

Policy Directive: compliance is mandatory

Partnering with Carers Policy Directive

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Summary SA Health is committed to improving the way we partner with carers. Through the *Carers Recognition Act 2005* the South Australian Government recognises the roles and rights of carers. SA Health is seeking to build on this recognition and empowerment through a commitment to ensuring better carer engagement in health care decisions.

Keywords Partnering, Partner, Carer, Carers Recognition Act 2005, Engagement, Advocate, Consumer, Policy Directive

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 G0085 Carers Participation Position Statement Guideline

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Contact Officer

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SA Health

Partnering with Carers Policy Directive

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SA Health

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Partnering with Carers Policy Directive

1 A Commitment to Carers

- 1.1 SA Health is committed to improving the way we partner with carers. Through the *Carers Recognition Act 2005* the South Australian Government recognises the roles and rights of carers. SA Health is seeking to build on this recognition and empowerment through a commitment to ensuring better carer engagement in health care decisions.

2 Purpose

- 2.1 The purpose of the SA Health Partnering with Carers Policy Directive is to recognise and support carers and their roles specifically with regard to how carers interact with the South Australian public health system. While SA Health has a suite of policies on consumer and community engagement, carers' specific interests and needs are unique to carers.
- 2.2 The policy refers to carers and their interaction with the public health system. Carers interact with, and need support from, many sectors and parts of government including financial, education and employment support. This policy identifies what is important to carers, based on feedback from carers.
- 2.3 The policy clearly outlines the principles, standards and individual and health care service responsibilities that SA Health will commit to in partnering with carers, and is aligned to the National Safety and Quality Health Service Standards.
- 2.4 The policy is to be read in conjunction with the SA Health Framework for Active Partnership with Consumers and the Community (the Framework). The Framework has been developed to strengthen and improve the practice of consumer and community engagement processes across South Australia. It identifies SA Health's position regarding the significance and value of engaging with consumers and community. The principles and standards outlined in the Framework apply equally to carers.
- 2.5 The policy aligns with the *Carers Recognition Act 2005* and provides a framework for how SA Health will meet its legislative reporting obligations to ensure compliance with the SA Carers Charter.

3 Scope

- 3.1 The SA Health Partnering with Carers Policy Directive establishes the individual and health care service roles and responsibilities in relation to partnering with carers. All SA Health employees or persons who provide health services on behalf of SA Health must adhere to this policy.

4 Definitions

- 4.1 **Advocate** means a person who advocates for the person they care for and has the requisite experience to speak as an informed carer.

- 4.2 **Carer**¹ means a person who provides care and support for their parent, partner, child or friend who has a disability, is frail, or who has a chronic mental or physical illness. An individual is not a carer merely because he or she is the spouse, de facto partner, parent, guardian, child or other relative of an individual, or lives with an individual who requires care. Carers can include parents and guardians caring for children and children caring for parents and guardians.

In the context of Aboriginal communities and kinship systems, caring is a collaborative act with many people helping care for a single person. Because of this, people looking after family and friends often do not recognise themselves as carers. Aboriginal carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged.

The definition of carer in this policy excludes employed care workers. A person is not a carer under this policy if he or she provides this support and assistance under a contract for the provision of services or in the course of doing voluntary work for a non-government organisation, or as part of the requirements of a course of education or training. Carers are not paid in their caring role however they may receive an allowance from the Australian Government.

- 4.3 **Consumer** means patients and potential patients.
- 4.4 **Representative** means a person who represents a carer or support organisation or group and is authorised to speak on behalf of that organisation or group.
- 4.5 **Responsible Person** means a person close to the patient who is available and willing to consent to or refuse consent to health care when the patient has impaired decision-making capacity. The SA Health Advance Care Directives Policy Directive provides further detail on Responsible Persons.²

5 The Roles of Carers in Health

- 5.1 **Carers are partners in care:** The role of carers as partners in care recognises the many functions and duties carers undertake in conjunction with the health system under the direction and advice of, and complementary to, health professionals. As a partner in care, carers might coordinate care, assist in discharge planning, advocate for access to services, and provide a range of everyday tasks such as daily living activities, personal care, assistance, organising finances, shopping, and transport to appointments.
- 5.2 **Carers can be patients and users of the health system:** Carers may access the health care system for their own individual health care needs.
- 5.3 **Carers can be representatives of both carers and patients in the health system:** Carers have experience and knowledge that can be used by the health system in service design, measurement and evaluation. Carers are to be supported by the SA Health Framework for Active Partnership with Consumers and Community and SA Health Guide for Engaging Consumers and the Community that promotes patient / consumer-centred care and consumer and carer engagement. Carers are involved in consumer and community advisory committees and reference groups, and as members of these groups, carers advocate at a system level for improved services for the person they care for.

¹ Carers Recognition Act 2005

² [SA Health Advance Care Directives Policy Directive](#)

- 5.4 **Carers can be an advocate for the person they care for:** Carers often represent the person they care for in making decisions, in advocating for services and coordinating and identifying options for care. This is particularly true when the severity of the illness, disability or condition prevents the care recipient from advocating for themselves. Carers may be a Responsible Person in accordance with the SA Health Advance Care Directives Policy Directive. On an individual level carers advocate for improved services for the person they support in the establishment of their treatment plans.

6 South Australian Carers Charter

- 6.1 The South Australian *Carers Recognition Act 2005* (the Act) states the obligations of applicable organisations relating to the South Australian Carers Charter (which is provided at Attachment 1). SA Health is an applicable organisation under the legislation.
- 6.2 The Act states that an applicable organisation must take all practicable measures to ensure that the organisation and its officers, employees or agents have an awareness and understanding of the Carers Charter and take action to reflect the principles of the Charter in the provision of the relevant services of that organisation.
- 6.3 The Act also states that an applicable organisation must consult carers, or persons or bodies that represent carers, in policy or program development; or strategic or operational planning, relevant to carers and the persons they care for.
- 6.4 The Act provides for a reporting mechanism to ensure compliance by applicable organisations including SA Health.
- 6.5 The South Australian Carers Charter states that:
- 6.5.1 Carers have choices within their caring role
 - 6.5.2 Carers health and well-being is critical to the community
 - 6.5.3 Carers play a critical role in maintaining the fabric of society
 - 6.5.4 Service providers work in partnership with carers
 - 6.5.5 Carers in Aboriginal and Torres Strait Islander communities need specific consideration
 - 6.5.6 All children and young people have the right to enjoy life and reach their potential
 - 6.5.7 Resources are available to provide timely, appropriate and adequate assistance to carers

7 Principles

- 7.1 SA Health listens to carers to understand what is important to them. This has led to the development of a set of principles. To support SA Health's implementation of the SA Carers Charter, SA Health commits to:
- 7.1.1 Maintaining carers as partners in care
 - 7.1.2 Recognising the different roles of carers
 - 7.1.3 Treating carers with respect, dignity and compassion
 - 7.1.4 Supporting carers both in their caring role and in maintaining their own health and wellbeing
 - 7.1.5 Providing carers with the right information about the care provided for the person they care for at the right time
 - 7.1.6 Providing guidance and direction to help carers navigate the health system and transition of care decision making

- 7.1.7 Ensuring services are flexible to the individual circumstances and needs of carers and the people they care for
- 7.1.8 Acknowledging carers' unique long term perspectives
- 7.1.9 Supporting carers as informed advocates for a better health system

7.2 More detail on these principles is provided at Attachment 2.

8 Standards

- 8.1 With the implementation of this policy, all organisations and services in SA Health will ensure that:
 - 8.1.1 carers are partners in decisions and choices about the individual care and treatment of the person they care for
 - 8.1.2 carers are informed if something goes wrong, and receive an explanation, apology and support as appropriate
 - 8.1.3 carers have the opportunity to provide feedback in accordance with the SA Health Consumer Feedback Policy
 - 8.1.4 carers are supported and guided through the health system
 - 8.1.5 carers are treated with respect, dignity and compassion
 - 8.1.6 services are provided that support carers
 - 8.1.7 carers are referred to services provided by carer support organisations outside of SA Health
 - 8.1.8 carers have access to information that enables them to fulfil their role as a carer
 - 8.1.9 carers' experience is captured and evaluated through existing systems
 - 8.1.10 flexible employment policies are offered to support SA Health employees who are carers
 - 8.1.11 mechanisms in place to actively engage with carers in order to identify their needs, and also develop appropriate services
 - 8.1.12 carers are partners in the planning, implementation and evaluation of services

9 Information Sharing and Consent

- 9.1 The principles and standards outlined in this policy directive apply when a consumer consents to their information being shared with a carer. Particularly in mental health, information sharing must be in the interests of good health, safety and wellbeing outcomes for consumers. Information sharing must occur within a framework that aligns with existing South Australian Government privacy and information sharing principles, guidelines and legislation.
- 9.2 Under the *Mental Health Act 2009*, a consumer's information may be shared with a relative, carer or friend of the consumer if the disclosure is reasonably required for their treatment, care or rehabilitation and there is no reason to think that sharing this information would be contrary to the person's best interests.
- 9.3 However, at times, a consumer may choose not to share their personal information with a carer. In these situations, information sharing/disclosure must not occur unless that person is subject to a Community Treatment Order or Inpatient Treatment Order under the *Mental Health Act 2009*. If a consumer is subject to a Treatment Order, information may be shared without the consent and/or against their wishes of the consumer, provided that the information is relevant to the carer's role in supporting the consumer's treatment.
- 9.4 In deciding whether or not to share a patient's information without consent, or informed consent has been sought and refused, it is important to consider whether the information shared will lessen or prevent a serious threat to the patient's life, or the life, health or safety of

a person, or a serious threat to public health or safety. If so, then the information can be legally shared.

- 9.5 Whilst it may not be appropriate for a clinician to share specific information about a consumer, it may be possible to share general information that could assist a carer to understand what a consumer might be experiencing. For example, a clinician might be able to provide information to a carer about the potential side effects of medications, describe symptoms of mental illnesses, or educate a carer about potential early warning signs.
- 9.6 Further information is available in the *Mental Health Practitioner's Guide to Sharing Consumer Information*.

10 Roles and Responsibilities

10.1 The Chief Executive, SA Health is responsible for:

- 10.1.1 ensuring carers are supported across SA Health in accordance with this policy
- 10.1.2 reporting on compliance with the SA Carers Charter in the SA Health annual report

10.2 Department for Health and Ageing Deputy Chief Executives, Executive Directors, Directors and other senior managers will:

- 10.2.1 ensure carers are included in governance and planning activities in the public health system
- 10.2.2 build the requirement for compliance with the *Carers Recognition Act 2005* into service agreements with organisations that provide services relevant to carers on behalf of SA Health
- 10.2.3 seek information from these organisations on their compliance to help inform the annual report

10.3 Local Health Network (LHN) / SA Ambulance Service (SAAS) Chief Executive Officers will:

- 10.3.1 ensure carers are engaged in service designing, planning and evaluation
- 10.3.2 monitor and report on compliance with the SA Carers Charter
- 10.3.3 encourage Governing Councils to support implementation of this policy
- 10.3.4 allocate appropriate support and resources to assist employees to support carers

10.4 Safety, Quality and Risk Managers and Consumer Advisors (as outlined in the SA Health Framework for Active Partnership with Consumers and the Community) will:

- 10.4.1 Support carer engagement and promote and implement the Partnering with Carers Policy Directive
- 10.4.2 develop and maintain own skills and knowledge in carer engagement methods and health literacy, and act as a resource for other staff
- 10.4.3 participate in planning, implementation and review of appropriate carer engagement with mechanisms that suit the social, economic, cultural and linguistic composition of the local population
- 10.4.4 record carer feedback in the Safety Learning System (SLS Consumer Feedback module) and respond to complaints in accordance with the SA Health Consumer Feedback Policy
- 10.4.5 participate or advise on carer consultation and design of carer feedback surveys
- 10.4.6 participate in the design and delivery of relevant training of staff around carer engagement methodology, and health literacy, including using the tools and resources in the SA Health Guide for Engaging Consumers and Community and Toolkit

10.5 SA Health Workforce will:

10.5.1 maintain policies that reflect best practice for SA Health employees who are also carers

10.6 All SA Health employees or persons who provide health services on behalf of SA Health will:

10.6.1 adhere to the principles of this policy and ensure they operate in accordance with its standards

10.6.2 actively partner with carers by supporting and contributing to carer engagement activities

10.6.3 support carers to provide feedback in accordance with the SA Health Consumer Feedback Management Policy

10.6.4 be aware of the services and supports available to carers

10.6.5 develop and maintain their own skills and knowledge about best practice in enhancing consumer / carer engagement, relevant to their role, including the use of the tools in the SA Health Guide for Engaging Consumers and Community and Toolkit, and Cultural Competency Learning and Development online training

11 National Safety and Quality Health Service Standards

11.1 Support to achieve the National Safety and Quality Health Service Standards is enabled by the SA Health *A Framework for Active Partnership with Consumers and the Community*. The Framework has been developed to strengthen and improve the practice of consumer and community engagement processes across South Australia. It identifies SA Health's position regarding the significance and value of engaging with consumers and community. The principles and standards for consumers outlined in the Framework will apply equally to carers as defined in this Partnering with Carers policy directive.

									
National Standard 1	National Standard 2	National Standard 3	National Standard 4	National Standard 5	National Standard 6	National Standard 7	National Standard 8	National Standard 9	National Standard 10
Governance for Safety and Quality in Health Care	Partnering with Consumers	Preventing & Controlling Healthcare associated Infections	Medication Safety	Patient Identification & Procedure Matching	Clinical Handover	Blood and Blood Products	Preventing & Managing Pressure Injuries	Recognising & Responding to Clinical Deterioration	Preventing Falls & Harm from Falls
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>								

12 Monitoring and Compliance

12.1 SA Health is required to report on compliance or non-compliance with the *Carers Recognition Act 2005* through the SA Health annual report. A reporting framework that reflects the principles and standards of this policy will provide a consistent mechanism for Local Health Networks and the Department for Health and Ageing to provide input into the annual report.

12.2 Local Health Networks are required to report annually on compliance with the National Safety and Quality Health Service Standards 1 and 2.

12.3 Carers SA holds regular meetings with the Minister for Health and the Department for Health and Ageing at which the progress of the implementation of this policy can be discussed.

13 Resources and Related Documents

South Australian Carers Recognition Act 2005

South Australian Consent to Medical Treatment and Palliative Care Act 1995

South Australian Health Care Act 2008

[Australian Commission on Safety and Quality in Health Care National Safety and Quality Health Service Standards](#)

[Dignity in Care](#)

[Mental Health Practitioner's Guide to Sharing Consumer Information](#)

[SA Health A Framework for Active Partnership with Consumers and the Community](#)

[SA Health Advance Care Directives Policy Directive](#)

[SA Health Guide for Engaging with Consumers and the Community](#)

[SA Health Guide to Engaging with Aboriginal People](#)

[SA Health Aboriginal Cultural Respect Framework](#)

[SA Health Consumer Feedback and Complaints Management Policy](#)

[SA Health Consumer Feedback and Complaints Management Guideline and Toolkit](#)

[SA Health Charter of Health and Community Rights Policy](#)

14 Attachments

Attachment 1: South Australian Carers Charter

Attachment 2: Principles of Partnering with Carers

South Australian Carers Charter

1—Carers have choices within their caring role

- (1) Carers should have the same rights, choices and opportunities as other South Australians.
- (2) Carers should be supported by individuals, families, business and community organisations, public institutions and all levels of government in the choices they make in their caring role.

2—Carers health and well-being is critical to the community

- (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) Carers should be supported to balance their caring role with their own needs.

3—Carers play a critical role in maintaining the fabric of society

- (1) Carers should be recognised and valued for their important contribution to the well-being of the Australian community.
- (2) Carers should be recognised for their unique experience and knowledge in the caring role.

4—Service providers work in partnership with carers

- (1) Caring is a social and public responsibility shared by individuals, families, business and community organisations, public institutions and all levels of government.
- (2) Carers should be recognised as individuals with their own needs, within and beyond the caring situations.
- (3) The relationship between a carer and the person they care for needs to be respected and honoured.
- (4) 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.
- (5) 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.

5—Carers in Aboriginal and Torres Strait Islander communities need specific consideration

- (1) Aboriginal and Torres Strait Islander carers should be specifically identified and supported within and outside their communities.
- (2) Aboriginal and Torres Strait Islander carers should be supported by business and community organisations, public institutions and all levels of government.
- (3) Aboriginal and Torres Strait Islander carers should be provided with culturally appropriate support services that take into account the history, health and well-being of their extended families.

6—All children and young people have the right to enjoy life and reach their potential

- (1) Children and young people who are carers should be specifically identified and supported by individuals, business and community organisations, public institutions and all levels of government.
- (2) The special needs of children and young people who are carers and the unique barriers to their access to service provision should be recognised and acted on so that, as far as possible, they have the same opportunities as other children and young people in Australia.
- (3) The caring responsibilities of children and young people who are carers should be minimised.

7—Resources are available to provide timely, appropriate and adequate assistance to carers

- (1) Carers need access to a wide range of responsive, affordable services to ensure informed decision making and support for them in their caring situation.
- (2) Carers from culturally and linguistically diverse backgrounds may have complex needs that require appropriate service delivery.
- (3) Carers in rural and remote communities have barriers to service provision.

Principles of Partnering with Carers

1. Carers are partners in care

Carers are recognised as part of the treating team due to their unique knowledge, experience and history. SA Health employees offer and provide opportunities for this collaboration to occur without carers having to demand to be involved.

Carers have active input into the development of care plans and their views are listened to. Carers input on the history of the patient is valued and acknowledged in forming a care plan. e-Health and other resources are used to record patient history and maintain consistent information across systems, services and over time.

Carer input is sought in a timely fashion and communication relating to care planning is done in a way that is understood by carers. SA Health employees explain when and why they will act against the advice of carers so that carers can feel confident in the decisions made by SA Health employees.

2. The different roles of carers are recognised and acknowledged

The role of the carer in a patient's care is acknowledged and assessed from the beginning and regularly reviewed. Carer information including contact details is provided once and is recorded electronically.

Diversity in carers is recognised, including age, cultural and linguistic diversity, gender, caring for multiple people and caring across multiple generations.

SA Health employees are provided training to ensure better awareness of the Act and accountability for SA Health's performance against the Act. SA Health employees listen to carers, acknowledge the different roles that carers play in the health system and recognise their rights.

3. Carers are treated with respect, dignity and compassion

Carers are respected in the role that they play. Their opinions are valued and they are treated with dignity. SA Health employees avoid stigmatising carers and are not blamed as the cause of the condition or illness of person they care for. Carers are not blamed when things go wrong, and carers are not criticised for asking questions or for clarification. Carers voices are listened to and their questions are answered. Carers can express their concerns to SA Health employees, to the people they care for or to third parties (such as the Health and Community Services Complaints Commissioner).

Communications with carers is done in a way they can understand and is tailored for care needs such as young carers and culturally and linguistically diverse communities. SA Health employees follow through and act on what they say they will do.

4. Carers are supported both in their caring role and in maintaining their own health and wellbeing

Carers self-identify as carers and understand what this means, in particular Aboriginal, culturally and linguistically diverse and young carers. SA Health employees have the skills to discuss the caring role with carers and what this means. A plan for how a carer can help provide health care is in place that gives specific tasks on how the carer can help and what it is useful for them to do. Carers' responsibilities and tasks are assessed and reviewed regularly. Carers have choices and can choose to change their level of care or relinquish care.

Carers own health and wellbeing is paramount, is maintained and is recognised as separate to those that they care for. SA Health employees ask how carers are going and what they need. Services are provided that monitor and improve carer health and provide respite. Reassurance is provided that the person they care for will be supported when the carer is unable to provide care, due to respite, the carers own health needs or any other reason.

Carers are provided information on what is available to them such as carer support groups, counselling support, financial assistance, respite options and accommodation. SA Health employees know where to send carers to get support and what options are available. Carer support organisations are available to support and resource carers.

5. The right information about the care provided to the person they care for is provided to a carer at the right time

Carers receive the information they need to enable them to fulfil their role as carer in a timely manner and without having to ask for it. As partners in care, carers are given the right information to be able to be involved in making health care decisions. This includes information to help inform decisions on clinical care, appointment bookings, care plans, discharge plans and medications. Carers are involved in and kept informed of the patient's status, their movements and whether they are discharged.

Patient information is also provided back to primary and community care providers following discharge to enable continuity and prevent the carer from having to monitor and be responsible for consistency of information about care.

6. Guidance and direction is provided to help carers navigate the health system

Carers who are new to the health system are given an induction and basic information, including definitions, knowing what services are available and how to get them.

Care coordination is led by SA Health employees. Programs are in place to support carers to make decisions and coordinate care, to advocate and to bring together multiple providers. Options for services and resources available are provided on discharge. When not all criteria are met for a service, carers are helped to find alternatives.

Employees change in SA Health but carers have continuity in their interface. Consideration is given as to how the decisions made by SA Health employees impact carers. SA Health communicates with other agencies, including non-government organisations, and information flows across agencies.

7. SA Health services are flexible to the individual circumstances and needs of carers and the people they care for

Services are flexible and are available when it suits carers and the people the care for, including outside of business hours. Services meet the specific needs of those in rural and remote areas, are culturally appropriate and interpreter access is readily available.

Patients are able to move across and between services without losing access. If services are moved out of hospital and into the community, sufficient supports are in place to support carers. Alternative options that are offered to carers are of high quality. Holistic services are provided that recognise co-morbidities and disabilities.

8. Carers' unique long term perspective is acknowledged

SA Health acknowledges that carers bring a unique perspective to the care of a patient that is holistic, longer term and focusses on maximising potential for optimum care. Carers provide spiritual and emotional support to patients.

Carers' continuity of care, their history and their experience and knowledge is valued and used by SA Health employees. Carers provide advice to SA Health on the contextual picture of a patient, considering their whole environment.

9. Carers are advocates for a better health system

Carers are able to provide advice, perspectives and input into system wide service planning and design. Carers participate in the development of state-wide and national standards of care. Carers are invited to be part of committees and working groups as and when they are established. Carers participate in the evaluation of health services at the point of delivery.