

# **SA CARERS REPORT**



**Prepared by  
Carers Ministerial  
Advisory Committee**

# **Report on SA Carers**

## **1. Introduction**

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The provision of care that enables people to reach their full potential is to be valued and supported by the community wherever it occurs. The Carers Report addresses the special situation of the nearly 250,000 Family Carers in South Australia who provide care and support in their role as mothers, fathers, husbands and wives, partners, children, brothers, sisters, aunts, uncles, cousins, friends and neighbours.

Family Carers make an essential contribution to the emotional, spiritual and physical health of many South Australians. By doing so they enable the people they care for, to achieve the fundamental right of remaining within the communities and families to which they belong. Their efforts are supported by other types of care provided by volunteers and professional care providers.

This Report provides a broad overview of Carers needs in many caring situations. It has been developed with South Australian Carers, with the aim of achieving a greater balance in consideration of their needs and the people they are caring for, so that everyone benefits.

By adopting the seven Core Principles in this Report, State Government agencies and funded services providers will be able to develop specific action plans that will achieve improved health and well-being for South Australian Carers through:

- A more consistent approach to responding to Carers needs.
- Better coordination between service providers.
- A strategic, planned approach to funding and resource allocation.
- Participation by Carers at all levels of policy development and services planning.
- Greater recognition and support for Carers by the wider community

## **2. Process for developing the Report**

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The development of this Report has involved specific research on South Australian Carers, investigations into overseas and interstate experience and background papers on Children and Young People as Carers and Aboriginal and Torres Strait Islander Carers.

South Australian Carers from a range of caring circumstances have provided critical input. Their views have been deliberately highlighted in this process as they are the major consumer group of the Report and because they have often been invisible in the past. In addition, there have been consultations with interested parties through written submissions and small group forums, as well commissioned consultations held by a number of key agencies.

An expert Ministerial Advisory Committee of Carers from a range of backgrounds was appointed to oversee the process of the development of the Report.

### **3. Scope of Report**

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#### *Who are Family Carers?*

Most people will at some time in their life provide care to others or are cared-for themselves, and often will experience both. This care can be provided by a combination of Family Carers, friends, volunteers, or paid professionals. Usually however, in ways defined by our cultures, traditions and languages, family members provide the bulk of this care.

The intention of the Carers Report is to focus on the circumstances and challenges experienced by family and friends who provide care and support to someone with needs associated with a disability, physical or mental illness, cultural deprivation, frailty or substance abuse problem. Disability may be physical, intellectual or psychiatric or a combination of these. Care and support includes physical care, such as preparation of meals, lifting, personal care and making appointments and emotional care includes support, advocacy and advice.

Family Carers referred to in this Report can be from any kind of family, including traditional two parent families and couples, extended families, single parent and step-families, same-sex parented families, or a friend or neighbour.

The development of this Report is a response to increasing awareness by service providers of the particular needs of a family member caring for someone they have a close relationship with and who has an illness or disability. This Report takes a new approach to Carers in South Australia by deliberately focusing on their rights and needs rather than seeing them as an extension of the cared-for-person.

#### *Federal, State and Local Government responsibilities for Carers*

State, Federal and Local Government (Councils) provide, fund and support services for Family Carers and the people they care for.

The Federal Government has responsibility for Income Support (Pensions) for eligible Carers and cared-for-people, as well as funding for a range of information and respite programs and community and aged care services. The State Government provides health and welfare services as well as programs for older people and people with a disability, drug and alcohol programs and education services and administers the joint HACC Carer support programs. These also include information, respite and other support services.

Many Local Councils in both metropolitan and rural areas of South Australia provide and support a range of locally based services for Carers and those they care for. Other community services for the wider community also assist Carers through community development and volunteer programs.

Nevertheless, South Australian Family Carers have said that they find the complexity of services and programs overwhelming and often unhelpful. The different layers of government involvement, the different funding arrangements and the different priorities means they often can't get the support they need, when they need it.

The lack of whole-of-government Carer policies at both Federal and State levels has resulted in a significant variation in the response to Carers needs, including overlapping in funding programs as well as gaps in services and great difficulty in measuring the effectiveness of the system as a whole. The Carers Report relates to State services, but also considers the opportunity for a more strategic and coordinated approach across all tiers of government.

## **4. Changing patterns of providing Care**

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Significant social and demographic changes in recent decades have had a profound impact on the way that family care is provided. The concept of Family Carer being addressed in this report emerged in the 1970s, when there was a significant increase in deinstitutionalisation of people with severe disabilities and mental illness, who were moved back into the community.

These policies have correctly emphasized the rights of people needing support and care, to live within the community and with their families. The consequence however, has been that it is often the families who have to take on the additional caring responsibilities with limited support and respite. For those on low incomes, single parent families and families that experience access difficulties because of culture, language or rural location, the burden has often been considerable.

In addition, advances in medical care and treatment, has meant that survival rates from severe accident and trauma resulting in high levels of disability has increased dramatically. South Australians also now live much longer, with increasing levels of frailty and a greater need for care and support.

Just like the wider South Australian community, Carers come from many different cultural backgrounds and circumstances which influence the ways they provide care and the kinds of support that will assist them. For example, many migrants who arrived in Australia after the war are now frail and reliant on their children to support them. Newer migrant and refugee communities such as those from the Sudan or the former Yugoslavia may have greater needs associated with caring for partners or children with mental health problems as a result of dislocation, detention, torture and trauma.

Other factors relate to the increasing diversity of family units, increasing numbers of women entering the work-force, smaller family sizes and greater mobility of families away from their kin. This has resulted in smaller numbers of available Family Carers, who were traditionally wives, mothers, sisters, daughters and daughters-in-law. One of the most significant groups of Carers emerging as an issue in recent years are Children and Young People, particularly in single parent families, who have taken on significant caring responsibilities in the absence of other family and community support.

The traditional caring unit is less common today and many Carers now expect that their rights to full and satisfying lives are acknowledged and supported by the community and government.

## **5. Caring Relationships**

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Within all cultures, caring for family and friends is part of the way we express our concern for others. Caring is a fundamental part of human existence, as we all need some level of care during our lifetimes, from infancy through to old age and often in between at various times. Many people will need considerably more care because of prolonged ill health or disability.

For Family Carers referred to in this Report, the care being provided is not the defining feature of the relationship they have with the cared-for-person. Rather, it is their role as mother, father, husband, wife, aunt, uncle, child and neighbour that defines who they are.

This is very important, because it is the emotions that go with family and kinship obligations and responsibilities which determine the extent and nature of care and often allow or encourage the Carers to continue caring despite considerable impact on their own health and well-being.

For volunteers and paid care workers, the close relationship they may have with the person they care for, is not a defining element, making it easier to move out of the caring role if the circumstances become unsatisfactory. This is not to diminish in any way the commitment and concern they may have for the people they care for, but to recognize that the obligations and pressures on Family Carers are far more complex and demanding, as well as being unpaid.

Carers can also be anyone, from any culture or background, any age from children to frail aged, any educational background and income. The circumstances of caring can be just as diverse. For example, the level of care provided could range from weekly assistance such as shopping for an elderly relative, to long-term intensive 24 hour care that has a significant impact on the Carer's life. It could last for a number of months with increasing intensity caring for a relative with a terminal illness or it could last for many decades caring for a child with a profound disability. It can be the primary responsibility of one person or shared with a number of people. It is also not uncommon for some Carers to be providing care to a number of family members or for the Carer to also have a disability or illness.

There are many positive and rewarding aspects of caring because of reciprocity, mutual support and concern and respect for each other. Indeed, most Carers will say that the care they provide is simply a normal part of being in a family and expressing love and one of the responsibilities that comes with being a parent, relative or friend.

There can also be more difficult aspects to providing this kind of care, depending on the resources of an individual Carer and their families, the level of care they need to provide, and the level of support they receive from the wider community and service

providers. Research has shown that depending on the circumstances, Family Carers may have higher levels of stress and anxiety than non-Carers, difficulties with work and study, restricted social and recreational opportunities, and feelings of grief, resentment and great emotional upheaval from the caring situation.

Carers also do not need to be living with the person they care for to have significant caring responsibilities. For example, when a spouse moves into a nursing facility with advanced Alzheimer's disease or a family member experiences a traumatic brain injury and is hospitalized for a long period, many Carers continue to provide support.

As well as travelling times, which may be significant in rural locations, Carers may spend many hours providing regular personal care and emotional support. In addition, the relationship they have with the person they are caring for, may be significantly disrupted as service providers take over much of the decision making responsibilities.

Carers in South Australia, irrespective of their backgrounds, report common experiences from caring responsibilities. However, for particular groups of Carers, there may be additional stresses because of a young age, difficulties accessing support because of cultural barriers or geographic remoteness, financial pressures or their own ill-health.

#### *Service providers and the Community*

The degree to which service providers and the community respect, understand and respond to the needs of Family Carers can have a profound effect on Carers well-being which may flow-on to the person they are caring for.

Service providers have similar cultural norms and beliefs about families and caring roles as the wider community. In addition, traditional ways in which they provide services are reinforced by the way that funding is provided by government. These include policies about privacy and confidentiality, levels of consumer participation in service planning, competing resource priorities and beliefs about the superiority of professional expertise compared to the value of the personal knowledge of Carers about the person they care for.

## 6. Recommended Principles

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### **Core Principle 1:**

#### ***Carers have choices within their caring role.***

##### *Statements about Principle 1*

- 1.1 *Carers are entitled to the same rights, choices and opportunities as other South Australians.*
- 1.2 *Carers should be supported by individuals, families, business and community organizations, public institutions and all levels of government in the choices they make in their caring role.*

Becoming a Family Carer is often unexpected and can have a profound impact on people's lives. Most people expect that families support each other in difficult times, but there is also an expectation that other supports are available through government and non-government agencies.

Carers are often put into the position of having to make urgent and important decisions about the person they care for, with little thought and concern given to the impact on family circumstances by health and other service providers. These initial decisions can have a profound impact on a family with a risk of becoming permanent options.

In other situations, Carers may have the opportunity to plan and accommodate increasing caring responsibilities, with significant support from other family members, the community and service providers.

Most South Australian Carers say they accept and embrace the responsibilities they have taken on for the person they care-for; despite radical readjustments they may have to make to their lives. Some Carers say they would feel guilty if they reduced their caring role or complained and they may believe that they will be criticized if they stop providing the care. They may also worry that the person they care for will be forced into other unsatisfactory care arrangements that will upset them both and as a consequence may feel trapped into continuing to provide care with little respite.

To be able to choose whether to take on the role of Carer in a family, or what level of care they have the capacity to provide, Carers need to have alternative options for themselves and the person they care for, and timely and specific information about what is available.

The range of services and support available for Carers needs to be responsive to their needs and circumstances. Service providers should make sure that the Carer's wishes are considered and understood at the very beginning of events that affect the person they may be caring for.

This approach requires agencies to find ways of considering family circumstances that include consideration of the Carers desire and ability to take on caring responsibilities, their emotional and financial resources and their location relative to the support and services they need.

Service providers also need to consider and balance their obligations to Family Carers as well as the person being cared for.

## **Core Principle 2**

### **Carers health and well-being is critical to the Community.**

#### *Statements about Principle 2*

- 2.1 *Carers are entitled to enjoy optimum health, social, spiritual and economic well-being and to participate in family, social and community life, employment and education.*
- 2.2 *The needs of both the Carer and the person they are caring for should be balanced.*

Family Carers are people of all ages, from a range of backgrounds and cultures and with different abilities. Depending on their circumstances, they also have different levels of family and community support as well as the financial means to back up their caring responsibilities.

Evidence shows that Carers can have higher levels of stress and poor health where they have significant caring responsibilities. They have the same need for fulfilling lives as everyone else in the community, including the need for opportunities and financial resources to meet and interact with friends and family, have leisure time and pursue career and educational opportunities depending on their hopes and aspirations.

Advice, information, and flexible and affordable support needs to be provided to Carers to reduce the negative impacts of caring, including specific measures to allow breaks from caring or special strategies to compensate for significant caring responsibilities.

In addition, Carers need the same kinds of protection, support, training and technical assistance in managing the needs of the person they care for as paid care workers and professionals, to avoid psychological and physical strain and injury.

Consideration also needs to be given by service providers, taking account of the legal requirements, to overcoming rigid adherence to privacy and confidentiality guidelines where they clearly undermine the ability of Family Carers to support the cared-for person. This includes health and welfare service providers as well as financial institutions.

The rights of Carers and the person they care for, need to be balanced in a way that maximizes the health and well-being of all family members. There should be measures in place that enable Carers to be involved in all levels of planning of services for themselves as well as the person they care for. Independent complaints and grievance mechanisms should be available to Carers as well as the people they care for.

## **Core Principle 3**

### ***Carers play a critical role in maintaining the fabric of society.***

#### *Statements about Principle 3*

- 3.1 *Carers should be recognised and valued for their important contribution to the well-being of the Australian community.*
- 3.2 *Carers should be recognised for their unique expertise and skills in the caring role.*

Many Family Carers feel that they are invisible providers of care who are undervalued and unrecognized by the community and service providers, including government. They often feel taken for granted and at times exploited by some service providers who may emphasize the exclusive rights and needs of the person being cared for, over those of the Carer.

Carers may also be invisible because they do not call themselves a "Carer" for a range of reasons. These include beliefs about the duties of a spouse or parent, because of shame or stigma associated with the condition of the person they care for, or because they are not aware that they have a right to seek assistance or that it is available.

Other Carers feel discomfort about the word because they prefer to describe their relationship to the Cared-for-person such as mother/father/daughter. Others feel that the word "Carer" is patronizing and implies a power relationship between two people which may not exist. For example, the spouse of someone with a disability may provide physical support, which is just one aspect of that particular relationship.

In addition, the concept and meanings applied to the word Carer are very culturally specific. Such a word may not even exist in some cultures or may have different, negative meanings to those in the English language. As a result, Carers from some cultural backgrounds may not seek help and support even where it is available.

Better public recognition of the importance of Carers and the role they play, will lead to better accountability for services and more Carers will feel confident and willing to seek support.

## **Core Principle 4**

### **Service Providers work in partnership with Carers**

#### *Statements about Principle 4*

- 4.1 *Caring is a social and public responsibility shared by individuals, families, business and community organizations, public institutions and all levels of government.*
- 4.2 *Carers should be recognised as individuals with their own needs, within and beyond the caring situations.*
- 4.3 *The relationship between the Carer and the person they care for, needs to be respected and honoured.*
- 4.4 *Carers should be involved in decision making that relates to their care situation.*

Traditional approaches towards Family Carers in South Australia range from ignoring or excluding them, to seeing them as a resource that can be tapped into by the community and service providers.

In recent years, there has been increasing emphasis on consumers' rights to be involved in the planning of services. Research has shown that participation at all levels of planning improves their health and well-being. However, in South Australia, Carers are often not seen as consumers of services, either when they are seeking assistance for the person they care for, or when they are seeking support and information for themselves from the same agencies.

This approach is often unhelpful to the cared-for-person as well as the Carer. A more holistic approach to families and the caring relationship will benefit all parties and has the potential to reduce stress on Carers and therefore achieve the best possible outcomes for the cared-for-person.

Such an approach also needs to take account of the specific expertise provided by Family Carers. They often have a better understanding than service providers of the range of needs of the person they are caring for and what kinds of intervention and assistance are most likely to work. Joint planning involving all concerned parties will have the best outcomes for everyone.

Organizations should encourage Carer participation in all levels of decision making about their rights and choices of the person they care for. Some agencies have established "Consumer and Carer" structures, which may unintentionally reinforce the belief that Family Carers are not consumers and are an appendage to the person they care for. There are times when the needs of both may be in conflict and Carers have a right to their needs being given separate and due consideration.

## **Core Principle 5:**

### **Carers in Aboriginal and Torres Strait Islander Communities need specific consideration.**

#### *Statements about Principle 5*

- 5.1 *Aboriginal and Torres Strait Islander Carers are specifically acknowledged and identified by their families and communities*
- 5.2 *Aboriginal and Torres Strait Islander Carers are supported by business and community organizations, public institutions and all levels of government.*
- 5.3 *Aboriginal and Torres Strait Islander Carers are provided with culturally appropriate support services that take into account the history, health and well-being of their extended families.*

The way Family Carers and extended families provide care and support to family members with an illness or disability and the response by the community and service providers is strongly influenced by cultural norms.

Within Aboriginal and Torres Strait Islander families and communities, kinship ties, responsibilities and obligations place a strong emphasis on sharing and mutual support. Many Aboriginal and Torres Strait Islander communities and individuals already create and sustain nurturing, healthy and successful families, positive community culture and safe community environments.

The stresses and pressures of caring for family members with an illness or disability are the same for all Carers. However, for Aboriginal and Torres Strait Islander families, the historical experience of dispossession and racism has had a profound impact, resulting in higher levels of poor health, poverty and family trauma. This history of dispossession and destruction of families has often led to a passive resistance to using non-Aboriginal services, including those for Family Carers and the people they care for.

Aboriginal and Torres Strait Islander Carers and the people they care for, therefore require specific consideration in resource allocation, planning and location of services.

## **Core Principle 6:**

### **All Children and Young People have the right to enjoy life and reach their potential.**

#### *Statements about Principle 6*

- 6.1 *Children and Young people who are Carers must be specifically identified and supported by individuals, business and community organizations, public institutions and all levels of government.*
- 6.2 *The special needs and unique barriers to service provision by children and young people who are Carers, should be considered so they have the same opportunities as other children and young people in Australia.*
- 6.3 *The caring responsibilities of children and young people who are Carers is minimized.*

There is a stereo-typical view in the community that a Carer is an adult caring for someone with a disability or who is frail aged. In recent years however, service providers have become aware that there is a significant hidden group of Carers that has largely been ignored, namely children and young people up to 25 years of age providing care to a parent or sibling with a disability or illness. Many of these children are living in single parent families without other family supports and some may be caring for a parent whose parenting capacity may be significantly impaired by a mental illness or substance abuse problem.

It is difficult for many people to imagine that children and young people are actually providing care to a parent rather than the other way around because this is not the social norm. Service providers may also not be aware children are providing this care because the caring situation is usually not disclosed. The reasons include embarrassment, worry that authorities will remove the children or the children are not aware that their situation is unusual. It may not occur to them to seek help because they rely on adults to identify and respond to their needs.

Children and young people can learn valuable life skills through caring responsibilities and these are increasingly being recognised as prior learning skills through the education system. However, they can also be profoundly affected in a negative way depending on their age, if they have unhealthy and inappropriate caring responsibilities and if they are the main care provider without support and assistance from others. In particular, where they are caring for a parent with a significant mental illness, the impact on their emotional well-being and development can be profound.

Children and young people have a right to their developmental and educational needs being met and that they receive the same level of parental support and nurturing as their peers. The community and the government, particularly through education, health and welfare services have specific obligations both morally and legally, to ensure that these needs are addressed and their rights maintained. Because of frequent contact, educational institutions are very well-placed to identify children and young people who may have caring responsibilities at home.

## **Core Principle 7:**

**Resources are available to provide timely, appropriate and adequate assistance to Carers.**

### *Statements about Principle 7*

- 7.1 *Carers need access to a wide range of responsive, affordable services to ensure informed decision making and support them in their caring situation.*
- 7.2 *Carers from Culturally and Linguistically Diverse (CALD) backgrounds may have complex needs and require sensitive and appropriate service delivery.*
- 7.3 *Carers in rural and remote communities have unique barriers to service provision.*

Family Carers have a wide range of needs depending on their circumstances, the kind of care they are providing and the availability of other support. They have needs associated with their own health and well-being as well as those relating to the person they care-for.

For Carers living in remote and rural parts of Australia, there are particular difficulties. There may be significant distances to support services for themselves and the people they care for, as well as limited availability of other kinds of personal, community and volunteer support available in urban areas. This has the potential to increase the stresses and pressures of caring responsibilities.

Other barriers may exist for people who feel that services provided to assist them and the people they care for, do not reflect or understand their cultural view of the world and therefore the kinds of caring circumstances they have. As a consequence they may feel uncomfortable about using existing support services or there may be none available that meet their particular needs.

In supporting Carers and considering their needs, service providers and funding programs should develop particular ways of assisting and supporting them, whatever their caring situations.

## **7. Summary and Implementation**

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The SA Carers Report focuses on the particular needs of Family Carers in South Australia, providing care and support to a family member or friend with needs associated with disability or illness. It has been developed with the advice and expertise of Carers from a wide range of caring situations.

The Report describes seven Core Principles that are identified as being important principles to be adopted by State Government agencies. In addition, it is considered that the distribution of funding for Carers support services and funding agreements with non-government organizations should also reflect these Core Principles.

As a result, the health and well-being of Family Carers will improve and they will have greater community recognition for their critical contribution to the well-being of South Australians.