



## Carer Workshop 2023

### Carer Feedback Key Summary

During 2023, Carers SA hosted a series of workshops across South Australia to listen to the voices of South Australian Carers. During these events, Carers shared with us their feedback, thoughts and ideas about services for Carers now and into the future.

This Report is a collective summary of the discussion with Carers who attended the workshops.

Carers SA held a Carer Workshop in the following locations:

- Port Lincoln,
- Metropolitan Adelaide – Salisbury,
- Metropolitan Adelaide – Reynella,
- Barossa Valley, Light and Gawler,
- Riverland,
- Limestone Coast.

In total **213 Carers attended across workshops**. The information and experiences shared by Carers will be used to advocate for services and for the recognition of Carers.

## Part 1: Value of Current Services

### We asked Carers what services currently available were of most value

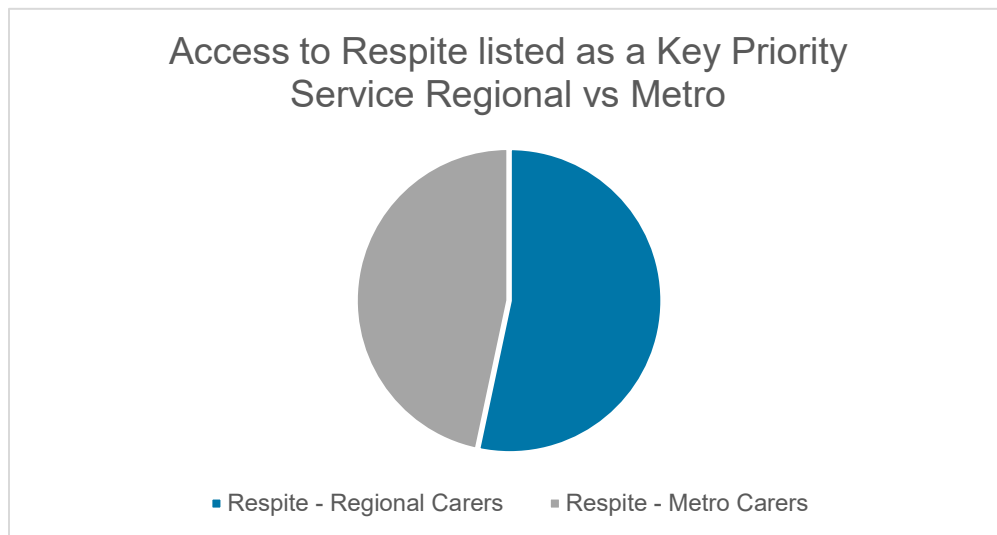
Overall, Carers told us that all services currently available via Carers SA are important and respond to the specific needs of individual Carers over time as caring roles and circumstances change.

Across regions, there were distinct differences in what services Carers valued most. Not all Carers had direct experiences of having accessed all of the available services, therefore Carers had an opportunity to share direct experiences with others and discuss the value of offered services to them or other Carers, depending on individual circumstances.

### Top Valued and Needed Services: Respite and Breaks for Carers

Without any doubt, having appropriate and timely access to respite services when needed and an opportunity for Carers to take a break from their caring role has topped the list of most needed and valued services.

**Timely access to respite** was close to equal importance and need for Carers in metropolitan and regional South Australia.



Some Carers mentioned the red tape involved when trying to access respite services.

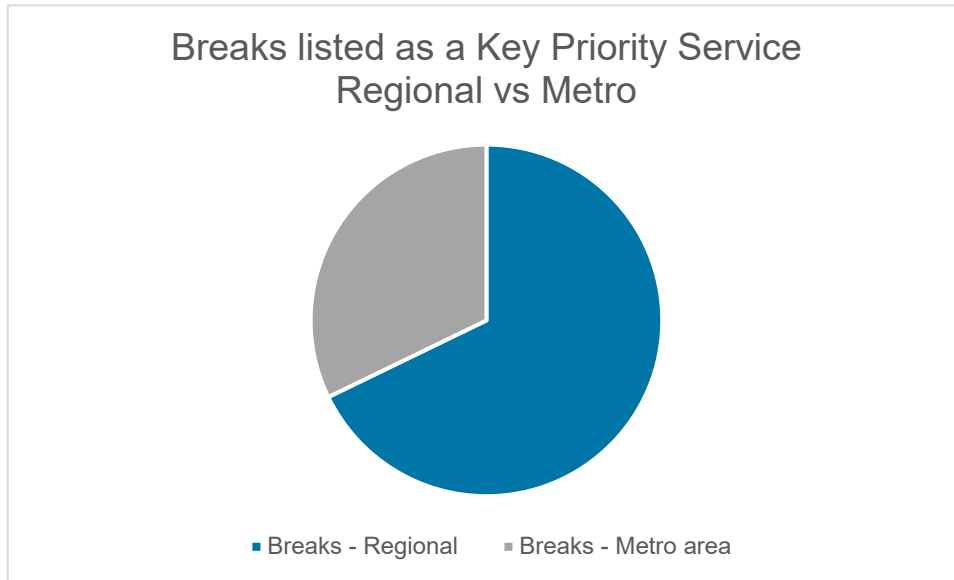
Regional Carers in particular, stated that respite services were difficult to access, as often a suitable provider is just not available, or is not available at a time when it is needed.

Some Carers see respite in a similar light as having a break from their caring role. Therefore, some of the discussions between respite and breaks for Carers overlap. This does not however distract from the in-principle need for respite as well as breaks for Carers.

### Breaks for Carers

About every third Carer from the Metropolitan area listed that breaks from their caring role is of key importance. Other Metropolitan Carers and Carers in the Barossa Valley/Light/Gawler region, generally also reported that although breaks are very important, they potentially have more local options to take a break from their caring role whether these are via funded 'breaks for Carers' initiatives offered by Carers SA or due to the proximity of wider support network options.

On average, 59% of regional Carers (representing Limestone Coast, Port Lincoln, and Riverland on average) listed breaks as key to their wellbeing.

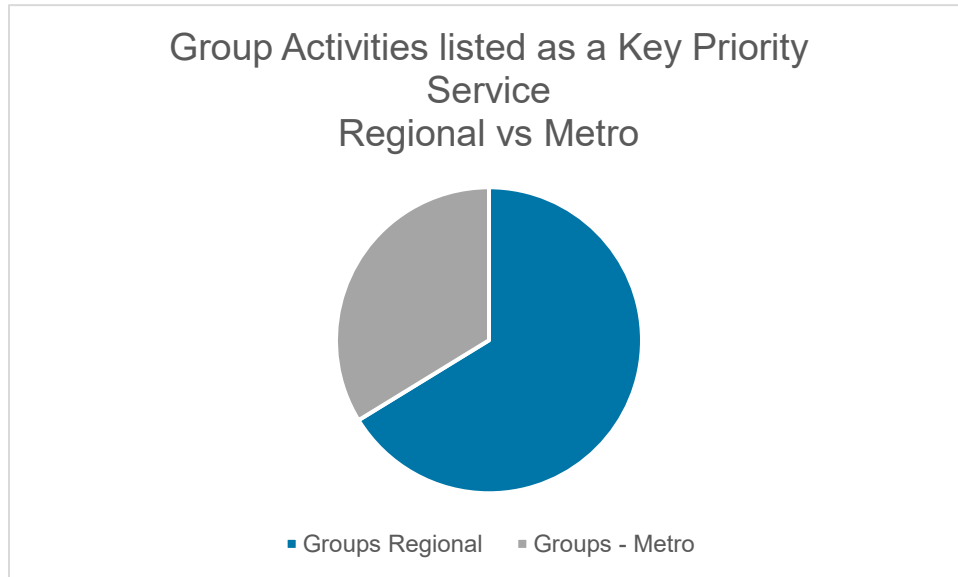


Carers explained that due to distances, their caring role and general task demands, they often may feel overwhelmed by the amount of time and general preparation required to take a break opportunity, especially where this requires farther travel. Quite often Carers may give up, or not even attempt to go on a break as it is 'just too hard' and not worth it for a 'short' break.

Break options that were well organised by providers with easy to access and complete summarised details provided well in advance were most appreciated by Carers.

### Group Activities for Carers

Meeting other Carers in a group environment was of key importance to 54% of regional based Carers who attended the workshops. Whereas on average, 27% of Metropolitan based Carers who attended, as well as Carers from the Barossa Valley/Light/Gawler region specifically, listed groups as their key valued service.



Some Carers who attended had accessed the Carer Gateway Peer Support Groups offered by Carers SA. Most Carers (including those who had not accessed that service, but may have heard about it on the day) identified Peer Groups more in their capacity to bring Carers together to talk.

Carers identified group activities as an important service as it can serve two distinct purposes. Most Carers identified social activities within a group as the key attractor to join a group, but many also acknowledged other benefits.

The other benefits of group activities are that Carers can share experiences in a safe environment, and discuss certain caring role strategies, learn from others, provide support and resources for others, especially if these activities are facilitated.

Most Carers however were very clear that the purpose and times assigned in group activities should be clearly differentiated whether these are purely social activities that provide a reprieve from the caring role (break-like), and those group activities that involve a structured sharing of experiences and role specific discussion.

### Counselling – a highly valued service

The specialist Carer Counselling service was valued equally high by all Carers across regional areas (37%) and the Adelaide Metropolitan area (32%). The value of Carer Counselling was seen to be related to getting access to someone when Carers were at the end of their tethers.

Feedback from Carers included statements that there was someone to talk to who would understand and one did not have to feel guilty about the feelings the caring role may conjure. Counselling seems to

have been predominantly seen as an opportunity to voice concerns in a trusted environment and an opportunity for Carers to be heard.

Different modes of accessing Carer Counselling were important to Carers as well. For example, easy access to face to face Counselling was beneficial and phone sessions were good for other times. One Carer mentioned that Counselling was "*a stress relief, life-saving, brilliant and respectful help*".

### Services for Young Carers

A small number of participants were Young Carers, who reported that specialist services for Young Carers are absolutely vital. This is especially the case as many Young Carers in the community are not aware of their status as Young Carers and more often become aware of specialist services for Young Carers accidentally, or when a crisis has arisen.

During the discussions with Carers, there was however strong solidarity and great compassion for Young Carers and their special circumstances in life and support needs. Senior Carers voiced strong concerns regarding the wellbeing of Young Carers, the struggle to achieve education outcomes and barriers to achieving their life aspirations.

As one senior Carer put it:

*"I am struggling with the demands of my caring role on a daily basis. There are often so many things that need doing at the same time, that I often don't know 'whether I am Arthur or Martha'<sup>1</sup>. I am really worried about Young Carers. They are just starting out in life and are already struggling. Young Carers really deserve all the help they can get – at home, at school and then to get good employment."*

Carers SA will continue to advocate for the recognition of Young Carers and a systemic approach to addressing their specific support needs related to their caring role, their education, and achieving their own life aspirations.

### Other Services

Other services like Tailored Support Packages, Planning Support, Coaching for Carers and assistance with practical help were confirmed by many Carers as of value and important, as these could be accessed especially when a particular need arises and life circumstances are best addressed by defining goals, additional planning or specific help, or topping up of specific skills.

#### Examples:

**Coaching:** Not many Carers who have attended the workshop seem to have accessed Carers SA's coaching services. However, the perceptions of what the coaching service provides has attracted positive responses as Carers identified the potential for good value for Carers.

Some Carers who have accessed the service agreed that it is a useful service.

---

<sup>1</sup> A popular mid-century expression, denoting a state of being highly stressed trying to deal with a number of competing priorities and/or excessively high work loads, or with sustained challenges.

Comment: *“Coaching - they help so much in what’s going on in your life and help you with what you can do in your process.”*

**Tailored Support Packages:** Carers who have accessed a Carer Gateway Tailored Support Package have seen it as *‘absolutely vital’*. During discussions many Carers disclosed financial hardship and conveyed that they manage under perpetually stretched budgets with limited, or no disposable income.

Carers discussed that they are regularly subsidising costs associated with health care or other needs of the (adult) person receiving care, adding additional budget stress. *“... we just hope that nothing breaks down, but fridges and washing machines are getting older and it will happen sooner or later. Utility cost and car rego [car registration fee] are ridiculous now”*.

**Access to Practical Help:** Carers certainly appreciated receiving practical support and help through Carers SA. Carers mentioned that practical help and support needs to be available with many more options, consistently and ongoingly.

Carers who have a specifically high need for additional practical help are:

- Older Carers
- Carers who provide care to more than one person.
- Carers who support people with mental illness.
- Carers who support people with Dementia.
- Carers who care for a person with a profound disability, or require round-the-clock supervision/support.
- Carers who juggle a caring role with employment to make ends meet.

Budget limits were a concern for one Carer who put the needs of others ahead of their own needs. The Carer did not take that support option up because there could have been another Carer out there who may be in an even worse situation.

This will certainly continue to be a funding advocacy item for Carers SA.

Across all workshops, Carers said that Carers SA services are important and good experiences were shared. Positive statements were specifically about how important it was for Carers to know Carers SA was getting them help when in dire situations.

Overall, there was not one service currently available that Carers considered not important for Carers at one point or another during their caring life.

## Part 2: Services into the Future

We also asked Carers to share ideas of services that are not available at all, or only available in a limited way.

Here are some key dot points that Carers shared which will feed into strategic considerations and Carers SA's advocacy for South Australian Carers:

### Preferred Mode of Service Delivery now and into the future:

- Carers certainly prefer person to person / face to face contact. However, once rapport is established, telephone, online video meetings are also accepted by Carers with confident digital literacy.
- Carers who were time-poor, or lived in regional areas, or were otherwise isolated, appreciated online access and video conferencing – including Carer Peer Support Group.
- Certainly, one size does not fit all – one option only does not work for various individuals and in changing circumstances.
- Some Carers mentioned that out-of-hours delivery of some services may be of benefit for Carers who cannot access services during normal business hours.
- Encouraging more connections via Facebook to address isolation and disseminate service information.
- Regardless of the modes of delivery of a service, Carers who had accessed a service mainly felt connected and respected.

### Carer Wishlist for Services

During the discussions Carers identified and offered ideas about services that would benefit them but were currently not available – or if available, would benefit from expansion/improvements.

Here are some key examples of the Carer Wishlist.

- Better attention to health, aged care, and disability support sector issues.

It is very easy for Carers to talk about the services needed for the person receiving care. It is a lot harder for Carers to think about their own needs. Carers told us that it is often the difficulties with sourcing and maintaining appropriate levels of suitable services that address the needs of the person receiving care that make their life harder than it could be.

Many Carers said that if they did not experience as many issues and stress negotiating My Aged Care and NDIS related services and providers, their stress levels and own wellbeing would be better, as their workload would reduce.

There are also quite a number of discussed gaps in the service landscape for people who are not eligible for My Aged Care or the NDIS or have mental health concerns or illnesses not yet or fully diagnosed, or are on waiting lists for assessments, packages or services.

Carers told us that this is a major cause of stress and also additional workload with no (even temporary) escape options. Carers told us that calling Carers SA is their only option of last resort.

- Carers told us regarding communication preferences:
  - a) Carers prefer now and into the future, effective, timely, complete, easy to access, and quick to understand communication across various media (i.e. text messages, emails, telephone calls, mail, social media, e-news, etc.), as a general principle.
  - b) Carers often receive items of communication and information from various sources across sectors, agencies, services, service providers, government departments, and utility providers. This can cause information overload, especially during times of stress or intense caring role needs.

Carers told us that in order to ensure that Carers have the right information at the right time, these issues, a) and b) must be taken into account during any communication with Carers.

- Carers SA and services for Carers should have a more prominent place in public. Carers don't know early enough that Carers SA is here for Carers. Carers suggested that general practitioners (family doctors), health services, service providers for the person receiving care (i.e. Aged Care and Disability Care providers), schools, local councils, Services SA and specifically Centrelink should have inbuilt Carer Recognition practices and automatically make Carer services information available to Carers 'straight away', not only in emergencies or as a crisis intervention.
- Carers feel that there is a much higher need for the following current services:
  - Timely access to suitable respite.
  - Breaks for Carers.
  - General facilitated Peer Support Carer Groups which provide social activities.
  - Facilitated Peer Support Groups that provide opportunities for shared Carer experiences, exchange of knowledge, and mutual support for specific caring roles.
  - Not all Carers require access to financial support, but for a number of Carers such support is absolutely vital for their wellbeing and/or for being able to continue providing care.
  - Practical help services would need to be more consistent and available longer term.

Following are some suggestions for future services that are currently not available or only available privately sourced and often out of financial reach for Carers:

- A 'one stop shop' fast access information service where Carers can get general information about Carer and caring role related info but also include where to go and how to go about caring role related issues. Carers said the information may be available online or otherwise accessible, but it usually takes incredible patience to work through online websites, telephone calls and numerous webpages across care and health related sectors and organisations to find the right answers. This is frustrating and causes stress to Carers.
- Navigating Services and Sectors / Cutting through bureaucracy and processes: Carers were clear about their need for support with any bureaucratic processes from navigating the Government landscape to identifying to signing up to a service. On top of the Carers wishlist is an in-person information and support service to 'walk through' the requirements, options and processes related to My Aged Care and NDIS. This service should include advocacy.



- Complaints and Concerns: One official place where Carers can go if they need to lodge a complaint or raise a concern. Currently, Carers need to find and negotiate several options (mostly online) across sectors.
- Where and how a concern can be raised or a complaint lodged depends on which services the person receiving care is accessing, or which services the Carer has accessed, or which department or agency has not provided appropriate services to the Carer.
- Training and Skills updates: Carers discussed how difficult it is to get the right skills and training that is particularly required for certain caring roles. Currently, there are minimal options for Carers to find and access the necessary training or workshops. Carers told us that if they were paid support workers doing the same job, they would get lots of initial training and professional development supplied by the employer.
- Carers said that this can be unsafe for Carers (i.e. heavy lifting) or the person receiving care administering medication, or misunderstanding signs related to a disability or illness. This is especially the case for Carers who are relatively new to their caring role. Carers mentioned that they just become a Carer without real preparation for it and must 'fumble' their way through via ad-hoc self-education.

"We also just don't know what we don't know."

- Equipment and Resource sharing: Carers suggested that there is a high need for a place or online site, where Carers can access, sell / make available surplus equipment and resources that are surplus to need.
- Care and Carer related legal advice / future planning support that is affordable. Most Carers find it difficult to finance that support privately. However, Carers see 'doing things right' as important for them and others. Advance Care Directives, Wills and Enduring Power of Attorney, and future proving financial security were key concerns.

The feedback and suggestions that Carers provided during these events become important for Carers SA's service strategy and will inform our Advocacy for Carers for better Recognition of Carers across sectors and across all levels of Government.

Thank you to the Carers who took part in this extensive project and who have so openly shared their knowledge and ideas with us.