



Carers information and technology project

Exploring the information needs and technology preferences of new carers in New South Wales



Health
South Eastern Sydney
Local Health District



BACKGROUND

In 2018 over 2.6 million Australians provided informal care to family members or friends with a disability, mental illness or chronic condition (ABS, 2019). Unpaid carers provide an extensive range of support, including health care, financial management and property maintenance. Carers may take on a caring role because they feel a sense of responsibility, social or financial pressure (FAHCSIA, 2011, p. 4).

Many carers report that caring is a positive and rewarding experience; however, they have their own health needs, separate to the person for whom they are caring. Carers generally experience poorer physical and mental health than the general population, have fewer social connections, and find it difficult to balance caring with family life and community participation (ABS, 2019; Cummins et al., 2007).

The effect that the caring role has on caregivers is diverse. Although some carers report a sense of fulfillment from their role, caring can often lead to stress, fatigue, burnout and feelings of entrapment (Mohanty & Niyonsenga, 2019; Stacey et al., 2018). Carers face many challenges as they manage their caring responsibilities with competing demands such as work and caring for other family members. Despite a growing awareness of the importance of carers from federal and state governments, it remains unclear whether Australian carers are well supported by current health resources (The Office of the Royal Commission, 2019).

Access to good information helps carers (Al-Janabi et al., 2019). Caring often starts suddenly and people need to quickly learn and adapt to being the person that is providing care for the care recipient. Throughout their caring journey people need information about services, resolving problems and getting personal support (NSW Government, 2014, p. 17).

CARERS IN SOUTH EASTERN SYDNEY LOCAL HEALTH DISTRICT

In SESLHD, 10% of the population over the age of 15 years are carers with 60% of the carer population being women. The majority of carers are aged between 50 and 69 years (70%).

Carers of people with disabilities in SESLHD provide care for partners (38%); children (29.6%) and parents (22%). The St George area (Georges River LGA and Rockdale LGA) has the highest percentage of carers by population across SESLHD (28% of the district population; 32% of the total carer population) (SESLHD, 2018).

Groups of carers with vulnerabilities include:

- Young carers aged between 15-25 years of age (9% of the carer population)
- Aboriginal and Torres Strait Islander carers (37% of the carer population)
- Carers who speak a language other than English (11% of the carer population)
- Carers who themselves have a disability (36% of primary carers of people with a disability have a disability themselves)
- Older carers aged over 85 years (6% of the carer population) who have the highest need for assistance across all carer age groups
- Working carers (48% of primary carers of people with disabilities are in the workforce) (SESLHD, 2018).

SOUTH EASTERN SYDNEY LOCAL HEALTH DISTRICT (SESLHD) CARERS PROGRAM

The SESLHD Carers Program:

- leads the development of the SESLHD Carers Strategy and implements NSW Health Recognition and Support for Carers Key Directions 2018-2020 (SESLHD, 2019; NSW Government, 2014);
- facilitates understanding of carer needs and ways to address these needs, including through targeted research;
- builds capacity of the local health district through training and education to health professionals; and development of resources;
- supports carer-inclusive strategies, including working carers;
- promotes participation of carers in the design and delivery of services;
- improves systems to assist carers to access information, support and services;
- works with key stakeholders and partner organisations to support carers (SESLHD, 2019).

NSW CARERS STRATEGY 2014-2019

The NSW Carers Strategy identifies five key focus areas for reforms and further development (NSW Government, 2014). Two of these five focus areas relate to the engagement of carers in the health system as well as the easy access of relevant information for carers when they need it. The Focus area three is *Information and community awareness* and the planned activities include ‘Embed and improve information for carers in the trusted systems they frequently use’ (NSW Government, 2014, p. 17) with an outcome stating carers are able to easily access information when they need it.

PURPOSE

In collaboration with South Eastern Sydney Local Health District (SESLHD), the South Eastern Research Collaboration Hub (SEaRCH) undertook qualitative research that focused on answering the following questions:

- What are the information needs of carers?
- Do different groups/types of carers have different information needs, and what are these?
- What barriers do carers face when trying to access information in NSW?
- What are existing or feasible uses of technology to meet carers' information needs?

Semi-structured interviews were conducted with people who had recently come into a caring role (within 6 months-3 years). The content of these interviews was intended to inform the development of more appropriate information resources for carers in contact with the health system, and to enhance the methods of information provision.

The research project included:

1. A qualitative research project investigating the information needs and technology preferences of new carers in NSW
2. Carers Validation Workshop – presentation of research findings to SESLHD Carers Consultants to ensure validity of research findings / interpretation
3. Research to Practice Workshop where key SESLHD services were invited to attend to discuss implications of research for their role/unit and the District.

KEY FINDINGS

QUALITATIVE RESEARCH WITH CARERS

PARTICIPANTS

- Thirteen semi-structured interviews were conducted.
- Participants were recruited from across NSW.
- Recruitment was restricted to those relatively new to the caring role – no less than 6 months and no more than 3 years at time of recruitment.
 - The rationale for limiting participation to people who has been in the role for more than six months was to ensure that people are familiar with their new caring role and that they were less likely to be experiencing distress as a result of recent changes to their roles and relationships.
 - The rationale for limiting participation to people who had been carers for less than three years was to increase the relevance and recall of information needs related to becoming and being a carer, and to minimise the extent to which the data may reflect reconstructed logic or hindsight bias.

“I just think that previously, because I was a registered nurse, I didn't think those carer things applied to me. Because I felt, "Well, I've been in that role as a registered nurse.”

KEY THEMES AND CONCEPTS

- Sources of information for new carers are both online, including Google and social media and in-person, such as from referrals or information provided by services that they are already accessing.
- There are generally two distinct types of information that carers search for
 - Factual – usually related to the carer needs or condition of the person they are caring for;
 - Narrative – most often sharing stories with other carers online.
- There are several barriers to carers accessing information, including:
 - The vast amount of information readily available online can make finding the information they need difficult and time-consuming;
 - The carers own level of knowledge of where to go to get the information they need;
 - Often the carer does not identify as being a ‘carer’ and therefore does not see the information as relevant to them.
- There are several facilitators to carers accessing information, including:
 - Being linked in with “gatekeepers” of information, often a worker within a service that the carer is already familiar with, or provided information at the time of service admission;

“It’s more support from others and reading about things and my eyes have opened in that Facebook group because there's a lot of people who are similar to me, but there's a lot of people that are better off and there's a lot of people who are worse off. So, it’s giving me a generalisation that I'm not the only one.”

- Being well linked in with supports and services;
- Own motivation to search for information.
- Information needs for carers change over time and at different stages of their carer journey. Often at the start of their carer journey they are looking for practical information, for example how to arrange Power of Attorney. As carers become more familiar with their new role, they are seeking information on services and supports and how to plan for changes that may arise.
- Carers need relatable information and support from reliable sources.
- Challenges that carers face in their role:
 - Navigating their way through services and systems;
 - Stigma from others;
 - Pressure put on themselves from self or others;
 - Lack of understanding of the carer role from others;
 - Changing relationships;
 - Lack of support;
 - Loss of identity and “me-time”;
 - The “unknown” – often not sure what the future looks like or how things might change over time for the person they are caring for.
- Many carers do not identify with the term ‘carer’ and often do not consider themselves as a carer until someone refers to them as such. This often occurs at a critical point in time, for example when the person they are caring for is admitted into hospital. This often acts as a catalyst for the person to commence looking for information about carer supports and services.

“How do I plan for my future? I have no superannuation, again taking time out from the workforce, what does that really mean? What are the possible difficulties that you can face and how to prepare for that. I guess it's a little bit of psychology and counselling, but preparing for re-entering the workforce.”

“Only if it was like a one-stop place where you can get all information.”

“Only “At first I would've never considered myself as a Carer. I think for the first year I was like, 'No I'm a mum and this is what I do, and this is what all mums do.' But then I got to realise you know that, 'No, I'm not in the same position as other Mums. So I even hated using that word 'as a carer'. For the first year I thought, 'No I'm not a carer'. But yeah it's evolved, it's become my new normal. At first I didn't like the idea of it but, yeah.”

CARERS VALIDATION WORKSHOP

A workshop was held with a group of SESLHD Carers Consultants. The SESLHD Carer Consultants are people living within SESLHD who have either had experience caring for someone or are currently a carer. that the District meets with at different stages to seek their input into activities within the Carers Program. The aim of the meeting was to first present the key themes and concepts of the research then to have a discussion amongst the group as to possible implications of the research findings and ensure that our interpretations were correct.

Key themes/concepts	Points raised in discussion
Different sources of information	<ul style="list-style-type: none"> • General Practitioners (GPs) are another key source of information for carers.
Types of information – factual and narrative	<ul style="list-style-type: none"> • Group generally found the idea of this interesting, in particular that a lot of carers are turning to social media platforms to find support from other carers and share their stories online. • Discussed issues with social media re. privacy and reliability of information.
Barriers to accessing information	<ul style="list-style-type: none"> • Group agreed that all barriers found in research were true to their experiences. • Discussion was had around having a “one-stop shop” where all information was available in one place but could be presented in different ways depending on what stage of the carer journey you were on, similar to an ‘ages to stages’ approach. • Additional barrier discussed – carers are time-poor and their days are often unpredictable, there often isn’t time to search for information.
Facilitators to accessing information	<ul style="list-style-type: none"> • GPs are gatekeepers and very important to be linked with. • Talking to others acts as another facilitator to information – talking about the carer role and ‘demystifying’ it.
Information needs change over time	<ul style="list-style-type: none"> • Needs of carer are different depending on what stage they are in e.g. employment vs reaching retirement age. • Practical information for carers is needed e.g. returning to work and superannuation.
Relatable and reliable information is needed	<ul style="list-style-type: none"> • Government websites • SESLHD Carers website • Issues raised about sorting the reliable information from unreliable / incorrect information.
Challenges carers face	<ul style="list-style-type: none"> • Discussed elements of isolation and loneliness. • Not wanting to tell others of carer role and therefore not gaining support.
Self-identity	<ul style="list-style-type: none"> • Members of the group agreed with findings – many had realized they were a carer when GP or other health professional labeled them as such during a consultation.
Other points	<ul style="list-style-type: none"> • Need to raise awareness of the carer role. • Including wider community services in programs and activities as they are often working with carers. • Importance of providing information in different languages, different forms. and have it available in different places.

SESLHD STAFF WORKSHOP

A workshop was held with twelve SESLHD staff members from various roles and departments, which was also attended by four carers consultants. The findings from the research were presented and staff were asked to consider the implications of the research for their individual roles or units, as well as wider implications for the District and recommendations moving forward. These are outlined below

IMPLICATIONS, CONSIDERATIONS AND RECOMMENDATIONS

IMPLICATIONS OF THE RESEARCH:

- Staff awareness about carers, their caring roles, and information available can vary.
- NSW Health staff and other health care workers have the opportunity to identify carers at early stages of their caring journey.
- Staff having access to the correct/relevant information for carers in order to provide meaningful support.
- This may have implications for other groups, for example GPs.

CONSIDERATIONS AND RECOMMENDATIONS

PROVIDING INFORMATION

- Carers should have a role in ensuring that information being provided is relevant and up to date.
- Information should be designed for, and provided to, wider networks, e.g. community services.
- Consideration should be given to monitoring and reporting on information provided to carers, and where they have been referred.
- Where possible existing sources of information should be used, e.g. Carers NSW, rather than developing new resources.
- Different forms of information should be developed/promoted, e.g. written information, videos, etc.

CONSIDERATIONS FOR SESLHD AND PARTNER ORGANISATIONS

- Consider providing workforce development activities that specifically focus on carers' information needs, e.g. staff training.
- Consider activities that support the inclusion of carers in project governance mechanisms across the District, including expression of interest processes and inclusion in standard committee terms of reference.
- Apply for funding for targeted projects to support providing information to carers in SESLHD, e.g. the concept of a Carers Hub within the District that was raised by carers involved in this project.
- Monitoring and reporting on:
 - the nature and extent of information provided to carers
 - how this information is accessed
 - the quantum of use (access, downloads, occasions of contact, etc).
- Raising the profile of carers within SESLHD as key partners in delivering and sustaining person centred care.
- Present findings of this research to key partner organisations, such as the Central and Eastern Sydney Primary Health Network and its Clinical and Community Councils.

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ABOUT SEaRCH

The South Eastern Sydney Research Collaboration Hub (SEaRCH) a partnership between the UNSW Sydney Centre for Primary Health Care and Equity (CPHCE) and the South Eastern Sydney Local Health District.

CPHCE is a research centre within the Faculty of Medicine, UNSW Sydney, that has been undertake primary health care since 1996. South Eastern Sydney Local Health District is a statutory authority responsible for 8 public hospitals and a range of community-based health services covering a culturally and linguistically diverse population of over 830,000 people.

SEaRCH's role is to strengthen the planning and delivery of evidence-based primary health and integrated care. We undertake research, evaluation and capacity building activities to strengthen primary health care and address health inequities, with the aim of contributing to better, fairer health in the community.

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