



WA Local Government: Carer Identification, Engagement and Support

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1. Who are carers?

Carers 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 aged¹.

2. The importance of carers in the community

It is estimated that more than 320,000 people in Western Australia are carers². This equates to more than 1 in 8 people in the community. Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, alcohol and other drug and palliative care systems. The replacement value of the care undertaken by carers in Australia will cost \$60.3 Billion per annum³.

Although carers undertake a vital, challenging and often intrinsically rewarding role, carers often have significantly poorer mental health and vitality compared to the general population, with similarly higher rates of depression⁴. The results of a carer's health and wellbeing survey undertaken by Deakin University showed that carers have the lowest wellbeing of any population group⁵. To enhance the health and wellbeing of carers it is important that carers are recognised and included in services and service planning within the community.

¹ Carers Australia (2015). Carers Recognition Act 2010. Accessed from www.carersaustralia.com.au.

² Australian Bureau of Statistics (2015). General Social Survey 2014. Commonwealth of Australia, Canberra.

³ Access Economics (2016). The Economic Value of Information Care in 2015. Deloitte and Carers Australia, Canberra.

⁴ The Australian Institute of Family Studies (2008). The Nature and Impact of Caring for Family Members with a Disability in Australia.

⁵ Deakin University and Carers Australia (2007). Australian Unity Wellbeing Index: Survey 17.1 Report 17.1, Melbourne.

3. Carers WA

Carers WA is the peak body representing the needs and interests of carers in Western Australia and is part of a national network of carer associations. The vision of Carers WA is that Australia values and supports carers providing the choice and opportunity to participate in all aspects of economic and community life.

4. Services offered by WA Local Governments related to carers

WA Local Governments (LGs) are well placed to connect carers to valuable services and programs to support their involvement and continued participation in the community. This document suggests good ways to identify and recognise carers within the LG's services and service planning.

The current services provided by LGs related to carers vary greatly and some LGs provide more services and activities for carers than others. These services and activities may include:

- Services through Home and Community Care Services, such as respite, transport, domestic services etc.;
- Hosting consultations and annual Carers Week events;
- Future planning for carers- Information sessions about Guardianship and Administration;
- Centre Based Day Care, which provides care and activities to frail aged and younger people with disabilities and their carers;
- Community support groups including for carers;
- Promoting support for carers from government and referrals to community organisations on their websites or in information guides;
- More broadly, carers are captured by community based initiatives such as Age Friendly WA grants program⁶, funded by the Department for Local Government and Communities. This encourages councils and communities to recognise the diversity of older people, promote their inclusion, respect their decisions, and anticipate/respond to ageing-related needs and preferences. Carers are directly

⁶ <https://www.dlgs.wa.gov.au/GrantsFunding/Pages/Age-Friendly-Communities.aspx>

referenced noting the importance of supporting and engaging carers, increased recognition and support, and strategies to encourage older people to remain at work, including flexible work conditions, and care and family friendly practices.

5. Carer participation

When considering developing or designing services for a cohort such as carers, utilising their expertise to inform them is extremely valuable. The International Association for Public Participation (IAP2) have developed a spectrum⁷ that outline different levels of participation to assist in defining the level of involvement the community has in decision making. This ranges from informing people of a decision; to empowering people to make the final decision on behalf of the organisation. Incorporating the views of the community in development of services and initiatives, can improve innovation, better meet the needs of the community and improve cooperation with stakeholders.⁸ As such, it would be beneficial for LGs to consider how carers participate in decisions related to them, as well as the person they care for.

6. Suggested actions

To assist LGs to include and recognise carers, below are a number of possibilities for LGs to ensure that carers are able to access its services, facilities and information across all local government areas in Western Australia, providing them with the same opportunities and rights enjoyed by other people in the community. These suggestions are made in relation to carer recognition and identification, improving carer's health and wellbeing and promoting equal employment opportunities. There are a selection of case studies included to provide examples of innovative ways to include and support carers.

⁷ IAP2 International Federation (2014). Public Participation Spectrum. Accessed from <https://www.iap2.org.au/resources/public-participation-spectrum>

⁸ Steen M., Manschot M., & De Koning N. (2011). Benefits of co-design in service design projects. *International Journal of Design*, 5(2), 53-60.

6.1. Carer Identification and Inclusion

Many people in a caring role don't self-identify as carers. They often see themselves as supporting a family member or friend who has a mental illness, disability, chronic illness or who is frail, because of their close relationship with the person, not as their carer⁹. When carers do not self-identify, they are unlikely to search for, or easily find services within the community that meet their needs as carers¹⁰. Some examples of how carers may be encouraged to identify with their caring role are below.

Case Study

For Carers Week in 2015, the City of Melbourne provided an intimate space for Melburnians to slow down and reflect during Carers Week. The project invited audiences to enter a bespoke dome on the Southbank Spillway and watch a three-minute film that reflected on what it means to care for ourselves and others. Artist Jodee Mundy collaborated with twenty primary carers and a team of artists to produce *The Carers Project: A Sanctuary in the City*. The carers' stories, derived through a series of workshops, daily diary entries, drawings, film making, sound recordings and conversations, inform an immersive art installation. This project aimed to encourage and help the wider community understand the experiences of carers.¹¹

6.1.1 *Use of the term 'Carer'*

Paid support workers are often referred to as 'carers', which is inconsistent with the definition of the Carer Recognition Act 2004. The incorrect use of the term 'carer' may

⁹ McMahan J. & Carson R. (2010). Identifying the Carer Project. Private Mental Health Consumer Network.

¹⁰ House of Representatives Committee (2015). Chapter 2, Carer Identification, Demographics and Support and Services. Parliament of Australia.

¹¹ City of Melbourne (2015). A Sanctuary in the City for Carers Week. Accessed from <http://www.melbourne.vic.gov.au/news-and-media/Pages/ASanctuaryintheCityforCarersWeek.aspx>.

create confusion for people in a caring role who are more likely to identify their relationship role as it is. Carers WA would suggest that all advertisements for support workers are not be titled as carers, but as support workers to denote that the role is paid.

6.1.2 *Disability Access and Inclusion Plan*

The Disability Access and Inclusion Plan (DAIP) aims to ensure that people with disabilities, their families and carers are able to access its services, facilities and information, Carers WA suggest actively consulting carers about carer specific needs and to seek input to best meet their needs. The outcomes can be incorporated when reviewing the DAIP. Strategies for greater carer involvement and inclusion, includes activities that both the person with care needs and their carers could attend. See examples under *Respite Activities* in section 6.2.5.

6.1.3 *Hosting a Local Carer Forum*

Carers' identification can be improved by, for example, hosting a local forum for people in a caring role, which will enable them to discuss how carers can identify themselves distinct to a person with disability within the local area. Issues that carers are facing in the LG's region can be discussed as well. Carers have needs that are separate to the person with care needs and may be more likely or comfortable to discuss these in a carer only forum.

6.1.4 *Information Sessions*

To enable LG staff to identify and support carers more effectively, delivering information sessions for staff and people in the community would be very beneficial. Carers WA would be available to partner with a LG to discuss the Carers Recognition Act 2004, role of the carer and support services available in different regions.

Another information session opportunity is sessions directly for carers to bring them together and provide information about available support services.

6.2. Recognising and Supporting Carers

6.2.1 *The Carers Recognition Act 2004*

To ensure that carers are included and have access to services, facilities and information, it is important that carers are recognised. The Carer Recognition Act 2004 currently applies to the Disability Service Commission, the Western Australian Department of Health and organisations funded by these agencies including public hospitals. LGs are not obligated to comply with the Carers Recognition Act 2004. However, Carers WA suggests including the best practice principles underpinning the Carers Recognition Act 2004 legislation, in

relation to service planning and evaluation, and their DAIPs. The Carers Charter within the Carers Recognition Act 2004 can be used to guide how carers are treated and involved in the planning and delivery of services.

The Carers Charter

1. Carers must be treated with respect and dignity.
2. The role of carers must be recognised by including carers in the assessment, planning, delivery and review of services that impact on them and the role of carers.
3. The views and needs of carers must be taken into account along with the views, needs and best interests of people receiving care when decisions are made that impact on carers and the role of carers.
4. Complaints made by carer in relation to services that impact on them and the role of carers must be given due attention and consideration.

6.2.2 National Carers Week Grants

Carers Week is held annually in the third week of October to recognise and celebrate the outstanding contribution that Australia's 2.7 million unpaid carers make to the society. National Carers Week is an opportunity to raise community awareness among all Australians about the diversity of carers and their caring role, relationships and services and supports for carers. Carers WA offers grants via Lotterywest funding to LGs to host their own event for carers during Carers Week. If you would like to host an event for carers during Carers Week, you can apply for grant to assist with the event via the Carers WA website; www.carerswa.asn.au.

6.2.3 Improving Carers' Health and Wellbeing

As mentioned earlier, research has shown that carers have the lowest wellbeing of any other population group¹². Because of the busy caring role, carers have little time to attend

¹² Deakin University & Carers Australia (2007). Australian Unity Wellbeing Index: Survey 17.1 Report 17.1, Melbourne.

to their own health care needs. To improve carer's health and wellbeing it is important to provide carers with support and information about available supports.

Case Study

For Carers Week 2014 and 2015, Carers WA and the West Coast Institute in Joondalup hosted a Wellbeing Expo. There were activities for children and adults, where students from the Institute gave massages, health checks and wellbeing demonstrations. Some of the other activities were:

- Free Morning Tea & Lunch
- Face Painter & Kids Craft Activity
- Bouncy Castle & Animal Farm
- Door Prizes & Giveaways.

6.2.4 *Marketing for Carers*

To enable carers to access support, they need to be aware of the support and services available to them within the LG's region. Ideally, local government websites would have a visible link on their homepage to information about available services for carers within the area.

LGs could also engage with service providers in the area and invite them to provide a training / information session to carers about their facilities.

6.2.5 *Respite Activities*

Respite is one of a suite of services, which supports families by providing breaks to the carer and other family members from care responsibilities. Research has shown that respite has a number of benefits. The most consistently reported finding is that respite care has positive effects on family functioning, including increased participation in social activities and decreased perceived family conflict¹³.

¹³ Merriman B. & Canavan J. (2007). Towards Better Practice in the Provision of Respite Services for People with Intellectual Disability and Autism. Galway Child and Family Research Centre, Ireland.

When organising activities for people with disability, local governments could consider activities for both the care recipient and their carer. A break from the caring role does not necessarily mean a separation from the person with care needs. It could mean that an activity allows the carer and the person they care for to focus on their relationship, e.g. parent, sibling etc. This provides the opportunity to strengthen the relationship, which will benefit the caring role in many ways.

Some examples of non-traditional respite activities are:

- **Art classes** - Art classes offers carers the opportunity for expression and communication. Research has shown that carers who participated in art classes reported a reduced level of anxiety and stress, enhanced creativity, communication and positive emotions^{14 15}.
- **Music sessions, such as drumming** - Group drumming has been demonstrated to be easily learned in a non-pressure manner and expand opportunities for expressing and dealing with pressures and stresses of daily living¹⁶.
- **Carers seeking respite along with the person they care for** – An example would be a support worker attending a respite activity with both the person with care needs and their carer, so that the carer can focus on their relationship with the person with care needs rather than providing care to the individual.

¹⁴ Walsh, S. M., Radcliffe S., Castillo L. C., Kumar A. M. & Broschard, D. M. (2007). A Pilot Study to Test the Effects of Art-Making Classes for Family Caregivers of Patients With Cancer. *Oncology Nursing Forum*, 34, 38.

¹⁵ Walsh S.M., Culpepper M.S., Schmidt L.A. (2004). Testing the Efficacy of a Creative-Arts Intervention with Family Caregivers of Patients with Cancer. *Journal of Nursing Scholarship*, 36, 214-219.

¹⁶ Bittman B., Bruhn K.T., Stevens C., et al. (2003). Recreational music-making: a cost-effective group interdisciplinary strategy for reducing burnout and improving mood states in long-term care workers. *Adv. Mind Body Med.*, 19, 4-15.

6.2.6 *Linking Carers Together*

Linking carers together can promote health and wellbeing. Especially in regional and remote areas where there is a lack of services and there are difficulties in accessing services, it may be beneficial to link carers together to provide peer support.

Organising carer support groups will link carers together to provide them with the opportunity to share their experiences of caring. Specific benefits of a carer support group include:

- The opportunity to share experiences with people who understand the impact of caring;
- Receiving emotional support;
- Making new friends. Carers are often isolated and support groups will give them the opportunity to expand their social network and reduce isolation;
- Sharing information with other members in the support group.¹⁷

Another way of linking carers together is providing public spaces to build, for example, community gardens. Research has found that community gardens promote health in the community and are seen as a source of advice and social support^{18 19}.

6.2.7 *Carer Peer Volunteers*

Carers WA have developed resources for a Carer Peer Volunteer service delivery model and training package. As a result, two documents were developed; 'Guidelines for Planning and Operating a Carer Peer Volunteer Program' and the 'Carer Peer Volunteer Training Workbook'. The resources aim to provide a platform for organisations and service providers to implement the model if funding permits. The model links volunteers who have a lived

¹⁷ Carers NSW (2015). Carer Support Groups: What are the benefits of attending a support group.

¹⁸ Armstrong D. (2000). A survey of community gardens in upstate New York: Implications for health promotion and community development. *Health and Place*, 6, 319-327.

¹⁹ Kingsley J., Townsend M. & Henderson-Wilson C. (2007). Cultivating health and wellbeing: members' perceptions of the health benefits of a Port Melbourne community garden. *Leisure Studies*, 28, 207-219.

experience of being a carer (they may be existing or former carers) with carers who would benefit from peer support.

The service delivery model and the training workbook recognises the value of a carer's lived experience, skills and knowledge that they have developed as a result of their own caring role. The resources are evidenced based, which supports the value of peer led programs to improve the wellbeing of both the Carer Peer Volunteer and the carer they are matched with. From July 1st 2016, the documents will be available from the Carers WA website; www.carerswa.asn.au.

6.3. Equal Employment opportunities

The number of Australians who balance work and unpaid caring is likely to grow due to the ageing population, longer working lives and the increasing responsibility of families to care for older people²⁰. People who combine their caring role with a professional job may experience difficulties that can impact their employment, including absences from the workforce, financial stress, and poor physical and mental health¹³. Carers WA encourage all employers to raise awareness of carers in the workplace and promote flexible work arrangements to assist carers in balancing paid employment with their caring role.

²⁰ National Seniors Australia (2013). A Juggling Act: Older Carers and Paid Work in Australia. Accessed from <http://nationalseniors.com.au/be-informed/research/publications/older-carers-paid-work-australia>.

Case Study

Westpac has a comprehensive carer's leave policy which allows employees to care for someone in their family when they are sick or injured, recovering from surgery or involved in an emergency. They also offer a wide range of flexible work options, recognising that employees with caring responsibilities may need different types of flexibility, depending on their circumstances. For employees who care for an older dependent, Westpac offer an Eldercare Kit to help their employees understand what is available in the community, provide information on specific government and community support services and checklists to assist in making key decisions.²¹

Some other examples may include:

- Flexible work hours
- Flexible work locations (e.g. options to work from home)
- Flexible leave arrangements (e.g. taking leave by the hour instead of the whole day)
- Allowing employees to make small adjustments to their job role and objectives²².

For more detailed information about carer friendly workplaces, there are more resources available from the following web pages:

- <http://www.carersaustralia.com.au/work-and-care/work-and-care-employers/>
- <http://www.carerswa.asn.au/carers-wa-services/care-resource-kit/>.

²¹ Westpac (2013). Accessibility Action Plan: Prosper and Grow. Cited in Carers Australia (2015), Work & Care Initiative. Accessed from <http://www.carersaustralia.com.au/work-and-care/work-and-care-employers/>.

²² Department of Consumer and Employment Protection (2008). Creating Carer Friendly Workplaces: Information and options for employers, West Perth.