Carer Gateway: providing support for country carers

Robyn Linkhorn
1Healthdirect Australia

Introduction

This paper will include information about:

- the Carer Gateway service
- the purpose of Carer Gateway
- the research conducted to inform the service development
- how Carer Gateway supports the work of health professionals
- a case study to illustrate different aspects of Carer Gateway, and when they may be most appropriate or relevant within a specific carer journey
- accessing Carer Gateway.

What is Carer Gateway?

Carer Gateway is a government-funded service that provides information about the services and support available for people who care for someone with a disability, chronic illness, dementia, mental illness or frailty due to age.

The national service consists of a website and telephone contact centre, and is managed by Healthdirect Australia on behalf of the Department of Social Services. The service launched in December 2015.

What is the purpose of Carer Gateway?

Carers play a vital role in the health care system. For every patient diagnosed with a serious condition, someone is usually helping them with day to day activities, such as getting to appointments, buying groceries, personal care and cleaning.

Prior to the launch of Carer Gateway, carers were accessing information and services via different pathways across disability, mental health and aged care sectors which were not designed to support their individual circumstances. In recognising a need to sustain this vital work of Australian carers, Carer Gateway was designed as an entry point for carers to navigate through the resources available to them, helping them find information and support and assisting them in every stage of the carer journey.

The service is the first step in delivering the Integrated Plan for Carer Support Services, released in the 2015-16 Federal Budget.
How did research inform the development of the service?

Research to inform development of the service was conducted by AMR. The overarching objective of the research was to understand the needs of carers to inform the development and design of a carer information and support service delivered via contact centre and website, and supported by service finder functionality.

The research comprised both qualitative and quantitative methods and included more than 1,300 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.

Some key statistics revealed by the research included:

- There are almost 2.7 million carers in Australia.
- More than 30% of carers live in rural, regional and remote areas of Australia.
- In outer-regional and remote areas carers experience higher rates of disability or long-term health conditions than those in the same regions who are not carers.
- 53% of carers are female, and 47% are male.
- Most carers are in paid employment—only 10% receive a carer’s payment.
- Carers are significantly time poor, spending an average of 4.4 hours per day caring.
- 54% of carers are the only person providing care.
- 79% of carers do not see themselves as a carer.

Through the research findings, carers needs were specifically addressed in the design and delivery of the service. Key research themes and corresponding design elements included:

**Understanding Australia’s carers**—this theme involved exploration of the different types of carers and the challenges and benefits of caring.

Research revealed that carers are extremely diverse across demographics, cultures, geographic locations, caring responsibilities and experiences.

Challenges of caring included putting their own needs second, isolation, the emotional impact of caring, difficulties in accessing support and services, complex navigation when accessing government services, financial burden, and lack of confidence in their own caring skills.

Benefits included being able to give back to the care recipient, pride in taking responsibility for their caring role, improving the care recipient’s quality of life, developing a closer relationship with the care recipient (especially when caring for parents and grandparents). For Aboriginal and Torres Strait Islander peoples, a key benefit to caring was the knowledge that their family members were safe and the family unit was maintained.
Size of the hidden carer population—this theme explored whether carers see themselves as carers (79% don’t) and investigated ways to communicate with the hidden carer population effectively. The term carer was found to be well understood but the majority of carers do not see caring as their primary responsibility or association with the care recipient.

Access to information, support and services—this theme explored how carers were getting access to the tools they need, and revealed in general carers were accessing limited services for themselves. When they were accessing information, support and services it was via different pathways across disability, mental health and aged care sectors which were not designed to specifically support carers.

These research findings informed inclusion of design elements to make navigation across these different pathways clear and simple. A powerful search function means finding information on the website is efficient and simple. Articles about certain elements of caring are grouped together in content hubs. Carers can search for local services with the ‘find a service’ tool—more than 16,000 services are searchable from Carer Gateway, for a variety of needs from respite to support groups and counselling. These features guide carers to the information and support they need without onerous browsing.

Research also showed most carers rely on mobile based online access so the website was designed with a mobile first approach whereby it adapts to all device sizes.

Developing Carer Gateway—this theme explored the wants, needs and expectations of carers and gathered feedback on the gateway concept. Carers need a central service which provides them with information on what services are available to them. The gateway concept was well received, with carers indicating they would either definitely or very likely access the service via the website (57%), the service finder (51%) or the contact centre (27%). Carers would be likely to seek both emotional and practical assistance via the service.

How does Carer Gateway support the work of health professionals?

Carer Gateway can be used by health professionals in a variety of ways to support their patients and the vital work of their carers. People can be directly referred to the contact centre or the website to explore information, support and services available to them in their local area. Health professionals can use the service themselves to identify services which would be appropriate for the specific needs of their patients and their carers.

Carer Gateway can be a time saver for busy health professionals, as it takes the work out of searching around for appropriate local services to refer carers to. Carers can easily do this research themselves, as the navigation is clear and simple. From the research many health professionals recognised this as a significant advantage to the service for them.

Carers see their GPs as a key source of support. The research showed that 66% of carers ask their GPs for information about support and services available to them, and that 71% of carers want more support from their GPs and other health professionals. Carer Gateway is the best place to start in providing this support carers are seeking, as it is the gateway into the whole suite of information, support and services available to them. Referrals to the Carer Gateway service carry weight when they are given by a trusted health professional.

Carer Gateway provides information and support which is highly relevant to the three critical times carers are most likely to need additional support—when caring starts, when the condition of the care
recipient changes or co-morbidity develops, and when caring ends. Health professionals who recognise these as the optimal times to refer to Carer Gateway are providing the right support when it is needed most.

Throughout our research, the difficulties faced by carers were often acknowledged by health professionals:

“Being a carer is a job that never ends.” (GP)

“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)

Health professionals included in the research agreed that their role was critical in providing carers with access:

“When I’m trying to link them into other services, I do the phoning myself, because I’m better at it basically. I’ve had more experience.” (Social worker)

“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 it might be difficult for them—they don’t have the same resources… know what to look for, or exactly where to look.” (GP)

Case study of a carer

Name: Joe

Age: 45

Location: West Wyalong, NSW, 2671

Joe cares for his wife, Jane, who is 45 years old and has multiple sclerosis. Joe and Jane have two children—Tim (14 years old) and Kate (12 years old).

Jane’s condition means she requires a wheelchair. Her fine motor skills are deteriorating and she requires help preparing her meals, taking her medication, showering, dressing, and getting in to the car but she is still able to drive. Jane has regular visits with her physiotherapist and her GP, and sees a specialist about her condition every six months.

Joe works as an interstate truck driver, and is often away from home. The children look after their mum when Joe is not home, and always assist with the cooking, cleaning, shopping and washing.

Tim saw an advertisement for Carer Gateway on Facebook one evening. He knows how much stress Joe is under, and told him about the service. Joe decided to call the contact centre the next day to find out about local services which may assist him.

The person Joe spoke to asked a range of questions to build a picture of Joe and Jane’s particular needs—from physical requirements to emotional support—to make appropriate referrals to local services. Joe was told about the range of resources available on the website for him to look though in his own time, and was referred to a home modification service run by the Bland Shire Council for assistance with modifications to make the home and garden safer and easier for Jane to get around. Joe was also asked whether he felt he needed access to counselling or respite care, which he declined at that time.
Joe was connected to the home modification service directly by Carer Gateway, and was then able to arrange for a case officer to visit and assess their needs at home.

Later, Joe visited the Carer Gateway website. From the home page, Joe explored the three main sections, and discovered a range of information relevant to his needs:

**Caring for someone**—in this section Joe found specific information about caring for Jane, including:
- Ways to help when caring for someone with a physical disability, including some which he had not considered before.
- Financial support available to carers, and managing money with the additional expenses relating to Jane’s condition.
- His legal rights as a carer, and advice on managing the relationship with his employer and his rights as a working carer.
- Taking a break through respite care, which he knows may be something he will need in the future.
- Other services available including disability support and transport services.

**Caring for me**—in this section Joe found specific information to help him and his children, including:
- Keeping himself fit and healthy through exercise and a balanced diet, which Joe struggles with due to his job as a truck driver and his caring responsibilities.
- Opportunities to connect with other carers for advice and support.
- Support available for young carers, as Tim and Kate are taking on more responsibility all the time and it is important they maintain their social networks, and continue with their high school studies while caring for their mum.

**When caring changes**—in this section Joe found information about how the caring role changes over time, including:
- How the relationship with the care recipient changes due to caring, which helped him understand and accept his changing feelings for his wife.
- How to plan for the future, as Jane’s needs will increase over time as her condition worsens.

Two months after Joe first contacted Carer Gateway, Jane slipped when trying to get herself from her wheelchair into her car unassisted. Joe and the kids all feel guilty because they weren’t there to help her at the time, and even more stressed as Jane broke her right arm in the fall—she now needs more daily care and can no longer drive.

A week after the fall, Jane visits her GP to check her cast. Jane’s GP recognises that a change in the caring situation can cause additional stress for the carer, and asks a practice nurse to spend time with Joe during Jane’s consultation to see if there are additional services available to assist Joe in his role.

The practice nurse walks Joe through the guided search function on the Carer Gateway website. This function gathers detailed information about what the carer and care recipient’s current needs are, and generates a list of relevant links to information, services and tools.
Joe finds information about transport options, including financial assistance that Jane may be eligible for to help with costs of travel. He can also see that there are several community transport services available which can assist Jane to get to her appointments. The practice nurse can also see that Joe might need some extra help at home while Jane is recovering from her broken arm and helps Joe look up some local services to contact. The practice nurse shows him how to email all the information directly to himself from the website.

Joe and Jane leave the GP practice feeling supported and confident that they can overcome their current challenges.

**Accessing Carer Gateway**

Anyone can contact the Carer Gateway service.

Telephone: call **1800 422 737** from Monday to Friday between 8am and 6pm for information about services and support available.

Website: visit [www.carergateway.gov.au](http://www.carergateway.gov.au) to access information about caring and support services available. A call back service is available through the website as well. People leave their details and the contact centre calls them back on the day and time that best suits them.

Service finder: Carer Gateway website has an interactive service finder to help carers locate their nearest carer support services.

**Presenter**

Robyn Linkhorn is the Carer Gateway Manager for Healthdirect Australia. Robyn leads the Carer Gateway service, which includes a contact centre and website providing access to information and services for carers and their support networks across Australia. Robyn has extensive experience working with digital technologies in not-for-profit, public, private and education sectors including project implementation, management, facilitation, learning design, and developing products with a user-centric focus. Robyn believes in authentic online experiences that integrate emerging technologies, innovative design and business strategy. She uses her knowledge and experience to clearly transfer technical jargon into plain English and enjoys exploring the utilisation of technology to provide content through appropriate channels to end users.