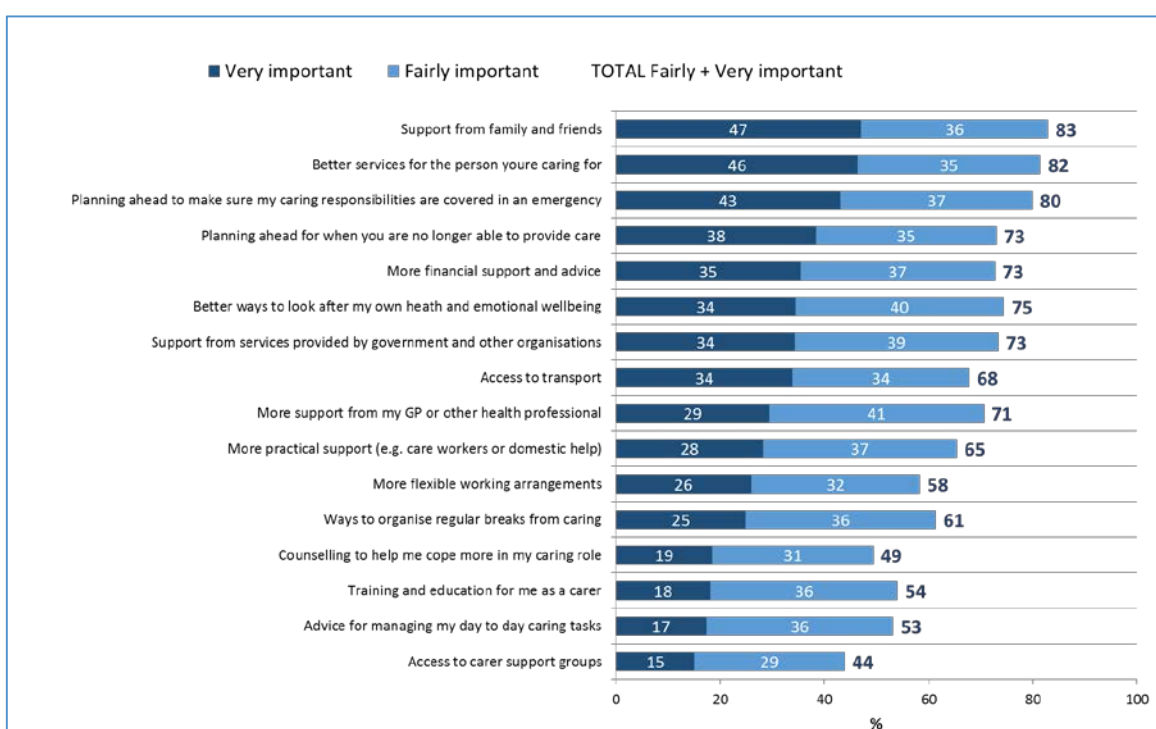
- *“As we learn that our own families can only do so much, we will require help and the types of services out there to manage our situation better. There is no solution other than that” (Greek carer, Terminally ill)*

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Findings from the survey among carers showed that support from family and friends will continue to be a key requirement for carers emphasizing the importance of the family network for carers (Figure 5). The second most important aspect was better services for the care recipient (82%) followed by planning ahead to make sure they are covered in an emergency (80%). Out of the 16 information, support and services listed, over 70% of carers viewed the following as important:

- Support from family and friends (83%)
- Better services for the person you're caring for (82%)
- Planning ahead to make sure my caring responsibilities are covered in an emergency (80%)
- Planning ahead for when you are no longer able to provide care (73%)
- More financial support and advice (73%)
- Better ways to look after my own health and emotional wellbeing (75%)
- Support from services provided by government and other organisations (73%)
- More support from my General Practitioner and other health professionals (71%)

Figure 5: Importance of information, support or services



Base: All carers, n=1205

Q. How important to you are each of the following types of information, support or services to help make your role as a carer easier?

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For the information, support and services carers viewed as important they were then asked to indicate if they knew how to access these services (Table 23). Less than 50% of carers knew how to access 12 of each of the 16 areas, indicating that while carers knew they needed the service most were not aware of how they could access these services.

Table 23: Knowledge regarding how to go about getting types of information, support or services

Condition of care recipient:	Total %	Disability %	Mental health %	Alcohol/ Drug* %	Chronic illness %	Aged care %	Terminal/ Other %	Sample Size n
Support from family and friends	75	71	72	60	75	73	84	1016
Better services for the person you're caring for	44	41	45	51	42	49	52	993
Planning ahead to make sure my caring responsibilities are covered in an emergency	46	42	48	51	48	46	59	981
Planning ahead for when you are no longer able to provide care	44	40	50	57	49	42	50	913
More financial support and advice	33	34	34	34	34	32	33	866
Better ways to look after my own health and emotional wellbeing	54	49	63	57	49	51	61	889
Support from services provided by government and other organisations	45	42	49	41	44	44	50	904
Access to transport	57	52	58	63	57	55	62	796
More support from my GP or other health professional	66	61	65	61	65	67	77	870
More practical support (e.g. care workers or domestic help)	45	41	45	40	45	50	56	804
More flexible working arrangements	47	41	50	54	47	46	51	651
Ways to organise regular breaks from caring	45	43	49	38	46	45	51	757
Counselling to help me cope more in my caring role	48	44	58	58	56	43	57	582
Training and education for me as a carer	34	34	39	47	28	33	38	643
Advice for managing my day to day caring tasks	44	43	53	43	47	42	43	621
Access to carer support groups	47	39	57	62	48	48	49	527

Base: Those who gave each a rating of Fairly or Very important for the following types of information, support or services.

Q. Do you know how to go about getting this support?

*Caution: Small sample size

5.2 How was the national carer gateway received?

In both the survey and qualitative research carers were shown a brief description of the national carer gateway, as follows:

- *"The Australian Government is developing a new service to provide information and support for carers. The service will include a telephone helpline and website. The website will include a tool to help you find relevant services, support and information"*

The concept was well received by most carers in the research indicating they would access one element or multiple elements of the service. The perceived benefit of the national carer gateway was seen as easing the burden of time and effort on carers to access information, support and services. Health professionals in the research also saw the value and would be willing to recommend the service.

- *"I think this is a really good concept. Sounds like a one stop website. I think it would also be a good source doctors can use to refer carers to."* (GP, Regional Victoria)
- *"It's a good idea."* (Aged and Frail)

There was a strong need for expert guidance to navigate the national carer gateway and the information, support and services available.

Carers were looking for an expert to help them navigate the system as most were currently accessing limited services and found it difficult to locate relevant services. The website was not viewed as 'enough' without the phone line which should be delivered by agents who were knowledgeable about caring and the support that can be provided to the care recipient. Carers suggested 'expert guidance' could be delivered through a number of ways including:

- Case manager: An experienced professional who works for the national carer gateway and can take ownership of the carer's issues.
- Online chat function: To help direct to relevant information when on the site. Carers find this functionality effective in getting to the information they are seeking.
- Phone line: Easy and quick access to an expert carer or professional that could quickly and efficiently provide relevant information, support and services.
- Warm-referrals and follow up: Carers were looking for direct linkages to services rather than a list of services for them to call themselves.

Carers were looking for a tailored service that contained information relevant to them and their caring responsibilities.

Carers in the research were positive about the 'tailored' aspect of the service. Many noted that their situations were complex and the information, support and services they required was different to other carers. Having a service which is built for carers and tailored to their situation was seen as a key driver of accessing the service.

- *"Most things are tailored for the patient and the carer is just seen as this person in the shadows. Nobody ever asks us or talks to us. So the tailored for carers, that is the part that is important...just to be treated as part of the whole process rather than someone in the background."* (Aged and Frail)
- *"There could be more personalised services for the cohort you are working with, tailored for specific needs such as Aboriginal carers, rather than one model fits all"* (Social worker, Regional Western Australia)

Developing and marketing the national carer gateway

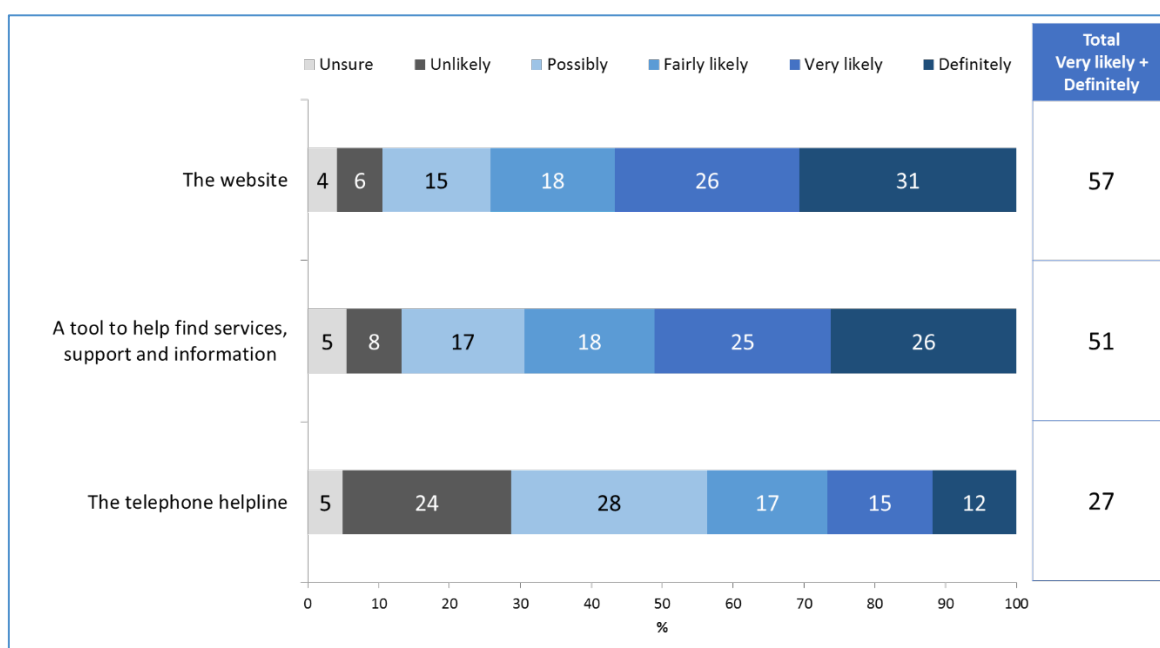
Findings from the survey (Figure 6) show that most carers would either definitely or be very likely to access the service, via the website (57%) or service finder (51%).

There was lower likelihood of carers accessing the phone line, while the phone line was seen as a critical component, carers were concerned about how this would be delivered effectively.

The phone line generated significant debate among carers in the research, some viewed this as a key element whereas others felt that the negative experience from other government managed phone lines would deter them from accessing the phone line. Carers outlined a number of key requirements for the phone line which included reduced waiting times, professional staff and ideally staff experienced in caring.

- *“They have to be skilled and knowledgeable.” (Aged and Frail)*
- *“With the phone number, hopefully they can man it properly, because most of the time there’s a phone number but the information that they get from that is not as good. Half the time they don’t know what they’re talking about.” (GP, Melbourne)*
- *“Do they actually understand? Is this someone that’s just reading from a textbook to answer you or is it somebody who’s actually got some information on the subject.” (Disability)*

Figure 6: Likelihood to access the service



Base: All carers, n=1205

Q. The Australian Government is developing a new service to provide information and support for carers. The service will include a telephone helpline and website. The website will include a tool to help you find relevant services, support and information. How likely would you be to use the components?

Carers definitely or very likely to access the service indicated the main reasons why they would access (Table 24). The main reason was to get information and ask questions (63%), get support, assistance, help and advice (27%), obtain skills and knowledge (22%) and because the services would be convenient and easy to access (20%).

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Table 24: Reasons carers would definitely or be very likely to use the service

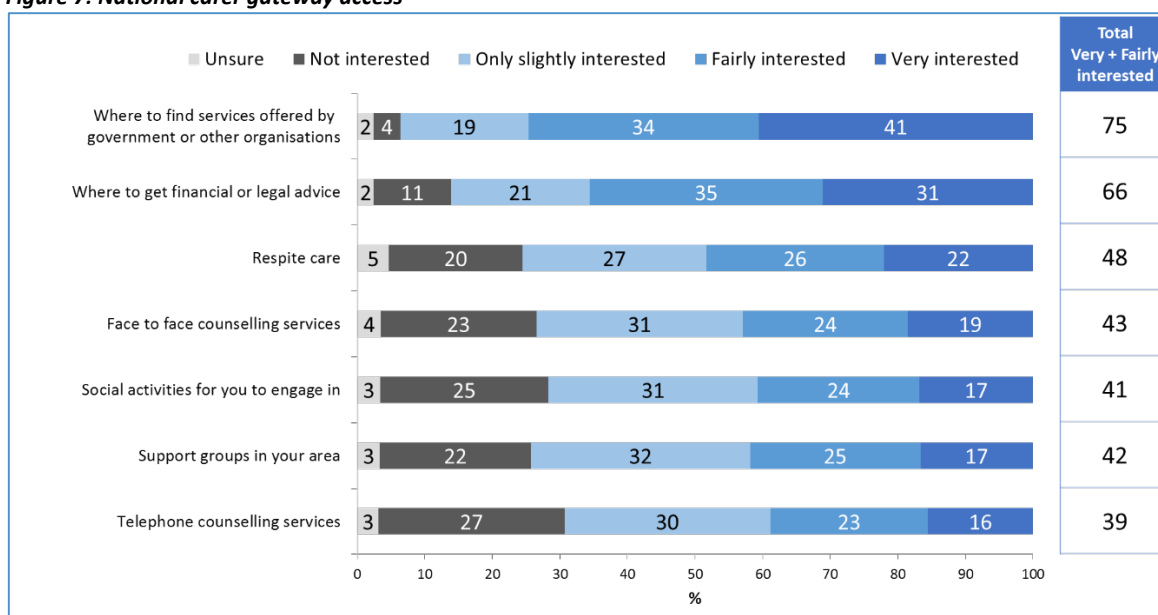
Condition of Caree	Total %	Disability %	Mental health %	Alcohol/ Drug* %	Chronic illness %	Aged care %	Terminal/ Other %
Get information and ask questions	63	65	63	64	64	63	60
Get support, assistance, help and advice	27	30	30	36	26	26	21
Obtain skills knowledge	22	25	25	24	20	25	25
Convenient and easy to access	20	22	19	12	19	20	17
Be aware of resources and services available in local area	13	14	11	10	11	14	11
Be a better carer and make sure I am doing the right thing	8	9	9	13	5	10	12
Sample size	775	267	256	55	202	298	99

Base: Carers who would definitely or be very likely to use the service, n=775

Q. What would be your reason for using the service?

The service finder tool was a key component of the national carer gateway and carers were asked in the survey how interested they were in using the tool for accessing a range of information, support and services (Figure 7). The majority of carers were either fairly interested or very interested in locating services from government or other organisations (75%) and obtaining financial or legal advice (66%). Carers were less interested in accessing telephone counselling services (39%), social activities (41%) and support groups in the local area (42%).

Figure 7: National carer gateway access



Base: All carers, n=1205

Q. The website will also include a service finder tool to help you find support and assistance. How interested would you be in using a service finder tool for each of the following?

Developing and marketing the national carer gateway

Those caring for someone with disability were more interested than other groups in where to get financial or legal advice (73%) (Table 25). Those caring for someone with a mental illness were more interested than other groups in counselling either face to face (57%) or over the telephone (48%).

Table 25: Carers who are fairly or very interested in using an online service finder tool

Condition of Care Recipient:	Total %	Disability %	Mental illness %	Alcohol/ drug %	Chronic illness %	Aged and frail %	Terminal/ Other %	Age of Carer	18-39 %	40-64 %	65+ %
Where to find government/other organisation services	75	80	72	59	78	78	81		61	80	85
Where to get financial or legal advice	66	73	65	58	68	69	62		62	71	57
Respite care	48	50	48	48	51	57	49		47	50	48
Face to face counselling services	43	46	57	52	45	39	44		49	41	36
Social activities for you to engage in	41	48	47	41	42	37	42		48	39	30
Support groups in your area	42	49	49	41	43	40	36		45	40	40
Telephone counselling services	39	44	48	37	38	38	37		44	38	32
Sample size	1057	356	324	83	283	385	128		252	542	263

Base: Those who would at least possibly use the online tool, n=1057

Q. The website will also include a service finder tool to help you find support and assistance. How interested would you be in using a service finder tool for each of the following?

The majority of carers preferred to access the service through reading on the website (82%), this was followed by online video (45%) and the telephone helpline (40%). Carers aged 18-39 were more likely to be interested in access through mobile application (43%) and online chat (41%).

Table 26: How carers would like to get information and advice from the service

Condition of Care Recipient:	Total %	Disability %	Mental illness %	Alcohol/ drug %	Chronic illness %	Aged and frail %	Terminal/ Other %	Age of Carer	18-39 %	40-64 %	65+ %
Reading it on the website	82	79	84	77	81	88	85		78	86	81
Online videos	45	47	47	46	43	48	43		47	44	42
Telephone helpline	40	40	43	45	40	48	45		38	41	39
Apps	34	35	36	37	34	32	32		43	34	15
Online chat	29	33	35	43	27	29	29		41	26	15
Video consultation	17	22	20	21	16	19	16		22	17	11
Sample size	1205	403	374	98	316	430	144		298	609	298

Base: All carers, n=1205

Q. How would you like to get information and advice from such a service?

Aboriginal and Torres Strait Islander carer feedback

Reactions to the national carer gateway concept for the service was not positive. This appeared to be primarily a result of disillusionment with multiple “government” actions and programs over their lives that were not aimed at Aboriginal people or did not have any element which addressed the needs of Aboriginal people.

- *“Why would I call a number and talk to some (whitefella) in Canberra? Or are they going to get someone in India to try and understand what we’re dealing with in this country?” (Aboriginal carer, Disability)*

There was agreement from the carers that more information should be provided but there was no trust in the ways this information would be delivered. Common to all the carers was a desire for a person to meet with them and *“explain all this stuff”*. Generic phone numbers and service finder applications would not be called even in emergency situations as they were perceived as *“government talk”* or *“they just send you back to the same places already been”*. Websites were regarded as *“great for young ones”* or *“people rich enough to have a computer”* but they were not an information source used by these carers.

Culturally and Linguistically Diverse carer feedback

The **telephone helpline** was very well received as it is readily accessible, *‘easy to use’* and *‘you can talk to a real person that can provide information and answer questions’*. These carers were used to telephone helplines as this was a common service delivery model. What they liked about this component included: it was provided by *‘experts’* who could help and support; it was a source of authoritative information; *‘just about everybody had a phone’*; and it was *‘free’*. Two of the carers questioned whether the telephone service operated in their preferred language (Lebanese, Chinese).

The **service finder** was also very well received given the importance of accessing *‘local’* services that carers could easily get to and have some potential familiarity with. It was also felt that this would *‘save carers a lot of time and running around’*. CALD carers felt it was important to know what support might be available to them, even if they may not necessarily seek it out or use it. They felt somewhat empowered by *‘knowing what was out there’*.

Critical to the provision of help and support for carers was accurate and authoritative **information**. They stated that the information needed to be empathetic and understand *‘what they were going through’* (e.g. time poor, stressed out, emotionally drained) in order for it to have the right tone and for the message to get through. They liked the idea that the information would be *‘tailored’*, given the inherent differences in care circumstances and the demands this created (e.g. caring for someone with dementia was different to looking after a frail older person)

The **website** component was also supported and again carers suggested that this mode of information and service delivery was commonplace. Some asked whether information in their preferred language would be included among the content online. What they liked: its ease of access at any time of the day; and that all of the information was in *‘one place’* (the national carer gateway concept). Some were less positive as they did not have internet access and felt that this was for younger, computer literate people.

5.3 Use case examples for the national carer gateway

Below are examples of potential use cases for the Gateway.

Mental Illness

Kay, aged 45, lives in regional Victoria and cares for her 18 year old son Matthew. Kay and her husband have had a very difficult 4.5 years attempting to get a diagnosis for Matthew after his behavior became erratic in his teen years. Matthew was recently diagnosed with schizophrenia following a severe psychotic episode. Kay and her husband have found it difficult to maintain regular employment and retain their social networks due to the time pressure and stress associated with caring for Matthew.

Main challenges

Getting a diagnosis, emotional impact on the carer and the whole family.
Social isolation and carer's own mental health issues (depression) caused by stress of the caring role.

Current experience accessing information, support and services

- Focus has been on support required for the care recipient.
- While waiting for a diagnosis, was "handballed" from one organisation to another.
- Case worker providing emotional support, advice and information about support.

Needs

A break, emotional support and knowledge of where to go to get help for care recipient.

How the national carer gateway can help?

- Centralised database that makes it easier to find what is available for carer and care recipient.
- Access to someone who can advise her on how to get the support needed for the care recipient. Important that they would be able to take on some of the workload of finding the support, rather than just referring the carer to numerous other organisations to follow up.

Aged and Frail

Jenny is in her late 40s, caring for her parents who are in their 80s. The level of care required increased 6 months ago after her mother had an emergency hip operation and is now having more trouble getting around at home. Jenny's father is more mobile than her mother, but is not able to solely maintain all of the tasks around the house.

Main challenges

Emotional stress of having to watch a loved one deteriorate.

The pressure to take on all caring responsibilities and trouble balancing daily tasks.

Current experience accessing information, support & services

Limited access for themselves due to obligation to care for family herself.

Experiencing resistance from care recipient when trying to use services.

Receives a Carers Allowance.

Home Care come once a week.

Needs

- Counselling, support groups, or some form of emotional support.
- Education on how to move and bath care recipient when they lose mobility.
- Advice on transitioning care recipient to paid carers or into a nursing home.

How the national carer gateway can help?

Contact with someone who can offer advice on what to expect, and how to handle situations – it is important that this person is experienced and empathetic.

Providing access to local services for both carer and care recipient and saving time

Disability

Andrea is in her mid-30s and has 3 children. The family moved to Brisbane from Canberra 12 months ago and her oldest child has since been diagnosed with Autism Spectrum Disorder. Andrea has transitioned away from work in order to be able to provide full-time care for her children.

Main challenges

Lack of easily accessed support.

Adjustment to having to leave the workforce and no time for self-creating stress on relationship.

- Planning beyond Early Intervention programs.

Current experience accessing information, support & services

- Good quality, long term support that is tailored to the care recipient is difficult to find.
- Spent significant time trying to find and access services that care recipient is eligible for.
- Support networks accessed are localised, community based or online.

Needs

- Activities for the care recipients that provide the carer with respite.
- Direction on how to navigate the system.
- Services to enable her to transition into the workforce (by looking after care recipients).

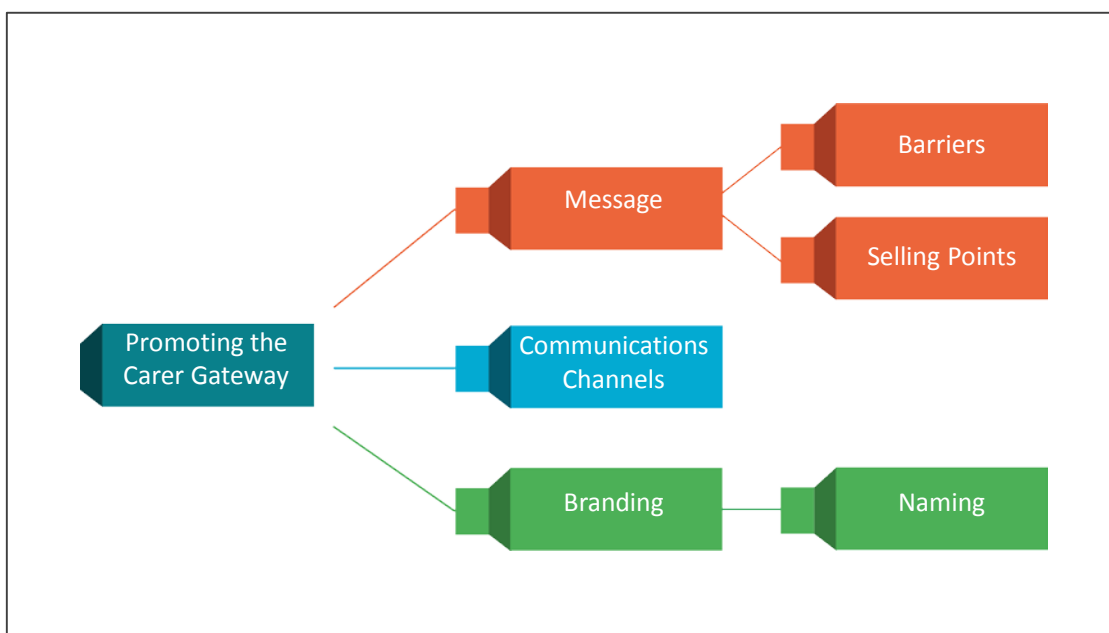
How the Gateway can help?

- Looking for 'active referrals' to services i.e. helping carers make the connections with the relevant support services.
- Someone to call when struggling to cope and feeling overwhelmed.

5.4 How can the national carer gateway be promoted?

The research with carers provides insights to inform the promotion of the Gateway. The diagram below outlines the different aspects of the communication and promotion strategy which the research can inform. The insights relating to each component are summarised in this section.

Figure 8: Gateway promotion



5.4.1 Marketing messages

The research identified a number of key selling points and barriers to accessing the service. While generally most carers would access the service and felt the service would assist them in their caring role, there were a number of barriers also mentioned. The table below summarises both the selling points and barriers to accessing the Gateway.

Table 27: National carer gateway selling points

Selling points
The national carer gateway can ease the significant burden associated with accessing information, support and services simply and efficiently.
Assistance and guidance in navigating the various government and other services care recipients and carers need.
One stop shop for all information, support and services for carers and care recipients.
Service built specifically for carers and their requirements for information, support and services.
Delivered by professional people who can discuss their situation and provide advice on the best course of action.
<i>"I like it. Because you might only know about that service, and that service might only do so many things. Whereas there's a service down the road that you can get more, other support from them." (Mental Illness)</i>

Developing and marketing the national carer gateway

Table 28: National carer gateway barriers

Barriers
Carers are time poor, are very busy looking after the care recipient and would not have time to access the service.
Carers viewed their individual situations as complex, unique and very different to other carers. Carers were concerned that the service would not offer anything specific to their situation.
Given the challenges most carers faced when accessing and navigating government services there was hesitation that the national carer gateway would offer a similar experience, particularly the phone service.
Some carers questioned whether or not the service would be delivered by inexperienced people or experts in care.
The national carer gateway would refer carers to many services without providing a direct linkage (warm referral) or follow up.
<i>"If they don't know what it's like to live with somebody with a disability as a carer, you can tell that in the conversation. It will be nice to have a bit of a relationship on the same basis, that they do get what you are going through. At least to have the empathy that they don't recognise what you are going through." (Disability)</i>

5.4.2 Communication channels

A wide range of information sources were identified by carers in the research (Table 29). There was a preference for multiple channels, however Google search was seen as the main channel for finding out about the national carer gateway (56%) followed by health professionals (55%).

Table 29: Communication channels

Condition of Care Recipient:	Total %	Disability %	Mental illness %	Alcohol/drug %	Chronic illness %	Aged and frail %	Terminal/Other %	Age of Carer	18-39 %	40-64 %	65+ %
Google search	56	59	58	60	57	57	47		58	56	52
At a doctors surgery or medical centre	55	57	56	38	56	57	66		45	57	66
Government health websites	47	48	48	33	48	53	51		42	50	49
TV advertising	36	40	35	30	37	38	37		37	38	30
Direct mail	29	38	25	15	32	31	31		19	29	49
Social media	26	27	33	28	28	22	23		41	20	10
Radio advertising	18	20	19	20	19	20	19		20	19	13
Commercial websites	13	15	11	12	16	14	18		16	13	6
A magazine or newsletter	3	5	3	0	3	3	10		0	3	10
Sample size	1205	403	374	98	316	430	144		298	609	298

Base: All carers, n=1205

Q. Where would you like to find out about a new helpline or website that would provide information on support for you as a carer?

The General Practitioner was seen as an obvious choice and would be most effective if the GP was aware of the service and what it offered so they can advise and refer carers onwards at the right moment.

- "Because all of us would see a GP or doctor or specialist"
- "Even just posters in the GP's waiting room. That's all they'd have to do"
- "I would think it would be referred through a [health] professional or doctor...or you would find it [a brochure] when visiting a service provider."

Hospitals were mentioned as a key source, this is where carers would be most receptive to the national carer gateway and when they would be most in need of information, support and services particularly following an emergency or diagnosis.

Mass media (TV, radio) was also viewed as beneficial, this would ensure a broad group of carers could be reached as carers are spending a significant amount of time in the house.

- "A lot of carers are housebound, and the people they care for are housebound, so they watch a lot of TV...the morning programs and things like that. And they listen to the old farts radio, the talkback radio. They don't get out there and network and things like that."

Targeted approaches through government carer pathways such as through the carer payment information or other pensions or allowances, were suggested.

- "To anyone who either gets a carer payment or a carer disability pension for looking after, they should automatically send it."

Developing and marketing the national carer gateway

Other sources mentioned include:

- Government health websites (47%) were also mentioned as a key source, government websites were a trusted source of information and a place where carers go for information.
- Council and local government pamphlets and magazines were accessed widely particularly for aged care services.
 - *"They (council) usually put out a little booklet, probably mention something about that in the community". (Disability)*
- Targeted sources such as pensioner magazines were suggested.
 - *"I'm not saying all pensioners are being cared for, but at some point they might be" (Aged and frail)*
- Direct mail.
 - *"You may receive something and you may go oh, I can talk to somebody and let them know about it" (Aged and frail)*

Aboriginal and Torres Strait Islander carers focused on the need for direct, personal and regular sources of information rather than mass media or targeted communications channels. There will need to be a face-to-face or on-the-ground follow up element in any communication approach to these audiences as written and electronic media materials will neither be trusted automatically nor even accessed unless they are via an existing network or trusted third party.

- *"Need someone local. Need another Koori to tell what's straight." (Aboriginal Carer, Disability)*

Among CALD carers regardless of time spent in Australia there was a lack of confidence in accessing mainstream information making first language resources the preferred channels. Ethnic and in English community media was preferred, such as *'Chinese newspaper'* and *'Vietnamese community radio'*. Similar to Aboriginal and Torres Strait Islander carers face to face forms of communication including home visits and via medical practitioners were welcomed as there were barriers to seeking out information due to isolation and lack of confidence and knowledge of the system.

5.4.3 Branding

A series of potential names for the website was tested with carers in the research. The five potential names for the national carer gateway tested in the research were:

- YouCare (youcare.gov.au)
- Carer Network (carernetwork.gov.au)
- Carer Central (carercentral.gov.au)
- Care for Carers (careforcarers.gov.au)
- Carer Access (careraccess.gov.au)

Developing and marketing the national carer gateway

Below are the average appeal scores and proportion preferring for each of the service names tested in the qualitative research (Table 30). Based on the Qualitative feedback, appeal and preference were strongest for two of the names; Carer Network and Care for Carers.

Table 30: Naming results qualitative research

Service Name	QA Average Appeal Score (1-10)	QB % Preference
	<i>Mean</i>	%
Carer Network	6.2	28
Care for Carers	6.1	29
Carer Access	6.1	19
Carer Central	5.1	13
YouCare	4.2	11
Sample Size	125	125

Base: n=125 (Qualitative research)

QA How appealing is each of the following names for the service? Please give a score for each concept, from 1 to 10, where 1 is 'Not appealing' and 10 is 'Appealing'

QB. If you were to name the service, which would you choose? Please write in one of the names provided above in the cloud below...

Carer Network had strong appeal, particularly among those who were looking for a service that would bring together all of the support and services available to them and help them navigate through those services.

- *"The word 'network' sort of suggested I can go in there and I can access everything in that one place" (Aged and Frail)*
- *"It has 'carer' in it and the 'network' says it's going to encompass lots of things behind it. I am a carer and behind it there is going to be lots of information" (Disability)*
- *"Network sounds like you've got links to everybody" (Aged and Frail)*
- *"Suggests a range of information from a range of sources" (Aged and Frail)*

The word 'network' was seen to encompass the one-stop-shop that carers were looking for.

- *"I like the word network, I think that basically anything that you need to know for both sides of the parties as well...like a one stop shop" (Aged and Frail)*

For some, it also suggested that they would be part of a wider network or community of carers, and comfort was felt in the idea of being able to share experiences and perhaps reduce the feelings of isolation.

- *"To feel as part of a wide network of people sharing the same problems, and being able to exchange those things" (Aged and Frail)*

Developing and marketing the national carer gateway

Care for Carers was popular among those who were looking for emotional support.

- *"It's going to look after us...it recognises carers need to be cared for also, the recognition we are not tough tanks" (Disability)*
- *"I like it because it clearly states that the carer is being looked after as well." (Disability)*
- *"Made it feel like it was supportive network not just an information network" (Aged and Frail)*
- *"I think it shows, or gives a sense of, that they need help and support just as much as they person they are caring for too" (Aged and Frail)*

However, Care for Carers was slightly polarising for some carers who were not seeking emotional support, as they perceived that it only offered counselling and advice and might not encompass the other information, support and services. Additionally, it was suggested by some that Care for Carers might have limited connotations, in that it is specifically focussed on carers, whereas their wellbeing and needs are inherently related to the needs of the person they are caring for.

- *"The title of it is already telling you a lot - what it's about. For example Care for Carers doesn't really give too much. That would be good for counselling, but if it's a website that's a gateway of information and all that, Carer Access is saying a lot... counselling, information, guidelines, forums... Whereas Care for Carers sounds like it would be a website name just for counselling" (Young Carer)*

YouCare was the least appealing of the names tested. Carers felt that this name lacked clarity as to what the national carer gateway would deliver. For most, the name was found to be generic, not specific to carers and could potentially apply to a number of different types of businesses or services (could relate to any subject that someone cares about). Reactions included that it sounded too similar to or too much like an insurance brand or a charity. For some, there was a sense that the name was somewhat patronising, or stating the obvious (*"YouCare? I know I care!"*)

Carer Central received mixed reactions. For some carers, the word 'central' was a positive and brought about ideas of a one-stop-shop. For others, the name didn't really stand out. A small group described it as sounding like a transport hub. Overall, the word 'central' was not as powerful or evocative as 'network' or 'access'.

- *"I just thought it was the central place for a carer, and it was just sort of one stop shop, everything at a click of a button" (Aged and frail)*
- *"It sounds like all the information is in one place." (Young Carer)*

Carer Access received mostly positive reactions, although not as strong as the reactions to Carer Network or Care for Carers. The word 'access' generally tended to create an expectation of numerous resources. As observed for the name Carer Network, carers were positive about how Carer Access would bring together all of the available support and services.

- *"Because it's carer which I am, and access is what I want. Access to everything" (Aged and Frail)*
- *"Carer Access summed it up - this is where you need to go to access the information for carers." (Disability)*

Aboriginal and Torres Strait Islander carer feedback

The proposed naming options were basically rejected due to a perceived sense of selfishness (“I know I care”), priority on those being cared for (“More important is those little ones”) and a sense that the terms were “very government”. The potential names considered, with some caveats, were ‘Carer Network’ and ‘Care for Carers’.

“It’s just another telephone line. Just call and come full circle back to (State Service Agency) even when they say they can help” (Aboriginal carer, Disability)

Culturally and Linguistically Diverse carer feedback

There was not one service name that was favored greatly in comparison to the rest but on average ‘YouCare’ received the most positive responses with it being easy to remember, meaningful and simple. ‘Carer Network’ and ‘Carer Access’ were also well rated.

Appendix A: Quantitative Questionnaire

4821 Healthdirect Carers Service Development

Online Questionnaire (Carers)

Final v2.3

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1. Sampling groups

- Online Research Panel
- Carers organisations and peak bodies – open survey

2. Survey Introduction and Privacy Statement

Introduction

Informed Consent

AMR is conducting a national survey for Healthdirect Australia and the Department of Social Services about services that are available to Australians. The research is about the different information, services and support that people across Australia access. The research will help the Australian Government understand needs of different groups in the community.

We understand that you're short on time so we really value your input. The survey will take 3-20 minutes to complete, depending on which sections you qualify for.

Your Participation

Your participation in this survey is entirely voluntary. You may decide not to answer certain questions, and you may withdraw at any stage.

Your name will not be collected or used in the reporting of the results. Your responses to the questions will not be able to be linked back to you.

Further information

If you would like to know more at any stage during the survey please feel free to contact *[insert email address]*.

3. Screening

NOTE: Screening on location, age and gender will allow an estimated weighting to the general population

The first few questions are about yourself, so that we can get a good cross section of people across Australia.

Q1 What state or territory do you live in?

- 1 New South Wales
- 2 Victoria
- 3 Queensland
- 4 South Australia
- 5 Western Australia
- 6 Tasmania
- 7 Northern Territory
- 8 Australian Capital Territory

Q2 What is the postcode where you live?

Record postcode

Q3 Which of these age groups do you fall into?

- 1 Under 16 *Thank and end*
- 2 16-17
- 3 18-25
- 4 26-39
- 5 40-54
- 6 55-64
- 7 65-74
- 8 75 and over
- 99 I prefer not to answer

Q4 Please record your gender.

- 1 Male
- 2 Female
- 3 Indeterminate, Intersex or Unspecified
- 99 I prefer not to answer

Appendices

Q5 Do you provide unpaid care and support to a family member or friend who has any of the following? This can include help and support in any of the daily activities of that person.

- disability
- chronic illness
- terminal illness
- mental health condition
- alcohol or other drug dependency
- frailty due to age

- 1 Yes *Continue*
2 No *Thank and end*
9 I do not wish to answer *Thank and end*

Q6 Which of the following would you use to describe your situation? Please select all that describe you.

Maintain Order – Multiple response

- 1 Full-time or part-time paid employment
2 Part-time or full-time student
3 Unpaid voluntary work
4 Keeping house
5 A part time carer
6 A full time carer
7 Receiving a pension
8 Retired
9 Unemployed – looking for work
95 Other situation (please specify)
99 I prefer not to answer

Q7 Are you employed as a Care Worker? A Care Worker is someone who is paid by either a support agency, a home care service provider or some other organisation to provide care in the home or residential facility.

- 1 Yes *Thank and end*
2 No *Continue*
9 I do not wish to answer *Thank and end*

4. Profile of Carers

The next part of the survey is about information, services and support that are available to people who are providing regular care and support. It is about your role as a carer, rather than how you help the people you care for. The research will help the Australian Government understand the needs of carers in our community.

We understand that you're short on time so we really value your input. The survey should take about 20 minutes to complete.

Q8 Who do you provide regular care and support to? You may select more than one.

- 1 My spouse, partner or de-facto
- 2 My child or step child
- 3 My parent or parent in law
- 4 My grandchild
- 5 Another relative
- 6 My friend
- 7 My neighbour
- 95 Another person (please specify)
- 99 I prefer not to answer

Q9 Do you provide unpaid care and support to more than one person?

- 1 Only one person
- 2 2 people
- 3 More than 2 people
- 9 I prefer not to answer

Q9a What [is the age of the person/are the ages of the people] that you care for?

- 1 __ years
- 2 __ years
- 3 __ years
- 9 I prefer not to answer

Q10 Do you live in the same household as the [person/people] you care for?

- 1 Yes
- 2 [If more than one] Some of them
- 3 Some of the time
- 4 No
- 9 I prefer not to answer

Q11 Which of the following [does the person / do the people] you provide care to have?

Multiple Response

- 1 A disability
- 2 A mental health condition
- 3 Alcohol dependency
- 4 Other drug dependency
- 5 Chronic illness
- 6 Frailty due to age
- 7 End of life care
- 95 Some other description (please specify)
- 97 Unsure
- 99 None of the above

Q12 What help and support do you provide? Please answer all that apply.

- 1 Personal care, such as showering, bathing, dressing, eating, or toileting
- 2 Help moving around the house or outside
- 3 Shopping
- 4 Meal preparation
- 5 Housework
- 6 Maintenance around the home
- 7 Communication (such as translating into the person's native language)
- 8 Guidance in decision making
- 9 Health care
- 10 Reading & writing
- 11 Transport
- 12 Financial assistance
- 13 Assistance with social participation
- 14 Supervision for safety reasons
- 15 Supervising & preventing certain behaviours
- 16 Coordination of services and support
- 17 Advocacy for their rights and support
- 99 None of the above

Thank and end

Q13 About how much time do you spend each day in your role of providing regular care and support?

- 1 Less than 1 hour
- 2 Number of hours _____
- 95 Some other period (please specify)
- 99 I prefer not to answer

Appendices

Q14 Are you the only carer for this person, or is there also another person who provides support?

- 1 I am the only carer *Go to Q16*
- 2 There is another person providing support? *Ask Q15*

Q15 Are you the primary, or main, carer?

- 1 Yes
- 2 No
- 3 Unsure

Q16 How long have you been providing regular care and support for the [person/people]?

- 1 Less than 6 months
- 2 6 months to 2 years
- 3 3 to 5 years
- 4 6 to 10 years
- 5 11 to 15 years
- 6 16 to 20 years
- 7 More than 20 years
- 99 I prefer not to answer

Q17 Do you personally have any of the following? You may select more than one

Multiple response

- 1 A disability
- 2 A mental health condition
- 3 Alcohol dependency
- 4 Other drug dependency
- 5 Chronic or terminal illness
- 6 Frailty due to age
- 95 Some other description (please specify)
- 97 Unsure
- 99 None of the above

If any 1-6 selected IN Q18, ask Q19 and Q20

Q18 Could you please give details?

Open response

Q19 Does your condition affect the following?

	Yes 1	No 2
1 Using a telephone		
2 Using the internet		

5. Awareness and sources of information

Q20 There are different sources of information, advice and support for you, in your role as a carer. Which of the following sources have you used for information or advice in the last 12 months?

	Used – and one of my preferred sources 1	Used – but <u>not</u> a preferred source 2	Not used 3	No sure 9
1 Telephone helpline				
2 Googling for information				
3 A specific website on the topic				
4 Your doctor				
5 A social worker				
6 A counsellor or psychologist				
7 A medical specialist or healthcare professional				
8. Local Council or Community Centre				
10 A specialised association or organisation				
11 A government website				
12 A commercial website				
13 Support group				
14 Online social network				
15 Friends				
16 Family				
17 Brochures or books				

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Q21 Have you heard of any of the following helplines which provide support for carers?

<i>Randomise</i>	Not heard of 1	Heard of but not used 2	Heard of and used 3	Unsure 9
1	Carers [state] Carer Line			
2	SANE Australia			
3	Alzheimer's Australia			
4	Mind Australia			
5	ARAMI			
6	Lifeline			
7	Mensline Australia			
8	My Aged Care			
9	Commonwealth Respite and Carelink Centre (CRCC)			

Q22 What other helplines have you used?

Open response

Q23 Have you heard of any of the following websites that have information, services or support for carers?

<i>Randomise</i>	Not heard of 1	Heard of but not used 2	Heard of and used 3	Unsure 9
1	My Aged Care			
2	National Disability Insurance Scheme			
3	State Health Departments e.g. QLD Health			
4	Some other State Government website			
5	Commonwealth Respite and Carelink Centres			
6	Department of Human Services (formerly Centrelink)			
7	Carers Australia			
8	State Carers Association e.g. Carers NSW			
9	Department of Veterans Affairs			
10	Working Carers Gateway			
11	Young Carers			
12	Aged Care Rights Service			

Q24 What other websites have you used?

Open response

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Q25 What other carer support services are you aware of to help you in your caring role?

	Aware 1	Not Aware 2	Unsure 9
1 Home help or domestic assistance for carers			
2 Personal/Nursing care			
3 Meal services for carers			
4 Respite Care, such as respite in your home, residential respite facility, day or overnight cottage (Respite care - also known as 'short-term care' - is a form of support for carers. It gives carers the opportunity to attend to everyday activities and have a break from the caring role. Respite care may be given informally by friends, family or neighbours, or by formal respite services).			
5 Counselling services for carers			
6 Support from other carers or other social groups			
7 Support to keep carers employed			
8 Training and education for carers			
9 Other (please specify)			

6. Needs and Experiences

The next few questions are about your experiences and needs as a carer.

Q26 How often do you engage in the following?

		More than once a week	About once a week	About once fortnight weekly	Occasionally	Never/ Not an area of interest
		1	2	3	4	5
1	Social activities at home, such as visits from family or friends					
2	Social activities away from home, such as visiting friends, or going to a restaurant or club					
3	Support group meeting					
4	Cultural activities					
5	Religious activities					
6	Online forums or social media					
7	Playing sport					
8	Other activities involving exercise such as walking, jogging, swimming or dancing					
9	Watching TV or movies					
10	Reading					
11	Listening to music					
12	Other indoor hobbies					
13	Shopping					
14	Visiting places of interest					
15	Travelling					
16	Other outdoor hobbies					

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Q27 Please rate how satisfied you are with each of the following.

<i>Randomise</i>	Very Poor	Poor	Fair	Good	Very good	Unsure
	1	2	3	4	5	9
1	How well you are coping with your situation					
2	Your health and wellbeing					
3	Your involvement with the community					
4	The amount of time you have to yourself					
5	Your financial situation					
6	How well you are supported by family and friends					
7	The level of formal support you get from government and community agencies					
8	If working: The support from your workplace to combine working and caring					
9	The recognition you get for your role as a carer					
10	Your social life					
11	Your emotional wellbeing					
12	Your understanding of your eligibility for financial assistance					
13	Time available for you to undertake religious or cultural activities away from home					

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Q28 Have you heard of any of the following respite services for carers?

<i>Randomise</i>	Yes	No	Unsure
	1	2	9
1 Types of respite that may be available in your area			
2 In-home respite care			
3 Day care programs for carers			
4 Residential respite care in an aged care home			
5 Residential respite care for younger people with an illness or a disability			
6 Weekend and holiday programs and opportunities			
7 Recreation activities in the community			

Q29 Have you used any respite services in the last 12 months?

- 1 Yes
- 2 No

If yes, ask...

Q30 What respite services have you used?

Open response

Q31 How important to you are each of the following types of information, support or services to help make your role as a carer easier?

<i>Randomise</i>	Very important	Fairly important	Low importance	Unsure
	1	2	3	9
1 Ways to organise regular breaks from caring				
2 Counselling to help me cope more in my caring role				
3 Support from family and friends				
4 Support from services provided by government and other organisations				
5 More support from my GP or other health professional				
6 More practical support (e.g. care workers or domestic help)				
7 More financial support and advice				
8 Access to carer support groups				

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<i>Randomise</i>	Very important	Fairly important	Low importance	Unsure
9	Planning ahead to make sure my caring responsibilities are covered in an emergency			
10	Better ways to look after my own health and emotional wellbeing			
11	Advice for managing my day to day caring tasks			
12	More flexible working arrangements			
13	Better services for the person you're caring for			
14	Training and education for me as a carer			
15	Planning ahead for when you are no longer able to provide care			
16	Access to transport			

Q32 Is there any other support that is important to you to help make your role as a carer easier

Open response

Q33 Do you know how to go about getting this support?

Bring up those rated very/fairly important

		Yes	No	Unsure
		1	2	9
#	...			
#	...			

7. Channels and New Service

The next few questions are about your preferences on how you would like to access information.

Q34 Which of the following devices do you use to access the internet? Please select all that apply to you.

Randomise (1-5)

	Yes	No
	1	2
1 Desktop computer		
2 Laptop computer		
3 Tablet		
4 Smartphone		
5 Other mobile phone		
6 Other device (please specify)		

Q35 How often do you use the internet for each of the following?

Randomise (Codes 1-5)	Every day	Most days	Occasionally	Not used
	1	2	3	4
1 Searching for information				
2 Shopping				
3 Social media				
4 Entertainment				
5 Communicating with others				
6 Other reasons (please specify)				

The Australian Government is developing a new service to provide information and support for carers. The service will include a telephone helpline and website. The website will include a tool to help you find relevant services, support and information.

Q36 How likely would you be to use the components?

	Definitely	Very likely	Fairly likely	Possibly	Unlikely	Unsure
	1	2	3	4	5	9
1 The telephone helpline						
2 The website						
3 A tool to help find services, support and information						

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If answered 1–4 to any component in Q37, ask...

Q37 What would be your reasons for using the service?

Open response

If answered 1–4 to 3 (tool) in Q37, ask...

Q38 The website will also include a service finder tool to help you find support and assistance. How interested would you be in using a service finder tool for each of the following?

Randomise	Very interested 1	Fairly interested 2	Only slightly interested 3	Not interested 4	Unsure 9
1					
2					
3					
4					
5					
6					
7					

If answered possibly/unlikely/unsure, to any component in Q37, ask...

Q39 You mentioned you would be less likely to use part of the new service. What would be your reasons for not using the service?

Open response

Q40 Where would you like to find out about a new helpline or website that would provide information on support for you as a carer? You may select more than one source.

Randomise (Code 1-9)

- 1 TV advertising
- 2 Radio advertising
- 3 Social media
- 4 Google search
- 5 Government health websites
- 6 Commercial websites
- 7 Direct mail
- 8 At a doctor's surgery or medical centre
- 9 A magazine or newsletter (please specify)
- 95 Other (please specify)
- 99 Unsure

Q41 And how would you like to get information and advice from such a service?

	Yes	No	Unsure
1 Telephone helpline			
2 Reading it on the website			
3 Online videos			
4 Online chat			
5 Apps			
6 Video consultation			

8. About You

Finally, we'd like to finish off with some questions about you so we can analyse the responses to this survey by different types of people.

Q42 Which of the following describes your current situation? Please select all that apply to you.

Multiple response

- 1 Student: Full-time
- 2 Student: Part-time
- 3 Work: Full-time (*35 hours per week or more*)
- 4 Work: Part-time (*less than 35 hours per week*)
- 6 Work: Casual
- 7 Work: Unpaid voluntary work
- 8 Unemployed looking for work
- 9 Keeping house
- 10 Receiving age pension
- 11 Receiving carers payment or allowance
- 12 Receiving disability pension
- 13 Receiving other pension
- 12 Retired
- 95 Other – Please specify:
- 97 Refused

Q43 Which of the following sources of income do you have?

Multiple response

- 1 Government benefit or allowance
- 2 Income from employment
- 3 Income from another person
- 4 A pension from another person
- 6 Superannuation or self-funded retirement
- 7 Other self-funded living (e.g. savings)
- 95 Another source of income (please specify)
- 99 I prefer not to answer

Q44 What is the highest level of education you have completed?

Maintain order – single response

- 1 Did not complete secondary or high school
- 2 Completed secondary or high school
- 3 Trade qualification
- 4 Vocational certificate
- 5 Tertiary education
- 95 Some other level (please specify)
- 99 I prefer not to answer

Q45 In which of these five categories would your household's total gross annual income fall, including government allowance?

Maintain order – single response

- 1 Under \$10,000
- 2 \$10,000 to \$30,000
- 3 \$30,001 to \$50,000
- 4 \$50,001 to \$75,000
- 5 \$75,001 to \$100,000
- 6 Over \$100,000
- 98 Unsure
- 99 I prefer not to answer

Q46 Is a language other than English spoken in your home?

- 1 Yes
- 2 No
- 9 Refused

If yes...

Q47 Which language is spoken?

Open response

Q48 Are you of Aboriginal or Torres Strait Islander origin?

- 1 Yes
- 2 No
- 9 I prefer not to answer

If yes...

Q49 Do you identify as...

- 1 Aboriginal but not Torres Strait Islander
- 2 Torres Strait Islander but not Aboriginal origin
- 3 Aboriginal and Torres Strait Islander origin
- 8 Don't know
- 9 I prefer not wish to answer

If Q3 (age) is 18+

The final question is about sexual identity. We are asking this, as with other questions about you, so we can look at the needs and experiences of different groups in the community. You may prefer not to answer.

Q50 Do you identify as any of the following?

- 1 Lesbian
- 2 Gay
- 3 Bisexual
- 4 Transgender
- 5 Intersex
- 6 Questioning
- 7 Heterosexual
- 97 Prefer not to say
- 99 None of the above

That's the end of the survey. Thank you for your time.

Our Privacy Policy is available [on our website](#) and contains further details regarding how you can access or correct information we hold about you, how you can make a privacy related complaint, and how that complaint will be dealt with. Should you have any questions about our research or any of the above matters, you should contact our Privacy Officer:

Quality.Manager@amrsydney.com

Appendix B: Focus Group Discussion Guide

4821 – Healthdirect Australia – Carers Service Development

Focus Group Discussion Guide

Final V3 18.06.15

NOTE: This discussion guide is intended as an outline only. There will be considerable scope within the discussion for exploring issues as they arise. Questions are indicative only of subject matter to be covered and are not word for word descriptions of the moderator's questions.

Research objectives

The primary objectives of this study are to:

- Identify and understand the different types of carers and their experience accessing information and support services
- Identify how carers access information, how they access services and what factors impair their ability to access information
- Understand carer information, support and services wants, needs and expectations – including at different stages of the carer lifecycle. Identify services that carers are currently accessing and what services are needed, but not currently available
- Determine carer response to the development of a carer information and support service (contact centre, website and service finder)
- Determine the most effective communication channels and messaging to reach the carer market

1 Welcome and introduction

(5 mins)

- Introduce AMR.
- Explain that this is market research, and is conducted under a code of practice of the Australian Market and Social Research Society. The discussion is recorded for research purposes, so that we can go over the discussion afterwards and make sure we don't miss anything. All your comments will be kept confidential.
- The research study has been sponsored by Healthdirect Australia and the Department of Social Services, and we are talking to a range of different people.
- Description of service: May 2015, the Minister announced the Government's commitment to establish a national carer gateway. The gateway will help carers find support and services, regardless of the need or the age of the person they care for.
- There are no right or wrong answers. Everyone should say something as all your views are important. Try not to talk over one another or hold separate conversations.
- Mobile phones off.
- The group will take approximately 1 hour 30 minutes.

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- DISCUSSION TOPIC: We are conducting this research around your role as a carer and the information, services and support you access and require. We want to focus on **you and the help you need, rather than the support for the person/people you are caring for.**

2 Getting to know the carers (10 mins)

Moderator's aim: Get to know the carers, understand their personal situation and begin to explore the challenges of being a carer.

Moderator: We're going to go around the room and I'd like you each to tell me a bit about your family, your interests, who you care for, how long you have been caring for them and what that involves.

- Go around the group one by one, letting each carer tell their story
- After all participants have taken their turn:
 - What is the most rewarding thing about being a carer?
 - What are the challenges or problems you have faced being a carer?
(Allow open conversation, don't need to probe accessing information or support at this stage, although it may come up spontaneously).

3 Awareness and current use of support, information, services (15-20 mins)

Moderator's aim: Understand what support, information and services carers are aware of and access and whether / where gaps exist.

Moderator: Let's talk about help, information, support and services that you might have access to in your role as a carer. Please remember, we are talking about the things that might be used by you as a carer, rather than by the person/people you are caring for.

- What do these terms mean for you as a carer (help, information, support, services)?

Moderator to write help, information, support, services on a flipchart sheet and write up top of mind responses.

Moderator: The focus of the group today is to talk about these things I have written up. Firstly I would like you to think about some of the help, information, support and services you access.

- What are some examples of information, support or services that you currently access or have accessed in the past? Please spend a minute or two thinking about and writing these down individually.

Moderator to ask participants to report back on their lists, and moderator to add the areas to a flipchart sheet.

- Can you tell me what you have accessed that was helpful / good? What was good about it? How did it help you? When did you access this? Was it accessed in the past or more recently? *Explore generally and ask for specific examples.*
- And can you tell me what you have accessed that may not have been so helpful? In what ways was it not helpful? *Explore generally and ask for specific examples.*
- How did you find out about the information, support or services you used? How easy or difficult were they to find?

Moderator: If they have not accessed services -

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- Why haven't you accessed anything to help you in your role as a carer? *i.e. nothing available for carers, no time too busy caring, not relevant to me and my situation, I am too worried about the person I care for not time for me?*
- Are there any areas that you wish were available but you could not find or access? *i.e. information, support or services that you think would be useful, but which you are not aware of having access to? List of areas to explore: financial support, counselling, support groups, respite care, support around the house e.g. cooking and cleaning, education and training, online social networks*
- If you were to look for information, support or services, how would you go about this? Where would you start looking? Who do you think would have this information?
- I would now like us to go through the following that we haven't mentioned and understand from you if you have accessed these areas and / or if you would be interested in accessing?
 - Telephone helplines
 - Websites
 - Health professionals (doctor / social worker / psychologist)
 - Counselling or advice services
 - Carer support groups
 - Respite facilities
 - Specialised association or organisation
 - Online social network

4 Needs at different stages of the lifecycle

(10-15 mins)

Moderator's aim: Identify the wants and needs of carers at different stages of the caring lifecycle.
Moderator: Now I'd like to talk about how the help you need changes over time. To do this, I'd like you to think about the time you have spent caring in a couple of different stages:

- Past – when you started in the caring role
- Future – looking beyond now

For each of you, when you started will be different in terms of how long ago it was, under what circumstances you came to be in the caring role etc. (reference examples based on the stories that the participants shared at the beginning if possible / relevant), but I want each of you to think about it individually from the point when you first started caring for the person/people that you care for through to the future.

Moderator to give participants 2 different coloured sets of post-it notes. Ask them to use one colour for Past and one for Future.

- Thinking about these different stages, write down what help you were looking for (and think you will be looking for in the future).
- What help were you looking for? Think about what information, support and services would have made a difference to your life as a carer.
- What information were you looking for?
- What support were/are you looking for at this stage?
- Who would you like help from? Why?

Get participants to report back on each stage – add to flipchart for each.

Explore differences and commonalities between the different stages.

On the flipchart, write up the needs and information sought at each stage (may cut across stages)

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5 Ideal information and support service (10 mins)

Moderator's aim: To explore the ideal service for carers, including access, content, resources and who would be delivering the service.

Moderator: Hand all respondents paper and place pencils/crayons in the middle of the table.

- I'd like us to do something a little bit different now. It's a little bit creative but it's very important that we complete this on our own for now; we'll be given the opportunity to discuss it in a minute.
- Thinking about all the needs and issues we just discussed, in an ideal world, where there were no restrictions and we had complete creative licence, what would the **ideal information and assistance service look like?** I would like us to take a few minutes to create that ideal service on paper. Write, draw pictures, symbols or anything else you want to help depict what you're looking for.

Moderator: give respondents 5 minutes to draw their service.

- Does anyone want to start us off by explaining their ideal service?
 - Why is that important?
 - How would that work?
 - What's the benefit of that? Why would this make a difference to my life?
 - Does anyone else in the group like this idea? Would we access a service like this?

6 Reaction to carers service concept and service name testing (15-20 mins)

Moderator's aim: To explore reactions to the Carers Gateway concept, capture language used to describe the service and test service name concepts to inform brand development.

Take series of cards with the different elements of the service, and explore each one by one;

- **Information, support, services tailored for carers that you can easily access**
 - What do you think of this? How likely would you be to access?
 - How would this help? What do you see as the main benefits?
 - What does 'easily access' mean?
- **Phone number you can call to talk to someone about what you are going through and provide you with advice on what could help you**
 - What do you think of this? How likely would you be to access?
 - How would this help? What do you see as the main benefits?
 - What should be included and covered?
 - Who would you expect to answer the phone?
 - What kind of advice would you expect them to give?
- **Website which acts as a gateway to all of the information, support and services you might access as a carer**
 - What do you think of this? How likely would you be to access?
 - How would this help? What do you see as the main benefits?
 - What should be included and covered on this website? *Probe for real examples of things they think they may need*
- **Service finder that helps you locate key services in your local area that could assist you in your role as a carer**
 - What do you think of this? How likely would you be to access?
 - How would this help? What do you see as the main benefits?
 - What should be included and covered?

Moderator: **And what about if we brought all of the above together into one service?**

- Would you access it, and why/why not?
 - Is it associated with helping you with the challenges you may face as a carer?

Appendices

Moderator: Hand all participants worksheet. Thinking about the service we have just discussed...

- Participants to work individually for a few minutes, filling in worksheet:
 - Rate each of the 5 concept names from 1 (Not Appealing) to 10 (Appealing) –
 - *YouCare (youcare.gov.au)*
 - *Carer Network (carernetwork.gov.au)*
 - *Carer Central (carercentral.gov.au)*
 - *Care for Carers (careforcarers.gov.au)*
 - *Carer Access (careraccess.gov.au)*
 - If you were to name the service, which one would you choose?
 - Why?
- Ask participants to report back on their preferences and reasons – for and against name concepts
- Which words do you like? Which words don't you like?
- Are there other words that you like better?
- Which of the words go together? Which of the words don't go together?

7 Communication (5 mins)

Moderator's aim: To explore the most effective communication channels for reaching the target audience.

- What are your preferred sources of information when seeking help or support?
- Which sources do you trust for information in this area? How regularly do you access those sources? *Sources to prompt: Social media, Online forums and blogs, Magazines, Newspaper, Newsletters*
- Where would you like / expect to find out about the new service we just discussed? *Sources to prompt: TV advertising, Radio advertising, Social media, Online forums and blogs, Government health websites, Commercial websites, Direct Mail Magazines, Newspaper, Newsletters, At a doctor's surgery*
 - Why would they be appropriate places to find out about the service?

8 Thank and close (2 mins)

Thank for their time and hand out incentives

Appendix C: Desk Research

The landscape of services currently available to carers is delivered by numerous providers offering different combinations of services. Findings from research commissioned by the Department of Health and Ageing (May 2013) identified 115 programs aimed solely at carers. The objective of this literature review was to identify carer information, support and services which align with the needs identified in the research, namely:

For Carer	For Care Recipient
<ul style="list-style-type: none"> • Emotional support: Guidance, advice and counselling 	<ul style="list-style-type: none"> • Condition specific information
<ul style="list-style-type: none"> • Practical support: relief from household and other duties 	<ul style="list-style-type: none"> • Financial information
<ul style="list-style-type: none"> • Advice about what to expect in the caring journey 	<ul style="list-style-type: none"> • Recreation and social activities
<ul style="list-style-type: none"> • Practical advice and training on key caring tasks 	<ul style="list-style-type: none"> • Access to services for the care recipient
<ul style="list-style-type: none"> • Respite services 	<ul style="list-style-type: none"> • Education and early intervention

Carer services are delivered through a number of difference service providers each with their own focus. Providers can be summarised into the following categories

- **Carer specific services**
- **Services aimed at condition of the care recipient** (aged, mentally ill and disability)
- **Cultural background and specific community groups for example specific services for CALD and Aboriginal and Torres Strait Islander carers or carers that identify as LGBTI**
- **Geographic location:** services accessed in specific state, territory or sub-regions.
- **Provider type** for example not for profit, community, religious affiliated, private, government).

Table 31 summarises the availability of services across the different carer needs offered by the different segments of providers. This shows that for carers to adequately fulfil their information, support and service requirements they will need to go to multiple providers.

Table 31: Availability of carer services

Source		Tailored Carer Services	Government	Cultural and community groups	Disability	Mental Illness	Aged	Chronic or Terminal Illness
For Carer	Emotional support: Guidance, advice and counselling	■ ■ ■	■	■	■ ■ ■	■ ■	■ ■	■ ■ ■
	Practical support: relief from household and other duties	■ ■	■	■	■ ■ ■	■	■ ■ ■	■ ■
	Financial Entitlements	■ ■	■ ■ ■	■	■ ■ ■	■ ■	■ ■	■
	Advice about what to expect in the caring journey	■ ■ ■	■	■	■ ■ ■	■	■ ■	■ ■ ■
	Practical advice and training on key caring tasks	■ ■ ■	■	■	■ ■ ■	■	■ ■	■
	Respite services	■ ■	■ ■ ■	■	■ ■ ■	■ ■	■	■
For Care Recipient	Condition specific information	■	■	■	■ ■ ■	■ ■ ■	■ ■	■ ■ ■
	Recreation and social activities	■ ■	■	■ ■ ■	■ ■ ■	■	■ ■ ■	■
	Access to services for the care recipient	■	■ ■	■ ■	■ ■ ■	■ ■ ■	■ ■ ■	■
	Education and early intervention	■	■	■	■ ■ ■	■ ■	■	■

■	Low
■ ■	Medium
■ ■ ■	High

The following provides a snapshot of the types of information and access to services available for carers across the different segments of providers.

9. Tailored Carer Services

Carers Australia and the Network of Carer Associations in each jurisdiction provide support for carers through a range of assistance including information, counselling and respite services. Jurisdictional services are run and structured differently depending on alliances with partner organisations and funding arrangements. Looking at Carers SA, for example, the network is broken down into regional and local providers which can usually be found via links from more general websites as the carer becomes more specific about where the services are needed:

- SA Country Carers
- Carers Link
- Carer Support
- Northern Carers Network
- South Coast Carer Support

The Carers Australia network supports the delivery of services funded through various government programs:

Carer Information Support Service (CISS)

CISS delivers the most appropriate information for carers on their pathway depending on their particular needs and circumstances, including counselling provided through the National Carer Counselling Program (see below), carer support groups, carer education, training, and respite services.

National Carer Counselling Program

The National Carer Counselling Program offers short term counselling, emotional and psychological support and assistance with coping with the emotions involved with the carer role such as grief, loss and stress. Counselling is offered one on one, in groups, over the phone or internet.

Several Community organisations cover carer services for all carers but within a certain region. For example:

- [Northside Community Forum Inc.](#) (Available in the Northern Districts of Sydney): “a non government, not for profit community based organisation that exists to improve care in our region. We help carers and the people they care for. Our community of care includes people who are aged, people with a disability, people with mental health issues, and people with a range of other personal circumstances. It includes their friends and family, our members, and other organisations involved in community based care”.
- [Catholic Community Care](#) (this particular provider operates throughout NSW and ACT): “Many of our services provide support to families, whether it be for older family members in need of home and community based services such as Community Aged Care Packages and Respite services; families where someone has a mental illness or intellectual disability and families where someone is experiencing a period of homelessness. Programs available include [Balancing Work and Care](#), [Carers for Young People with Disabilities](#), [Centre Based Respite](#) and [Counselling and Advisory Service \(CAS\)](#) ()

Carer specific organisations also provide access to resources and support specifically for young (carers aged up to 25 years of age), CALD, Aboriginal and Torres Strait Islander and LGBTI carers.

10. Government

Commonwealth

The Commonwealth Government provides funding for carer initiatives through Carers Australia and other bodies as well as offering direct access to services outlined below:

- **Young Carers Respite and Information Services** - Respite and information services for young carers up to 25 years of age. Specifically, young carers who meet the criteria can access two types of respite support:
 - Direct Respite – planned, flexible hours of in-home respite care to free the student to spend time on their education; and
 - Educational Support – short term or immediate activities or support that meets the educational needs a student with a significant caring role may have.
- **Young Carers Bursary Program** - Bursary packages for eligible young carers aged 25 years and under to assist with remaining in or returning to education.
 - Respite Support for Carers of Young People with Severe or Profound Disability Program – Provides immediate and short-term respite for carers of young people with a severe or profound disability as well as facilitates access to information, other support or assistance appropriate to the individual needs and circumstances of both carers and care recipients. It focuses on carers' needs and allows carers to exercise choice and control over their respite care arrangements.
 - Supports carers whose needs are not being met through existing Australian Government or state/territory government initiatives; and
 - Expects to alleviate unmet demand for short-term and unplanned respite care that currently causes significant stress to carers.
- **Mental Health Respite: Carer Support** - Flexible respite and support options for carers of people with severe mental illness/psychiatric disability and carers of people with an intellectual disability.
- **MyTime Peer Support Groups for Parents of Young Children with Disability** - An Australia-wide network of peer support groups for parents and carers of young children with disability or a chronic medical condition.
- The **NDIS** and **Myagedcare** provide the gateway to services for carers of people with a disability and aged people respectively, including details of financial entitlements.

Jurisdiction

State and Territory Health, Community and Family Services Departments offer carers varying combinations of assistance, with some providing substantial information and linkages to services and others assisting mainly through funding to agencies such as their state branch of Carers Australia. For example in NSW, Carer Support Services have been established in the 10 Local Health Districts to work with health staff and carers to raise awareness of the needs of carers and to enhance the capacity of staff and service providers to better meet those needs. They refer carers to appropriate NGO/community sites, and provide navigation through the local services available.

Queensland Health provides information and links to providers of services for older carers, young carers, community home care services and information on financial help for carers.

11. Carer groups

As well as the general carer sites mentioned above catering for special needs groups, a number of specific community organisations provide specific groups with information for carers. These are predominantly advocacy or specific ethnicity community groups, and work to promote awareness, education and acceptance of their circumstances as well as activities.

1.1 Culturally and linguistically diverse

Some ethnicity specific organisations such as Australian Chinese Community Association (ACCA) provide access to services for carers. ACCA is a non-political, non-religious, and a not-for-profit organisation that was specifically formed to serve the Chinese-Australian community in New South Wales. They offer (among other things) access to **MingShi Dementia Respite Day Care**.

- *“The objectives of the Dementia Day Centres are to relieve pressure on families and carers. The dementia care-recipients from Chinese background are afforded the opportunities to socialise and meet new friends. Help are provided for them to engage in activities that maintain their physical and mental well-being. Support for carers, information and educational programs, and referral services are also provided”.*

There are some carer specific services available through various other CALD associations. However carer support services are usually ancillary to other services and community activities. Some examples include:

- **The Vietnamese Community in Australia** provides access to aged care services for Vietnamese people and their carers, who are over the age of 65, affected or impacted by dementia or under 65 years of age with disability or affected by multiple health conditions. Other services include drug treatment support and counselling for Asian drug users from 13 years of age and their families and a Vietnamese Gambling Help Service which involves one-on-one support to individuals and their partners, carers or family who are affected by gambling problems in order to increase access to gambling treatment and other services.
- **Co.As.It.**, the Italian Association of Assistance offers, among many other things, community care programs for the frail aged, people with drug and alcohol problems and other mental illnesses.
- **ADEC** – Action on Disabilities within Ethnic Communities. This organisation runs groups throughout the Southern Sydney region for ethnic carers of people with a disability:
 - Vietnamese Carer Support Group
 - Turkish Carer Support Group
 - Arabic Carer Support Group
 - Chinese Carer Support Group
 - Afghan Carer Support Group

1.2 Aboriginal and Torres Strait Islander

There are few Aboriginal and Torres Strait Islander specific resources readily available on the internet outside of the Carers Australia network and government websites mentioned above. First Peoples Disability Network Australia (FPDN) is a national organisation of and for Australia's First Peoples with disability, their families and communities. However, enquiries about support for individuals and their families are directed to the government's National Disability Advocacy Agencies and Program Provider finder. In the current study, the support services Aboriginal and Torres Strait Islander carers accessed were extremely limited - the range included the following, although these were used sporadically unless they were the "trusted person" base:

- Benevolent Society (Sydney City/Eastern Suburbs)
- Kurranulla Disability and Aged Care (Southern Sydney, Sutherland region)
- Wyanga Aged Care (Redfern)
- Aboriginal Education Officer at the local school
- Uniting Care Barnardos Family Support (Western Sydney)
- Aboriginal Health Care Worker (trusted family connection working in D&A but used as a one-stop-shop for all health matters)

This reiterates the importance of face to face assistance for Aboriginal and Torres Strait Islander carers, provided through trusted sources.

1.3 Lesbian, gay, bisexual, transgender and intersex (LGBTI)

The National LGBTI Health Alliance is the national peak health organisation in Australia for organisations and individuals that offer health-related programs, services and research focused on lesbian, gay, bisexual, transgender, and intersex people (LGBTI) and other sexuality, gender, and bodily diverse people and communities.

Other sites such as [The Gender Centre](#) provide information for example Caring for L.G.B.T.I. People with Dementia. However these are sparse compared to mainstream carer information websites.

Specific carer websites acknowledge the diversity of needs. For example:

"At Care Connect we value the diversity and contribution of the lesbian, gay, bisexual, transgender or intersex (LGBTI) community. We will partner with you and your broader support network to ensure you have access to services and supports that help you live independently."

Carers Victoria states:

*"LGBTI carers face many of the same joys and pressures as any other carer. However, they may also experience specific challenges related to invisibility, discrimination and exclusion. ...Carers Victoria's vision is that **all** carers and caring families⁺ are valued and supported - regardless of age, background, culture, sexuality, sex or gender identity. This includes access to inclusive and appropriate services at all stages of life."*

1.4 Young carers

The assistance available for those up to 26 years of age through the Carers Australia Network appears easily navigated and prominent in any internet search around 'young carer'. Young carers are also catered for by Commonwealth Government respite and bursary programs described in the Government section above. In addition, there are a few organisations who specifically address needs of young carers.

Young carers have help available not only through the above channels, but youth specific care organisations such as Community Supporting Youth Network.

Community Supporting Youth Network is *"a Network of local like-minded community organisations committed to the ongoing growth and development of their community through the engagement and participation in partnerships and initiatives that enhance and support young people."*

This includes links specific programs for young carers and is supported by numerous community groups such as local councils, charities (e.g. Anglicare, Salvation Army, Australian Red Cross, Barnardos) and branches of the Police & Community Youth Clubs.

"[ReachOut.com](https://reachout.com.au) helps under 25s with everyday questions through to tough times". While it covers mental health issues faced by young people, it is placed as a youth assistance space which may be more likely to be found by young carers looking after aged and frail, or chronically ill people.

1.5 Carers of people with disability

The offering of care for carers of people with disability takes place amid the service provision addressing core needs of the care recipient. These carers can also access services through Carers Australia. For example, for carers of people with a disability, organisations such as [Ability First Australia](https://abilityfirst.org.au) has a membership of several localised, on-the-ground service providers to which they would refer enquiries or requests for help.

In the case of disability support, Ability First Australia member organisations provide a similar range of services to their particular communities. However, they also share information and best practice, benefit from economies of scale and ensure research and learnings which all benefit people with disability.

A typical example of a member organisation would be [CARA](https://cara.org.au).

"Our philosophy is simple, we assist people in their daily lives with support to live at home, to take a break, to get out and have fun, to learn and to grow. We have a long and proud history of over 60 years providing support for hundreds of South Australian children, young people and adults with a disability and their families." (Underline added)

For carers, these organisation typically provide (or refer to) counselling, respite, information resources on specific care recipient needs, networking opportunities (either online communities and/or face to face groups). They also often provide links to further information sources such as the NDIS, and support services such as Lifeline and Beyond Blue.

CPL (Cerebral Palsy League) is another Ability First Australia affiliated organisation, originally for those with Cerebral Palsy in Queensland:

- *"It's important to know you're never alone. At CPL, our friendly and understanding team is always here to support you and your family with whatever you need. We offer home support and respite, plus family education and support to help you and your family. You can also have your say on the services your child receives and connect with other families at our Parents and Guardians Association"*

Appendices

Another example, **Lighthouse Disability** (Leveda Ltd), operates within a portion of South Australia around Adelaide, but welcomes enquiries from people and families seeking a service irrespective of the nature of the disability.

- *“We strive to improve outcomes for all of the people we support. Aside from engaging with families, this involves working in partnership with other service providers such as allied health staff, day programs, General Practitioners and organisations that provide equipment.”*
- *“We currently provide services to people with Cerebral Palsy, Prader-Willi Syndrome, Epilepsy, Downs Syndrome, Blindness, Spastic Quadriplegia, Autism, Asperger’s Syndrome, Cerebral Dysgenesis, Microcephaly, Stroke, Bi-polar Disorder, Schizophrenia, Deafness, Multiple Sclerosis, Developmental delay and Wilson’s Disease. In many instances people experience multiple disabilities.”*

The results of the primary research show there is overlap and comorbidity among care recipients and often carers so there is a challenge in reaching people with the most appropriate information and services for them.

- *“Given the complexities associated with most of these disabilities, we carefully develop a range of plans to optimise the quality of the support we provide. For example, aside from having a person centred plan, most of the people we support have a range of plans including health care plans, medication plans, nutrition plans and recreation plans. These are regularly reviewed and amended as circumstances dictate.”*

www.lighthousedisability.org.au/

Further, navigating the various systems involved has been cited as an issue by the carers in the current research. The myriad of disability support service providers located throughout Australia tend to recognise this and offer help in this area.

For example, [Northcott](#) claims:

- *“We can help you understand the disability service system so you and your family can access relevant support groups, services and other assistance if you are facing difficulties or a crisis. We offer counselling for you and your family members, connect you with others in a similar situation so you can share experiences, act on your behalf in times of difficulty and arrange support groups and mentoring suitable for your needs.”*

1.6 Carers of people with mental illness

Information for those caring for people with mental illness is abundant through a number of general and disorder specific sites. As for those caring for people with a disability, carers of the mentally ill have access to a range of support services via websites predominantly set up to help sufferers of mental health issues. While most websites are quite upfront about providing information *'for you or someone you care for'*, services and advice are usually to address the needs of the care recipient rather than the carer.

ARAFMI is one agency which primarily focuses on the provision of support for families, carers and friends of those with mental health issues. The agency uses the principles of mutual self help and support to build the capacity of families and improve their quality of life.

The Carers Forum is an Australian service provided by Mental Health Australia for families, friends and other carers of someone living with mental illness. It provides a safe, anonymous online space for us to share our stories and help each other. However it advises that *"the Carers Forum does not provide crisis support or counselling services. If you or someone you know is in crisis and needs urgent help call Lifeline on 13 11 14 or Emergency on 000"*.

Healthdirect's mindhealthconnect advises that

- *"Caring for a person with **mental illness** brings unique challenges, depending on the needs and requirements of the person with **mental health** issues. Carers can be a parent, spouse, relative, neighbour, friend or paid carer. The one thing different types of carers have in common is that they're instrumental in supporting a person with mental illness on their **recovery** journey. Families are often thrown into the role of day-to-day care. Unfortunately this can happen with little or no training or support, sometimes at the detriment of the carer's own mental health and **wellbeing**."*

The services provides links to a number of disorder specific websites' carer help information pages such as Beyond Blue Guide for Carers, Eating Disorders Victoria – friends and carers, On Track - for Families and friends, a free online program for people who are supporting someone with a mental illness.

Some examples of resources and websites for those caring for people with mental illness are discussed briefly below. There is a national and are state based '**Mental Illness Fellowships**', which focus more on families and carers:

- *"Peers—consumers, carers, families, friends—are at the heart of all our program design, governance, delivery and evaluation—and our services are better for that. We work closely with families, carers and friends as well as the person with a mental illness, including those who are hard to reach. Our objectives are holistic -- we work to assist individuals and families in their journey to recover mental health, physical health, social connectedness and equal opportunity in all aspects of life."*

The Black Dog Institute specifies

"Information and support for carers:

- Carers NSW
- Carers Australia
- ARAFMI (Association of Relatives and Friends of the Mentally Ill"

as well as providing advice on dealing with people with depression, anxiety and other mental disorders.

Headspace is a youth specific resource centre: *“ehespace which offers specialist help for parents, families and other supportive adults who are looking for assistance due to concerns about a young person’s mental health. If you are a parent, family member or other supportive adult, you can access support through phone, webchat or email.”* However these services do not appear to be carer focused other than advising how to cope with a mentally ill younger person.

1.7 Carers of aged and frail

There is substantial material available to help carers of the elderly, both online and through publications. My Aged Care provides a government sponsored gateway to access all government supported aged care services in Australia. Outside of the gateway, the number of service providers is overwhelming. In order to ensure the legitimacy of these service providers, the importance of accessing assistance through the My Aged Care gateway or through a trusted referral should be emphasised to carers.

In addition to the Commonwealth and State government health agencies, there are substantial resources available for carers of older people through Carers Australia and its State organisations.

As well as My Aged Care and Carers Australia, as major entities providing information and resources, a number of other non-government organisations provide a gateway function.

[AgedCarer](#), an organisation with a goal of providing an online site, content and services with easy to understand information, tips from experts and other carers, easy navigation of the complexities of the aged care system, and a community forum of carers to support each other.

The [Benevolent Society](#) has a range of information about ‘being a carer’ and the site also includes a services directory that can be searched for relevant services.

The [DPS Aged Care Guide](#) provides news, information and service finders.

In addition, there are other networks of aged care providers offering services to the aged and their carers.

[Hunter Aged Care Palliative Care Network](#) (HAPCN) through a network of liaison nurses, has been leading the Palliative (Comfort) Approach in Aged Care for many years. Nurse Representatives from aged care facilities and community aged services across the Hunter, its website has links to other service providers and numerous pdf format advice sheets for families and carers.

The WA State government Aged Care Network is a collaboration of health professionals, carers, consumers and other individuals, organisations and groups. These groups have a diverse experience in aged care and a common interest in planning and developing aged and health care policy and services across the state.

1.8 Carers of people with chronic or terminal illness

Information and services for carers and families of the chronic and terminally ill are offered through State based Palliative Care organisations. There is more emphasis on the emotional journey for carers and care recipients facing the end of life.

[Caresearch](#) provides a service finder and numerous information sheets for carers to download, covering topics such as:

- Continuing to Work,
- What to Say,
- Social Support,
- Respite,
- Coping with Long Distance Caring,
- Family Carer Coordinating Role and
- Practical Caring resources.

[Lifecircle](#) provides help sheets (information fact sheets) and resource referral lists for carers of those at the end of their lives. Lifecircle says “Caring for someone at end of life can be the one of the most daunting experiences we face, and yet it can also create opportunities for us to develop a deeper understanding and experience of life.”

Southern Cross University research has published a Guide to Advance End-of-Life Care Planning For Gay, Lesbian, Bisexual, Transgender and Intersex People '[Respect my decisions: It's My Right](#)'

[Caring for the Dying](#) provides a number of resources for carers, mostly authored by Michael Barbato who has been in medical practice for more than 40 years and has been a palliative care physician for over 20 years. During this time he has directed several palliative care services within NSW and the ACT and has held the positions of Medical Director at the Sacred Heart Hospice, Darlinghurst, NSW and the Palliative Care Unit at St Joseph's Hospital, Auburn NSW and was Director of Palliative Care for the ACT Canberra. He retired in late 2008 and now runs courses on Death and Dying for professional and community groups and his website lists resources for carers.”

[Living Caring Working](#) offers online information and resources for those living with a terminal illness, carers and their work colleagues. Booklets and info can be downloaded. The website was developed by Palliative Care Australia with funding from the Australian Government Department of Health and Ageing.

The Lung Foundation, The Cancer Council, MS Society, Muscular Dystrophy Association and many other such organisations all offer condition specific advice for carers of those suffering chronic or terminal cases.

We see here again that the abundance of information and support for carers available is widespread and usually depends on the characteristics of the care recipient.