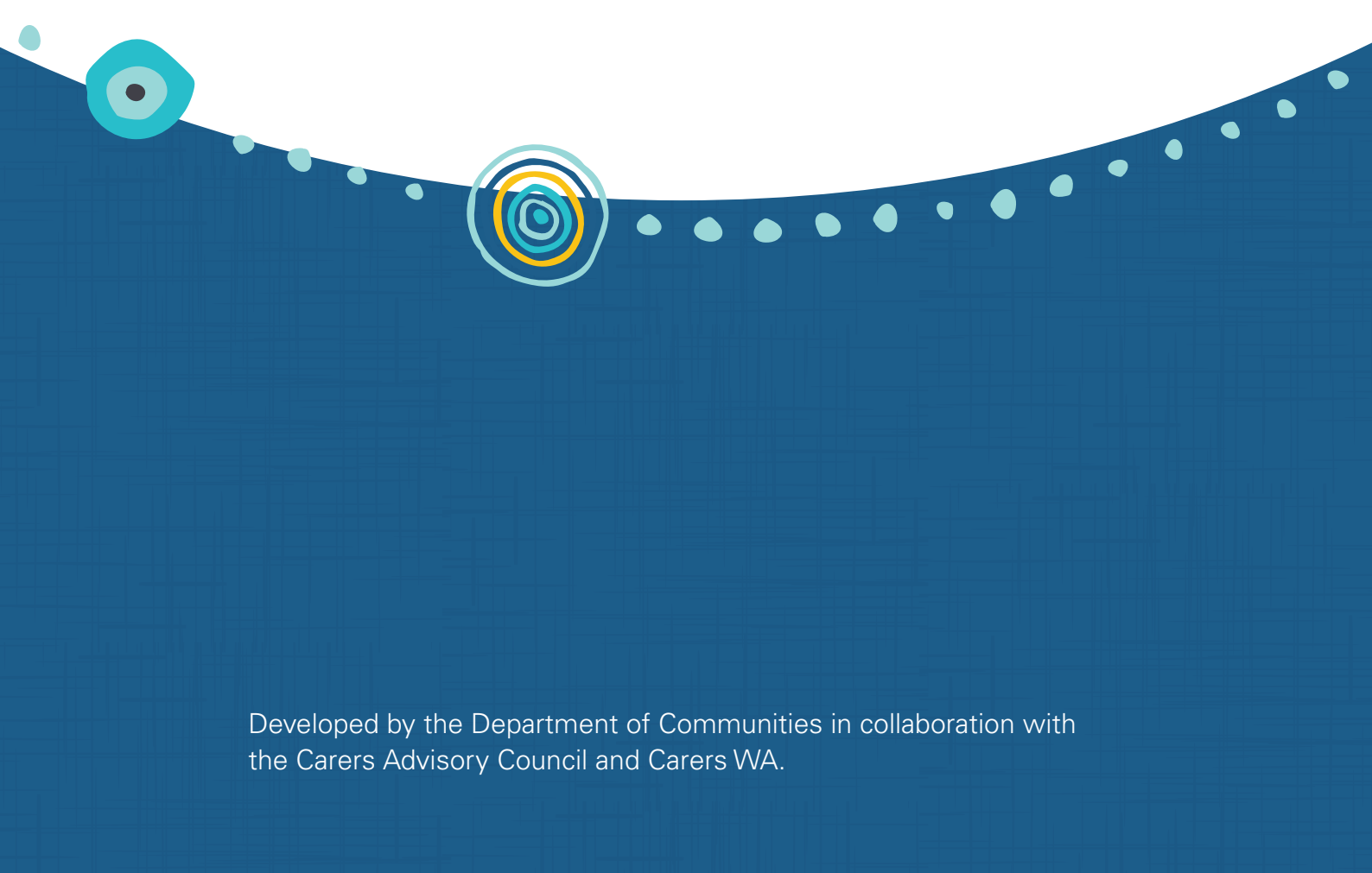




Government of **Western Australia**
Department of **Communities**

WA Carers Strategy



Developed by the Department of Communities in collaboration with
the Carers Advisory Council and Carers WA.

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Introduction

Western Australia's carers

It is estimated that about 320,000¹ West Australians are carers. They provide unpaid personal care, support and assistance to a person(s) who needs help with daily life due to disability, impairment, mental illness, chronic condition or terminal illness, an alcohol or drug issue, or being frail aged.

It is intended that this strategy will guide government departments and agencies, service providers and the community towards greater support for and recognition of carers and their needs. Like most strategies, it focuses on high level objectives and suggests initiatives that can be undertaken by all stakeholders to ensure good outcomes for carers and the people they care for.

Carers provide care within the context of a personal relationship which includes, but is not limited to:

- parents caring for children who have additional needs
- adults caring for other adults such as an elderly parent, adult child, spouse or partner, friend or neighbour
- children and young people who care for a parent, sibling or relative.

Carers, and the people they care for, are as diverse as the rest of the community. They range in age from children through to seniors and come from diverse cultural, linguistic and religious backgrounds, socio-economic circumstances, and gender and sexual identities. These factors may influence whether they identify as carers and access essential support services.

Their caring responsibilities are also diverse. They commence and end their caring roles at different stages in life. They may be providing care on a part-time or full-time basis, in the short-term or throughout the life of the person they care for. The support they provide can range from assistance such as paying bills, transport to appointments and weekly grocery shopping, to round-the-clock assistance with core

activities such as emotional support, personal care and health care, including medication management.

Many of us will become carers at some point in our lives, or we may need care ourselves. Not all people choose to become carers. It is a role that can develop gradually or may be required unexpectedly at any time, and one for which many people are rarely given a choice.

Most carers do not see themselves as extraordinary: they are simply doing what anyone else would do in the same situation. The reality is that carers make a difference to the lives of the people they care for, and make an invaluable social and economic contribution to Western Australia.

Carers support the people they care for to:

- stay connected with and involved in the community
- maintain their independence and remain in their homes
- have choice and control over their own lives
- live with dignity
- continue to live with their families and friends
- achieve and maintain quality of life.

Carers are vital to achieving the State Government's vision of a community where people who require support can remain in their own homes for as long as possible, participate fully in their communities and receive person-centred care.

The care they provide reduces the demand for and dependence on paid care and the health and community services sector. In 2015, the estimated replacement value of informal care in Australia was more than \$60 billion annually².

Why Western Australia needs a Carers Strategy

In the future, the demand for carers in Western Australia will grow. Changing demographics and health trends, social norms and economic circumstances are driving this demand. An ageing population, longer life expectancy and a rising prevalence of disability mean there will be more people in need of care.

¹ The number of known carers ranges from the 2001 Census figure of 185,1190 to 320,700 according to the 2014 General Social Survey.

² Deloitte Access Economics and Carers Australia (2015), The Economic Value of Informal Care in Australia in 2015, www.carersaustralia.com.au.

A shift from institutionalised care to care in the community, ageing in place and person-centred care means that more people are likely to be cared for in their own home. Community-based care can deliver better outcomes as well as enable governments to better balance the rising cost of and demand for care against budgetary constraints. More carers will be needed to sustain this.

The caring role has a range of impacts. While carers report that their role can be rewarding and fulfilling, it can also be difficult. Carers often put the interests of the person they care for ahead of their own needs. This may come at an increased risk to the carer of social isolation, disconnection from education and employment, poor health and limited opportunities to pursue personal goals.

The challenges faced by carers are heightened by a lack of community recognition, awareness and support. Thanks to decades of advocacy, the community is more aware of the needs of people accessing care, and the support services available to them. However, fewer people are aware of the role and contribution of carers and the services available to them.

Recognising and supporting carers is critical to the future of carers and the people they care for, and to overall community wellbeing.

The WA Carers Strategy is the next step towards greater community recognition of, and support for, West Australian carers. It builds on the foundations laid by the *Carers Recognition Act 2004*, WA Carers Charter and other supportive legislation and policies.

The strategy recognises that the lives and needs of carers and the people they care for are entwined, but they are not the same. It also recognises that supporting carers' health and wellbeing is as important as supporting their capacity to provide care.

While the State Government can provide general leadership, recognising and supporting carers is everyone's responsibility. It requires a concerted effort by all levels of government, non-government organisations, the private sector and the whole community to do what they can to support carers.

This means not only recognising the important role of carers, but also taking the necessary steps to ensure that carers can access the support they need and pursue the same life opportunities as other West Australians.

Legislative and policy context

Carers Recognition Act 2004

The Western Australian Government has a long and proud history of recognising and supporting carers. WA was the first Australian jurisdiction to introduce carer-specific legislation— the *Carers Recognition Act 2004* and the Western Australian Carers Charter. The Act and Charter recognise the role of carers, and provide mechanisms for their involvement in the development and provision of services that impact on them and the people they care for.

The State Government has funded, supported and driven a number of initiatives designed to raise awareness and understanding of carers and caring, including: establishing the Carers Advisory Council in 2005; partnering with and funding peak body Carers WA; workplace and school-based awareness raising activities; funding and support for research and conferences; and sponsoring Carers Week events and awards.

The *Carers Recognition Act 2004* came into effect on 1 January 2005. The Act applies to the Department of Health and the Disability Services and the organisations they fund to provide services. These agencies are required to report compliance with the Act to the Carers Advisory Council, which reports to the Western Australian Parliament through the relevant Minister. The Mental Health Commission reports voluntarily.

The legislation requires all State Government funded and administered health and disability services to take all practicable measures to ensure that they comply with the Act and Charter.

The Carers Charter provides clear direction on how carers are to be treated and involved in the delivery of services, stating that:

- carers must be treated with respect and dignity
- 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
- 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

- complaints made by carers in relation to services that impact on them and the role of carers must be given due attention and consideration.

Representing carers

The Carers Advisory Council was established under the Act and is supported by the Department of Communities. It reports to parliament of WA on compliance with the Act and provides advice to the relevant Minister.

Carers WA is dedicated to improving the lives of the estimated 320,000 carers living in Western Australia. The Department of Communities provides substantial funding to Carers WA to manage the Carers Counselling and Support Service, which provides counselling, support and information to carers, their families and significant others.

Complementary strategies, policies and legislation

The WA Carers Strategy is complemented by a number of State and Commonwealth Government policies, strategies and legislation that uphold individual rights, support the involvement of carers and people accessing care in decision making, and are designed to ensure they receive optimum service outcomes (Appendix 1).

Vision

Carers are recognised and valued for making a positive difference to the lives of families, friends, the community and the people they care for. Carers will be able to access support to build their capacity to care as well as maintain a balance between their caring responsibilities, their own wellbeing and pursuing life goals. Carers will be able to access the same life opportunities as all West Australians and participate in the community as full and equal citizens. Carers' knowledge and experience will be respected, and they will be included as key partners in care.

Outcomes

1. Carers' contributions will be recognised and respected by the community.
2. Carers' diverse situations, circumstances and backgrounds will be respected and accommodated.
3. Carers will be respected and included as expert care partners.
4. Carers will have access to appropriate services and information that support them to care with confidence and maintain their personal wellbeing.
5. Carers will be able to balance their caring responsibilities, personal wellbeing and life outside of caring.
6. Carers will have the same life choices and opportunities as other members of the community.
7. Young carers will be supported to learn, develop and thrive, and enjoy positive childhoods.
8. Carer policy, planning and service delivery will be evidence based.



Priority Area 1:
**Awareness, Identification,
and Recognition**

.....

“It was about two years into looking after him
that I realised I was a carer – and that was when
Carers WA asked if I was the primary carer.”

.....

Am I a carer? The importance of early identification

Early identification as a carer is critical to ensuring carers access information, advice, support and intervention for themselves and the person they care for. It gives carers the opportunity to understand what caring for someone means and involves, as well as make informed decisions about care options and managing the life – care balance.

However, some people with caring responsibilities do not readily identify or want to be labelled as a carer. As a result they may become ‘hidden’³. Carers may be hidden for a number of reasons, including:

- fear or perception of stigma and discrimination about caring or the condition of the person they care for
- social attitudes toward the person they care for
- cultural understanding of family roles and caring responsibilities
- being unaware of the caring role
- lack of opportunity, time and energy to seek support
- perceived lack of benefit in identifying as a carer
- desire for privacy
- being unaware of the term carer and what it means.

“My family and friends already know that I am a carer for my husband. Is it necessary for the public to know?”

While the decision to identify is personal and must be respected, it is important that people with caring responsibilities are made aware of what caring is and the information and support services available to them. It is important they are supported and encouraged to identify as carers and/or seek services.

People may better identify with the idea of ‘supporting or assisting’ rather than ‘being a carer’. In the early stages, it may be useful to discuss and describe the feelings, tasks and responsibilities associated with the daily life of a carer, rather than asking ‘are you a carer?’

It is also important to recognise that carers’ experiences are very diverse, and that this may also influence their decision to self-identify. Each carer will have different feelings about their caring role at different times. Using emotive terms such as ‘your loved one’ could lead to negative feelings such as shame, obligation and guilt, and therefore reluctance to self-identify.

Awareness and recognition

Carers report that while friends and community members are generally sympathetic to their circumstances, deeper understanding of the term carer and the caring role is often limited. The term is often confused with being a paid carer.

Broader understanding and awareness can lead to greater, and earlier, carer self-identification or make carers more identifiable.

Raising awareness, changing negative attitudes, and reducing stigma contributes to building more responsive and inclusive communities where carers:

- feel valued and supported
- are recognised and supported in the workplace and/or place of education
- find it easier to ask for help and find support
- can remain connected and involved in the community.

Staff and service providers who interact with families on a regular basis—regardless of industry—are well placed to identify carers and direct them to appropriate supports and information. It is therefore important that they have the knowledge and capacity to identify carers and are aware of available information and supports.

³ Carers NSW (2001), Reaching Hidden Carers, position paper by the Carers Coalition, Sydney

Carers diversity

While carers share similarities, each person is different. Carers are diverse in terms of the condition of the person they care for, their life circumstances, age, gender, religious conviction, race and ethnicity, language, geographic location and sexual orientation.

Carers from diverse backgrounds are more likely to be 'hidden' than other carers. It is therefore important to consider how their values, experiences and circumstances could influence whether they identify as carers, limit their access to services and support, and impact on their capacity to provide care and manage their own wellbeing. Addressing the different challenges diverse carers face requires targeted and tailored responses.

In addition, the *Western Australian Equal Opportunity Act 1984* makes it unlawful to discriminate against a person based on the above characteristics. Service providers, and the broader community, must ensure that they do not directly or indirectly discriminate against carers.

Compared with other Western Australians:

Carers from **Aboriginal and/or Torres Strait Islander** backgrounds are more likely to be carers⁴ or young carers, care for more than one person, and experience poor health and wellbeing. Almost half of the carers in remote areas identify as being Aboriginal and/or Torres Strait Islander.⁵ They are less likely to self-identify as carers, and to access, or have access to, services for a number of reasons, including:

- a perception of caring as being a natural part of kinship responsibilities
- a lack of culturally appropriate services
- language barriers
- a distrust of officials and service providers due to experiences of racism and discrimination
- physical barriers to access such as distance, lack of transport and limited access to telecommunications services.

⁴2011 data shows that Aboriginal and Torres Strait Islander carers were 1.3 times more likely to be providing care than other Australians. Australian Institute of Health and Welfare (2013) Australia's Welfare 2013, Australia's welfare series no.11. Cat. no. AUS 174. Canberra: AIHW.

⁵Edwards B, et al (2008), 'The nature and impact of caring for family members with a disability in Australia,' Australian Institute of Family Studies, Research Report No.: 16

"community and service provider and carers and person being cared for and the whole family in general ... gotta be sit down and worked out together."⁶

Carers from **culturally, linguistically and religiously diverse** backgrounds are less likely to access services for a number of reasons including:

- a lack of awareness about service availability
- being unaware of the rights of people with disability and mental ill-health to receive treatment and their own right to access support
- language barriers and culturally inappropriate service provision
- competing settlement priorities.

They are also less likely to self-identify as carers due to: cultural norms of family responsibility and caring; a limited knowledge or understanding of care—the concept of carer is difficult to translate; or their reluctance to disclose the need for care due to cultural stigmas surrounding disability and mental illness.

Older carers are less likely to self-identify as carers because the role and responsibility has been a constant and long-term part of their life. Almost 43,000⁷ West Australian carers are aged 65 years and over.

Research tells us that older carers⁸ are more likely to have the knowledge and skills, and a strong social and support network needed to provide care without assistance but often lack the physical capacity to do so.

Older carers may be in greater need of physical assistance and/or emotional support as they transition out of a long term caring role, and support with future planning for the person they care for.

⁶ Smith, K et al (2011), Gotta be sit down and worked out together: views of Aboriginal caregivers and service providers on ways to improve dementia care for Aboriginal Australians, Rural and Remote Health, 11, p 1650

⁷ ABS (2009), Disability, Ageing and Carers, Australia: State Tables for Western Australia, Commonwealth of Australia, Canberra.

⁸ Australian Institute of Health and Welfare (2015), Australia's Welfare 2015, Australia's welfare series no. 12 Cat. No. AUS 189, Canberra. Estimated at 579,700 Australians aged 65 years and over in 2012

Young carers have specific needs. A significant number⁹ of children and young people aged 25 years and under are carers. Data suggests that more than 17,000 West Australian carers are aged 18 years or under.¹⁰ Their caring role and responsibilities can have a negative impact on their social, educational and emotional needs, and life prospects.

Many find it difficult to balance learning and caring responsibilities because their role is not always acknowledged, understood or supported by education providers. This can lead to high rates of absenteeism and disengagement, and poor education outcomes.

They may be reluctant to identify as carers for a number of reasons including the fear that their siblings will be removed and their family broken-up; having little or no knowledge about the caring role; or having witnessed or experienced bullying based on stigmas associated with the conditions of the people they care for.

Young carers are also less likely to access services because they may be unaware of the supports available; unable to access services due to a lack of transport or unsuitable operating hours; or find that the services are not appropriate to their needs.

Carers of **diverse sexual orientations** are less likely to self-identify as carers or access services because they have witnessed or experienced prejudice and discrimination within the services sector and wider community. Research has shown that these carers' identity and status can affect who they ask for help, and how easy it is for them to do so.¹¹

Some carers may feel uncomfortable disclosing or discussing their sexual or gender identity. This can add to their stress and affect their wellbeing, which may undermine their capacity as carers.

Research shows that carers in **regional and remote areas** are more likely to be younger and experience lower rates of employment and social participation. About one-quarter of West Australian carers live outside the Perth metropolitan area.¹²

Carers in regional areas are less likely to have access to services due to distance, the limited availability of services generally and poor internet access. Specialist medical, carer-specific and respite services are often unavailable, inadequate or unaffordable. The cost of travel can be prohibitive, is often not included in respite funding, and may also lead or contribute to financial hardship.

Priority Area 1 (Outcomes 1 and 2)

Strategies

- 1.1** Support people to self-identify as carers, including carers from diverse backgrounds.
- 1.2** Develop and implement specific initiatives to improve carer identification.
- 1.3** Raise awareness to support early identification of carers.
- 1.4** Promote and celebrate carers' valuable contribution to the community.
- 1.5** Support service providers to meet the specific needs of carers from diverse backgrounds.

⁹ Estimated at 306,000 Australians aged under 25 years in 2012. Australian Institute of Health and Welfare, *ibid*.

¹⁰ Commonwealth of Australia (2007), *Intergenerational Report*, Canberra.

¹¹ Carers Victoria (2015), *Young, queer and caring survey results*, Melbourne available at www.carersvictoria.org.au

¹² ABS 2009, *op cit*.



Priority Area 2: **Respected Partners in Care**

.....

“Why don’t they listen more to the carer? We have a lot of knowledge about her condition, but they don’t ask...”

.....

The benefits of involving carers

Actively engaging carers in the design, delivery and evaluation of care and services and in discharge planning, is likely to result in better outcomes for the carer and the person they care for. However, carers report that many professionals do not recognise or respect carers as partners.

Carers report that they often feel undervalued and ignored, which causes them frustration and unnecessary anxiety.¹³ This can result in poor relationships between service providers and carers, which may undermine the provision and quality of treatment and care.

Carers have unique knowledge and expertise that is important to supporting the person they care for. Carers can provide valuable information about, and clearly articulate, the person's likes and preferences. In the case of diverse communities, carers can provide information about the values and circumstances that could influence care planning and outcomes.

Carers are well placed to work with the person they care for to decide which care and treatment arrangements will be most suited to their situation. Carers need to be supported to do this by being made aware of the care and treatment options available. They should also be given choices about their caring role; the level of care they have the capacity or willingness to provide; and the types of services that they would find most suitable.

In addition, including carers in discharge planning and care management can increase the likelihood of treatment compliance and reduce the likelihood of re-admission. This can lead to better health and care outcomes, and reduce costs to the carer and provider.¹⁴

¹³ Feedback from carers provided to Patterson Research Group and Carers WA, 2015.

¹⁴ Tao, H et al (2012), 'The influence of social and environment factors on rehospitalisation among patients receiving home health care services, *Advances in Nursing Science*, 35:4, pp 349-358

Involving and engaging with carers

Professionals can support carers by considering, understanding and respecting:

- their choices and preferences, and how involved they want to be in providing care
- their desire and ability to take on a caring responsibility, including emotional capacity, financial resources and proximity to supports and networks
- the stress and frustration they may be feeling and expressing
- their emotional attachment to the person they care for.

This can lead to better outcomes for carers and the people they care for.

The *Carers Recognition Act 2004* and Western Australian Carers Charter provide clear directions to government and public sector agencies, and the services they fund, about how they must treat and engage carers, stating that carers:

- must be included in the assessment, planning, delivery and review of services that impact on them and their role
- have their views and needs taken into account along with those of people receiving care when decisions are made that impact on them and their role
- must be treated with respect and dignity
- must have their complaints in relation to services that impact on them and their role as carer given due attention and consideration.

It is recommended that the Carers Charter is used by all private and community sector service providers as guidelines for best practice.

"They need to regard carers as being in partnership with the service providers and health professionals – the carers need to be part of the treatment/support package."

Priority Area 2 (Outcome 3)

Strategies

- 2.1** Ensure and/or encourage respect for carers' knowledge and experience.
- 2.2** Ensure and/or encourage the inclusion of carers in care and discharge planning, and their engagement in decision making.
- 2.3** Facilitate the inclusion of carers and carers' needs in planning and decision making across all levels of government.





Priority Area 3: **Supporting Carers**

.....

“The information is there, but the problem is linking it to carers ... they need to be made aware that it exists.”

.....

Information and training

Capable and confident¹⁵ carers find it easier to provide care. This can lead to better outcomes for them and the person receiving care, including greater self-confidence and esteem, better overall wellbeing and fewer care-related injuries. Information and training that is reliable and easy to access is critical to building carers' capacity.

Carers require a range of knowledge and skills to manage complex health and care situations, which can arise and change very quickly. This includes information on:

- medical conditions or disability types
- options for treatment, including therapy, aids and equipment
- legal and financial issues, including guardianship and substitute decision making, mental health legislation, social security, financial and future planning
- the services and supports available to them, including self-care, personal support and respite.

They may also require practical care skills including:

- basic nursing care; personal care and behavioural management
- how to navigate the health and community care service systems
- how to manage the physical, emotional, financial and logistical changes at the different stages of the caring journey, including the transition into or out of a caring role.

Carers report¹⁶ that the main challenge is finding and accessing information. Many feel the onus is on them to seek information, which is difficult if they don't know what to ask for or where to find it. Dedicating energy, time and resources to finding information and services detracts from caring and can cause unnecessary or additional frustration and stress.

¹⁵ See for example Department of Families, Housing Community Services and Indigenous Affairs (FaHCSIA) (2011), National Carers Strategy Evidence Base October 2011, Commonwealth Government, Canberra.

¹⁶ See for example the House of Representatives Standing Committee on Family, Community, Housing and Youth (2009), Who Cares? Report of the inquiry into better support for carers, Commonwealth Government, Canberra.

Making information and training easily and readily accessible will support carers. This can be achieved by making it available in the places carers usually visit, through established carer networks or a single information access point.

Information and training should also be provided in a range of formats and languages to make it accessible to people with low or no English language proficiency and other specific communication requirements. The use of plain English and non-technical language will make information more accessible to a wide audience.

Training and support sessions need to be planned with carers' needs in mind. This includes the time and location of sessions, the availability of respite or on-site care provision, and the specific needs and considerations of diverse carers.

Good health and wellbeing

While caring can provide opportunities, friendships, connections and skills, it can also be emotionally and physically challenging. Carers¹⁷ are more likely to experience poorer physical and mental health outcomes than non-carers. This can result in poor outcomes for the carer and the person they care for.

“Carers need to develop their own care plan...”

Carers know that their health and wellbeing is important, however many find it difficult to find the time to look after themselves. Some feel guilty for focusing on their own needs. Often by the time a carer accesses support they are at crisis point.

“Even when I was away for a day or two, I would worry that he was being properly looked after.”

¹⁷ Office for National Statistics Survey (2011), provision of unpaid care in England and Wales 2011, Her Majesty's Government, United Kingdom available at www.ons.gov.uk

The most effective ways to support carers to remain physically and mentally well¹⁸ are to:

- provide services that support them in their full range of responsibilities
- provide information on when to recognise that their own health is at risk
- provide respite that is affordable, flexible and suitable to the needs of carers and the people they care for
- ensure that services are responsive, flexible and accessible enough to meet their diverse and complex needs.

Carers need support and respite services that:

- are available as, when and for as long as they need them
- provide respite, and emotional, psychological, social and peer support
- assist with household and personal care tasks
- provide information and education related to caring, and support the transition into, during and out of the caring role
- are culturally and linguistically appropriate, and accommodate the uniqueness of each care relationship
- consider the barriers to, and facilitators of, access by carers from diverse backgrounds
- are easy to access and time flexible
- can support the whole family.

“Contact with support networks – so you don’t feel so alone. Also to share lessons and contacts...”

“Some supports involve so much administrative burden and time for the carer to organise they are not thought to be worth it.”

Priority Area 3 (Outcomes 4 and 5)

Strategies

- 3.1** Ensure carers can easily access information, advice and support.
- 3.2** Support carers to remain physically and mentally well.
- 3.3** Support carers to pursue life opportunities alongside their caring responsibilities.
- 3.4** Support carers to perform their full range of daily care responsibilities.

¹⁸ FaHCSIA, op cit



Priority Area 4:

Participation in Education and Employment

.....

“I had an opportunity to take an overseas posting
and promotion – we just couldn’t do that.”

.....

Impact on carers

Compared with other West Australians,¹⁹ carers are at a greater risk of becoming socially isolated, anxious and stressed. This can be addressed by supporting carers to balance their caring responsibilities and personal needs so that they can fully participate in the community, and develop and maintain their personal, family and community networks.

Two areas of particular concern to carers are employment and education, where they face a number of barriers to participation, including:

- the lack of alternative or suitable care arrangements
- disruption to and stress for the person they care for
- difficulties arranging flexible work or study hours
- lack of awareness of, or capacity to, negotiate their employment and study rights
- loss of skills or lack of opportunities to develop them
- the financial cost of care.

As a result, carers have a lower workforce participation rate than non-carers, and young carers have lower education participation and attainment rates than their non-carer peers.

This can lead to poorer outcomes for carers, the people they care for and their families across the lifespan²⁰. Almost one-quarter of carers have an income that is below the poverty line.²¹ Many are unable to accumulate sufficient superannuation for retirement.

Supporting carers to participate

Employers, educators and trainers have a role to play in supporting staff and students with caring responsibilities to participate. The benefits to employers include:

- improved productivity and employee morale
- reduced levels of absenteeism and disengagement
- higher rates of attraction
- higher rate of retention
- reduced turnover costs and improved corporate image
- the acquisition of new and varied skills and attributes that come from caring such as organisation, time management, dedication and communication
- employer of choice status.

“The company has been good to me, but I really put my career on hold over the last five years.”

Priority Area 4 (Outcomes 6 and 7)

Strategies

- 4.1** Support carers to participate in education.
- 4.2** Support carers to return to or remain in employment.
- 4.3** Support employers and education providers to understand carers roles, responsibilities and needs.

¹⁹ Australian Institute of Health and Welfare 2015, op cit

²⁰ Carers Australia (2011), Young Carers in Education: Supporting rural and remote young carers, available at www.carersaustralia.com.au

²¹ ACOSS (2012), Poverty in Australia, ACOSS Paper 194, Canberra



Priority Area 5: Data and Evidence

.....

“Reliable data is essential to
good policy and services.”

.....

Reliable data: The key to better services

It is estimated that there are approximately 320,000 carers in Western Australia. The number of known carers ranges from the 2011 Census figure of 185,119 to 320,700 according to the 2014 General Social Survey.

While a range of organisations such as the Australian Bureau of Statistics and Australian Institute of Family Studies routinely collect data on carers, the use of different methodologies, criteria and definitions means that we do not have a definitive number of carers in Western Australia.

In 2009, the House Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers expressed its concerns about the lack of comprehensive, contemporary and reliable data on carers. The committee recommended that the Australian Bureau of Statistics should expand the information it collects on carers to include secondary carers; carers providing episodic care; carers providing palliative care; and carers aged 15 years and under.

Comprehensive, consistent and reliable data is essential to developing effective policy and to establishing systems that are capable of delivering appropriate supports and services, and therefore better outcomes, for carers.

Priority Area 5 (Outcome 8)

Strategies

- 5.1** Support and encourage initiatives to improve carer data collection, consistency and sharing.

Appendix 1:

Australian and West Australian carer-related policies and legislation

Policies and Legislation

<i>Equal Opportunity Act 1984</i>	National Mental Health Standards 2010
<i>Disability Opportunity Act 1984</i>	National Practice Standards for the Mental Health Workforce 2013
<i>Disability Services Act 1983</i>	National Framework for Recovery-Oriented Mental Health Services 2013
<i>Disability Discrimination Act 1992</i>	Mental Health Statement of Rights and Responsibilities 2012
<i>WA Mental Health Act 2014</i>	Accessible Mental Health Services for Providers with an Intellectual Disability: A Guide for Providers 2014
<i>Commonwealth Carer Recognition Act 2010</i>	WA Chronic Conditions Self-Management Strategic Framework 2011–2015
<i>Health and Disability Complaints Act 1995</i>	The Model of Care for the Older Person
<i>Fair Work Act 2009 (2014)</i>	Dementia Model of Care 2011
National Carer Strategy 2011	WA Primary Health Care Strategy 2011
Count Me in: Disability Future Directions	WA Language Services Policy 2014
National Standards for Disability Services 2013	Disability Access and Inclusion Plans
The Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015–2025	WA Disability Health Framework (draft)
Mental Health 2020: Making it personal and everybody's business	The Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015-2025 (draft)
Mental Health Partnership Agreement	

Priority Area 1: Awareness, Identification and Recognition

Strategies and Actions

Outcome 1 - Carers' contributions will be recognised and respected by the community.

- 1.1 Support carers to self-identify, including carers from diverse backgrounds.
- 1.2 Develop and implement specific initiatives to improve carer identification
- 1.3 Raise community awareness to support the early identification of carers.
- 1.4 Promote and celebrate carers' valuable contributions to the community.

What's already in place?	What will help?	Who can act?
<p><i>Carers Recognition Act 2004.</i></p> <p>WA Carers Charter.</p> <p><i>Commonwealth Carer Recognition Act 2010.</i></p> <p>Carers WA provide a range of information and services, including:</p> <ul style="list-style-type: none"> • by phone on 1300 227 377 • workshops and information sessions for carers and service providers • online information and resources at www.carerswa.asn.au. <p>Carers Australia provide information by phone on 1800 242 636 and online at: www.carersaustralia.com.au.</p> <p>Carers Week events and awards.</p> <p>National Carers Awards.</p>	<p>Developing and/or distributing:</p> <ul style="list-style-type: none"> • the WA Carers Charter • information about carers roles and responsibilities, including the difference between unpaid carers and paid care workers • guidelines and/or checklists to help people identify whether they are a carer • posters for public display • a carers information hub or directory • guidelines to help frontline staff to identify carers – this includes GPs, teachers and nurses • school-based education and awareness programs for staff and students. <p>Carer identification card.</p> <p>Displaying the WA Carers Charter in places carers frequent.</p> <p>Promoting the carer role, responsibilities and contributions through:</p> <ul style="list-style-type: none"> • all media formats • community and public events • workshops and forums • information and resources • carer stories • professional development, training and induction processes. <p>Supporting and promoting carer events and awards.</p> <p>Media stories, profiles and campaigns.</p> <p>Community initiatives and events that facilitate carer-community interaction.</p>	<p>Western Australian Government:</p> <ul style="list-style-type: none"> • Department of Communities • WA health organisations • Disability Services (now within Department of Communities) • Mental Health Commission • Department of Education including schools. <p>Local governments.</p> <p>Health professionals and service providers.</p> <p>Carers WA.</p> <p>Carer organisations.</p> <p>Media.</p> <p>Employers.</p>

Outcome 2 - Carers' diverse situations, circumstances and backgrounds will be respected and accommodated.

1.5 Support service providers to meet the specific needs of carers from diverse backgrounds.

What's already in place?	What will help?	Who can act?
<p>The Office of Multicultural Interests provides the following resources:</p> <ul style="list-style-type: none"> Diverse WA online cultural competency training is available free of charge to WA state and local government, and not-for-profit community organisation staff. The WA Language Services Policy 2014 requires State Government agencies to fund language services to clients who need assistance with written and spoken English – www.omi.wa.gov.au. The WA Interpreter Card enables the holder to tell agencies and providers the language they need an interpreter for www.omi.wa.gov.au. <p>The Public Sector Commission provides an online cultural confidence module - Sharing Culture: Aboriginal and Torres Strait Islander People - www.sharingculture.publicsector.wa.gov.au.</p> <p>Carers WA provides:</p> <ul style="list-style-type: none"> information in Arabic, Chinese (traditional and simplified), Croatian, Czech, Dari, Italian, Serbian, Spanish, Vietnamese Linking Together Care Group (CaLD) information for young carers. <p>www.carerswa.asn.au</p> <p>WA <i>Equal Opportunity Act 1984</i>.</p> <p>Age <i>Discrimination Act 2004</i>.</p> <p>Australian <i>Human Rights Commission Act 1986</i>.</p> <p>Disability <i>Discrimination Act 1992</i>.</p> <p>Racial <i>Discrimination Act 1975</i>.</p> <p>Sex <i>Discrimination Act 1984</i>.</p>	<p>Supporting service providers to address the barriers faced by carers from diverse backgrounds.</p> <p>Cultural competency training (Aboriginal and CALD) for all staff.</p> <p>Engaging staff, peer support workers and volunteers from diverse backgrounds.</p> <p>Better understanding of:</p> <ul style="list-style-type: none"> the specific needs of diverse carers State and Commonwealth anti-discrimination laws. <p>Information and resources on the specific needs of carers from diverse backgrounds and ways to meet these needs.</p> <p>Targeted information and support for hidden carer groups.</p> <p>The consistent use of interpreters and translated materials.</p> <p>Information in a range of languages and formats.</p> <p>Ensure State Government agencies are aware of their obligations under the <i>WA Language Services Policy 2014</i> and <i>WA Equal Opportunity Act 1984</i>.</p> <p>Ensure carers and service providers are aware of the protections available to them under State and Commonwealth anti-discrimination laws.</p>	<p>Western Australian Government:</p> <ul style="list-style-type: none"> Department of Communities Office of Multicultural Interests WA health organisations Disability Services (now within Department of Communities) Mental Health Commission WA Equal Opportunity Commission State Administrative Tribunal. <p>Australian Human Rights Commission.</p> <p>All tiers of government.</p> <p>Aboriginal and multicultural community organisations.</p> <p>Health professionals and service providers.</p> <p>Carers WA.</p> <p>Interpreter and translator institutes and associations.</p>

Priority Area 2: Respected Partners in Care

Strategies and Actions

Outcome 3 - Carers will be respected and included as expert care partners.

- 2.1 Ensure and/or encourage respect for carers, their knowledge and experience.
- 2.2 Ensure and/or encourage the inclusion of carers in care and discharge planning and decision making.

What's already in place?	What will help?	Who can act?
<p><i>Carer Recognition Act 2004</i> and WA Carers Charter.</p> <p>Carers Advisory Council compliance reporting.</p> <p><i>Mental Health Act 2014</i> provides for the recognition of the role of families and carers in providing support.</p> <p><i>Disability Services Act 1993</i> requires State Government agencies and local governments to develop a Disability Access and Inclusion Plan (DAIP) for better access and inclusion for people with disability and their carers.</p> <p>WA Health has produced guides and guidelines for consumers and providers on:</p> <ul style="list-style-type: none"> • consumer and community engagement • sharing information with mental health clinicians • collaborative health care planning • communicating with carers and families. <p>Carers WA Carer Participation and Representation Program.</p> <p>The Health and Disability Services Complaints Office is a free, confidential and impartial resolution service for complaints relating to health or disability services and available to all users, including carers.</p> <p>The State Administrative Tribunal is an independent body that makes and reviews administrative decisions about issues including guardianship and administration, equal opportunity and mental health appeals.</p>	<p>Ensuring State Government agencies are aware of the <i>Carers Recognition Act 2004</i>.</p> <p>Monitoring and reporting on compliance with the Act.</p> <p>Ensuring service providers are aware of the WA Carers Charter.</p> <p>Encouraging community and private sector organisations to implement the WA Carers Charter guidelines.</p> <p>Encouraging and supporting agencies and organisations to develop frameworks for engaging and communicating with carers.</p> <p>Longer GP and other health appointment times.</p> <p>Including carer-related content in tertiary curriculums.</p> <p>Including carer-related content in induction, training and professional development.</p> <p>Identifying carers on admission and other formal patient documentation.</p>	<p>Western Australian Government:</p> <ul style="list-style-type: none"> • Department of Communities • WA health organisations • Disability Services (now within Department of Communities) • Mental Health Commission. <p>Carers Advisory Council.</p> <p>Carers WA.</p> <p>All service provider staff.</p> <p>Health and Disability Services Complaints Office.</p> <p>State Administrative Tribunal.</p> <p>Professional bodies and industry associations.</p> <p>Education and training providers.</p>

Outcome 3 - Carers will be respected and included as expert care partners.

2.3 Facilitate the inclusion of carers in decision making.

What's already in place?	What will help?	Who can act?
<p>The Department of Communities provides advice about carers needs at the national and state levels.</p> <p>Carer advocacy services - see www.dlgc.wa.gov.au/advice-support.</p> <p>Integrated Planning and Reporting requires local governments to engage all community members in the development of Community Strategic Plans.</p> <p>Carers WA Carer Participation and Representation Program.</p> <p>Carer and consumer representation on State Government agency advisory groups and committees.</p>	<p>Routinely engaging carers and carers organisations in government decision making.</p> <p>Promoting community consultation and feedback opportunities.</p> <p>Encouraging and supporting carers and carers organisations to provide input into policy and service development.</p> <p>Promoting opportunities for carer and consumer representation.</p> <p>Supporting and promoting advocacy services.</p>	<p>Western Australian Government:</p> <ul style="list-style-type: none"> • Department of Communities • WA health organisations • Disability Services (now within Department of Communities) • Mental Health Commission. <p>Local governments.</p> <p>Carers Advisory Council.</p> <p>Carers WA.</p> <p>All service provider staff.</p>

Priority Area 3: Supporting Carers

Strategies and Actions

Outcome 4 - Carers will have access to appropriate services and information that support them to care with confidence and maintain their personal wellbeing.

Outcome 5 - Carers will be able to balance their caring responsibilities, personal wellbeing and life outside of caring.

3.1 Ensure carers can easily access information, advice and support.

What's already in place?	What will help?	Who can act?
<p>Online WA Carers Services Directory www.dlgc.wa.gov.au/AdviceSupport/Pages/Carers-Services.aspx</p> <p>Information, advice, advocacy and support programs provided by government agencies, and community sector and private providers.</p> <p>Telephone and online support and information services.</p>	<p>Asking carers what information, training and support they need and how they want to access it.</p> <p>Reviewing and updating existing information and resources.</p> <p>Identifying, promoting and/or:</p> <ul style="list-style-type: none"> • implementing new and innovate training packages • distributing new information, training opportunities and support services. <p>Ensuring State Government agencies are aware of the relevance of their work to carers.</p> <p>Encouraging relevant State Government agencies to:</p> <ul style="list-style-type: none"> • host or participate in carers workshops • produce carer-specific information and resources. <p>Ensuring carers can access information on relevant topics such as:</p> <ul style="list-style-type: none"> • enduring powers of attorney • advanced health directives • financial planning. <p>Promoting and distributing the Carers Recognition Act and Charter.</p> <p>Using communication technology such as video calls and conferencing to reach carers in regional and remote areas.</p> <p>Flexible service delivery and respite or care for the person receiving care.</p> <p>Dedicated carer liaison officers.</p> <p>Using interpreters and translated materials.</p> <p>Providing information in a range of languages and formats.</p>	<p>Western Australian Government:</p> <ul style="list-style-type: none"> • Department of Communities • WA health organisations • Disability Services (now within Department of Communities) • Mental Health Commission • Department of the Attorney General • Office of the Public Advocate • State Administrative Tribunal. <p>Commonwealth Government agencies, particularly Centrelink.</p> <p>Local governments.</p> <p>Carers Advisory Council.</p> <p>Carers WA.</p> <p>All service provider staff.</p>

Priority Area 3: Supporting Carers continued

Strategies and Actions

Outcome 4 - Carers will have access to appropriate services and information that support them to care with confidence and maintain their personal wellbeing.

Outcome 5 - Carers will be able to balance their caring responsibilities, personal wellbeing and life outside of caring.

3.2 Support carers to remain physically and mentally well.

3.3 Support carers to pursue life opportunities alongside their caring responsibilities.

What's already in place?	What will help?	Who can act?
<p>Respite, self-care and wellbeing programs provided by government agencies, and community sector and private providers.</p> <p>www.dlgc.wa.gov.au/AdviceSupport/Pages/Carers-Services.aspx</p> <p>Carer Allowance, Health Care and Pensioner Concession Card holders may be eligible for discounts on a range of products and services.</p> <p>www.concessions.wa.gov.au/Pages/default.aspx</p> <p>Older carers may be eligible for the WA Seniors Card, enabling them to access a range of concessions and discounts.</p> <p>www.seniorscard.wa.gov.au</p> <p>Online and telephone mental health support programs and counselling services.</p>	<p>Ensuring carers are aware of the importance of their own health and seeking help for themselves.</p> <p>Flexible, affordable, quality and appropriate respite – such as in-home, mobile, occasional and family options, and services that can care for people with challenging behaviours.</p> <p>Carer discounts for health, wellbeing, recreation and self-care.</p> <p>Carer specific mental health prevention and early intervention programs and services.</p> <p>Ensuring that staff at services regularly used by carers – such as GP clinics, schools, and allied health services – can direct carers to appropriate support services.</p> <p>Supporting carers to identify and pursue the life opportunities of their choice.</p> <p>Outreach and follow up mechanisms and processes.</p> <p>Staff consistency.</p>	<p>Western Australian Government:</p> <ul style="list-style-type: none"> • Department of Communities • WA health organisations • Disability Services (now within Department of Communities) • Mental Health Commission. <p>Commonwealth Government:</p> <ul style="list-style-type: none"> • Department of Social Services • Department of Human Services. <p>Local governments.</p> <p>Carers WA.</p> <p>Businesses and the private sector.</p> <p>Service providers.</p>

Priority Area 3: Supporting Carers continued

Strategies and Actions

Outcome 4 - Carers will have access to appropriate services and information that support them to care with confidence and maintain their personal wellbeing.

Outcome 5 - Carers will be able to balance their caring responsibilities, personal wellbeing and life outside of caring.

3.4 Support carers to perform their full range of daily care responsibilities.

What's already in place?	What will help?	Who can act?
<p>The WA Taxi User Subsidy Scheme (TUSS): subsidises taxi travel for eligible people with disability and their carers.</p> <p>Free and concession travel on Transperth Services for eligible concession card holders.</p> <p>Transperth's Disability Assistance measures ensure that transport and facilities are accessible to all, and includes assistance at train stations.</p> <p>Respite and support programs provided by government agencies, and community sector and private providers.</p> <p>For more information: www.concessions.wa.gov.au/Pages/default.aspx</p>	<p>Affordable and reliable:</p> <ul style="list-style-type: none"> domestic/household assistance in-home and/or occasional respite and support home delivery of meals. <p>Practical training in personal care such as showering and dressing, equipment use and handling, and managing and administering medication.</p> <p>Flexible service provision including location, hours of operation and delivery.</p> <p>Simplify application and administration processes.</p>	<p>Western Australian Government:</p> <ul style="list-style-type: none"> Department of Communities WA health organisations Disability Services (now within Department of Communities) Mental Health Commission Department of Transport Transperth. <p>Commonwealth Government:</p> <ul style="list-style-type: none"> Department of Social Services Department of Human Services. <p>Local governments.</p> <p>Carers WA.</p> <p>Businesses and the private sector.</p> <p>Service providers.</p>

Priority Area 4: Participation in Education and Employment

Strategies and Actions

Outcome 6 - Carers will have the same life choices and opportunities as other members of the community.

Outcome 7 - Young carers will be supported to learn, develop and thrive, and enjoy positive childhoods.

4.1 Support carers to participate in education.

4.2 Support carers to return to or remain in employment.

What's already in place?	What will help?	Who can act?
<p>Scholarships, bursaries and learning clubs provided by not-for-profit and philanthropic organisations.</p> <p>Carers Australia Young Carers Bursary Program.</p> <p>Canning and Tuart Colleges offer:</p> <ul style="list-style-type: none"> • secondary education (Years 10-12) and university and TAFE pathways courses for young people and adults • flexible learning options such as online teaching (Tuart) and leaving campus between classes (Canning). <p>Pensioner Concession and Health Care Card holders and their dependents may be eligible for a 50% discount on eligible government subsidised VET courses.</p> <p>Under the <i>Fair Work Act 2009</i> (2014), carers—as defined in the <i>Carer Recognition Act 2010</i>—who have worked with the same employer for at least 12 months can request flexible working arrangements.</p> <p>Employees of businesses covered by the WA industrial relations system – which includes government, sole traders, unincorporated partnerships and some trust arrangements – are entitled to use any amount of their sick leave entitlement as paid carers leave providing they have been employed with the business continuously for 12 months.</p>	<p>Financial assistance for young carers.</p> <p>Encouraging, promoting and implementing flexible learning and attendance options.</p> <p>Ensuring schools understand the barriers to participation and attainment faced by young carers.</p> <p>Encouraging and supporting schools to develop and implement programs and guidelines to support young carers.</p> <p>Ensuring employers and employees are aware of State and Commonwealth legislation on flexible working conditions.</p> <p>Affordable and flexible training and skills development opportunities for carers.</p> <p>Flexible provision of career and employment services.</p> <p>Flexible work options, including carers leave.</p> <p>Assistance with written job applications and interview techniques.</p> <p>Programs and plans to support carers to return to or prepare for work.</p> <p>Programs and plans to supporting young carers to transition from education to employment.</p>	<p>Western Australian Government:</p> <ul style="list-style-type: none"> • Department of Communities • Department of Education • Department of Mines, Industry Regulation and Safety • Department of Training and Workforce Development • WA Industrial Relations Commission • Public Sector Commission • Small Business Development Corporation • State Administrative Tribunal. <p>Commonwealth Government:</p> <ul style="list-style-type: none"> • Department of Education and Training • Department of Employment • Fair Work Commission • Fair Work Ombudsman • StudyAssist. <p>Australian Human Rights Commission.</p> <p>Carers WA.</p> <p>Business and industry councils.</p> <p>Employers.</p> <p>Education and training providers.</p>

Priority Area 4: Participation in Education and Employment continued Strategies and Actions

Outcome 6 - Carers will have the same life choices and opportunities as other members of the community.

Outcome 7 - Young carers will be supported to learn, develop and thrive, and enjoy positive childhoods.

4.3 Support employers and education providers to understand carers roles, responsibilities and needs.

What's already in place?	What will help?	Who can act?
<p>Carers WA and the Western Australian Government have produced the following resources for employers and education providers:</p> <ul style="list-style-type: none"> • Young Carers WA – online resources for schools • Business Case for Carer-friendly Workplaces • Creating Carer Friendly Workplaces • CARE Resource Kit. <p>www.carerswa.asn.au</p> <p>Carers Australia's Work and Care resources.</p> <p>www.carersaustralia.com.au</p> <p>Australian Human Rights Commission Supporting Carers in the Workplace: a toolkit.</p> <p>www.humanrights.gov.au</p>	<p>Provide information on carers role, responsibilities and needs.</p> <p>Encouraging and supporting employers to develop and implement carer-friendly workplace strategies.</p>	<p>Western Australian Government:</p> <ul style="list-style-type: none"> • Department of Communities • Department of Education • Department of Mines, Industry Regulation and Safety • Department of Training and Workforce Development • WA Industrial Relations Commission • Public Sector Commission • Small Business Development Corporation • State Administrative Tribunal. <p>Commonwealth Government:</p> <ul style="list-style-type: none"> • Department of Education and Training • Department of Employment • Fair Work Commission • Fair Work Ombudsman. <p>Carers WA.</p> <p>Business and industry groups.</p> <p>Employers.</p> <p>Education and training providers.</p>

Outcome 8 - Carer policy, planning and service delivery will be evidence based.

5.1 Support and encourage initiatives to improve carer data collection, consistency and sharing.

What's already in place?	What will help?	Who can act?
<p>Data collection by Commonwealth Government bodies including the:</p> <ul style="list-style-type: none"> • Australian Bureau of Statistics • Australian Institute of Family Studies • Australian Institute of Health and Welfare. <p>Research undertaken or funded by carers organisations, government agencies, universities, and private and community sector organisations.</p>	<p>Consistent collection of information and data about carers, particularly hidden carers.</p> <p>Advocating to:</p> <ul style="list-style-type: none"> • increase the frequency of the Survey of Disability, Ageing and Carers • include carer specific census questions. <p>Supporting and funding research about carers and their needs, particularly hidden carers.</p> <p>Data sharing processes and protocols.</p> <p>Developing consistent definitions, criteria and methodologies for carer data collection.</p>	<p>Western Australian Government:</p> <ul style="list-style-type: none"> • Department of Communities • Department of Education • WA health organisations • Disability Services (now within Department of Communities) • Mental Health Commission. <p>Commonwealth Government research bodies.</p> <p>Universities and research centres.</p> <p>Private and community sector organisations.</p>

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