

# Carer Participation Position Statement



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## 1. Introduction

A family Carer is someone who provides care and support for their parent, partner, child or friend who has a disability, is frail aged, or who has a chronic mental or physical illness.

There is an important distinction between paid care workers who attend care recipients in a professional capacity and Carers, usually family members or close acquaintances, who provide for their care at all other times. Carers SA acts as a peak body for family Carers. This document refers to family Carers.

Family Carers play an important role within the health care system as:

- Health service users.
- Carer representatives in the consumer participation framework.
- Advocates for the consumer.
- Partners in the delivery of care.

It is critical that these roles are identified by the health care system and each is addressed in its own right and dealt with through policy and practice.

In their roles as health service users and Carer representatives, family Carers are acknowledged and supported within the health care system via the consumer participation framework.

The fourth role that family Carers play within the health care system as 'partners in care' is not currently supported and in order for that support to occur partnership between the two is essential.

Generic policies on community participation often lead to family Carers' interests and needs being overlooked. The role of a family Carer as a partner must be separated from that of health service users or consumers within language, policy and programs.

Family Carers should be identified in their own right to ensure that their own health needs are valued and recognised within the system.

## 2. Family Carers' Roles and Functions

The roles that a family Carer plays within the health care system are interdependent of each other. Family Carers perform the following roles:

<b>As a:</b>	<b>Reason</b>	<b>Involvement with System</b>
User (consumer)	Patient	Treatment / self management
Carer representative	Advisory / reference group member	Quality assurance
Advocate for consumer / patient	Ensure consumers needs are met	Representing the needs of the consumer via quality assurance systems, treatment plans and clinical processes to improve services provided to the consumer
Family Carer	Partners in care	Clinical process and practice

### 2.1. Family Carers as Health Service Users

As a 'service user' family Carers are patients because they access the health care system for their own individual and unique health needs. They visit a doctor because they are sick and the doctor or other health professional provides them with treatment and this is their involvement within the health care system as consumers.

The health and wellbeing of family Carers can also be dramatically affected by their role and the tasks that they perform as family Carers. In fact, family Carers are an at risk population group due to the stresses of their caring role.

A population based study in 2004 by the University of York found that diminished immune response and susceptibility to physical illness and infection such as flu may result from the stress associated with providing round-the-clock care as well as physical injuries sustained from lifting or moving the person they care for. The study also found that emotional and mental health problems

are more often associated with being a Carer than physical problems (Hirst, 2004). Family Carers need to be identified as a population health group within the public health framework because of their caring role.

## **2.2. Family Carers as Representatives**

Family Carers are involved in consumer advisory committees and reference groups. Consumer health advisory committees are formed as a mechanism to measure the quality of the health care service.

As representatives on these committees family Carers provide information about their role as a Carer, however the major emphasis of their feedback is about the service provision they received as a user of the service.

## **2.3. Family Carers as Advocates**

Family Carers also represent the needs of the consumer within the health care system. As members of reference groups, self help groups and advisory committees, Carers advocate at a systems level for improved services for the consumer / patient (the person they care for). On an individual level they advocate for improved services for the person they support in the establishment of their treatment plans. This is particularly evident when the severity of the illness, disability or condition prevents the consumer / patient from advocating for themselves.

## **2.4. Family Carers as Partners in Care**

The role of family Carers as 'partners in care' recognises the many functions and duties family Carers undertake in conjunction with the health system under the direction and advice of, and complementary to, health professionals. These tasks range from those defined as high level nursing tasks to those usually carried out by allied health professionals.

The range of possible tasks that a family Carer may undertake can be divided into five main areas:

- a) Professional tasks and activities: such as peg feeding and coordination of care and support within and across sectors. Family Carers are often the main care coordinators for consumers, especially for services beyond the health sector.
- b) Duty of care and responsibility: taking responsibility for treatment in the context of

'hospital in the home' programs, after health professionals first prescribe this.

- c) Discharge planning: Family Carers are also involved in discharge planning for care recipients. Shorter lengths of stay in hospital mean that family Carers are required to take on more responsibility for the care in the home.
- d) Informal and formal advocacy roles: taking on roles of advocacy to access services, treatment and obtaining services that do not exist.
- e) Routine roles: such as personal care assistance, organising finances, shopping, transport to appointments etc.

## **2.5. Enhancing the Family Carer's Partnership Role**

It is fundamental that family Carers are valued as partners within the health system and that health professionals work together to ensure that the care recipient is receiving the most appropriate and high quality support available.

It is also important that family Carers receive assistance with their own health needs that are a direct result of their caring role. The health of the family Carer may impact on their role as a 'partner in care' as they may require temporary, additional support whilst they are ill and having health problems of their own.

It is crucial that the family Carer's role as a 'partner in care' is recognised and valued as being separate to the other roles they play in the health sector as a health service user and consumer.

True partnership between health professionals, the broader health care system and family Carers can only be established when the role and functions of a family Carer are understood, respected and recognised by the individual professionals and the entire health care system. Part of this respect is valuing input from family Carers and involving them in decision making and clinical processes.

Research shows that family Carers can be better judges of the life skills / impairments in social functioning of people with a mental health problem than formal care coordinators (Woof et al 2003). Studies have also shown that family Carers who participate in the care planning process with professionals have a more positive attitude toward their role and this can assist them with coping (Woof et al 2003). Partnerships are

therefore the key to ensuring that family Carers are well supported in their role.

Family Carers need to be provided with information from the health professional about the condition of the person they are caring for. They also need to be allowed to play a part in the decision making process. The most obvious ways in which this can occur is in the care planning process and in planning for discharge, treatment, medication and general health reviews and checks.

Family Carers also need to be provided with information which will assist them to fulfil their caring role, including contacts for local support groups, resources available, medications, health conditions, complications, financial assistance, health care concessions and respite.

It would be of benefit if the health professional recognised the needs of family Carers and provided them with access to additional support services to assist them to continue to function in their caring role.

### **3. Carers SA Position**

#### **Key Rights in Participation**

1. Family Carers have the right to participate on consumer participation structures and have their various roles recognised as service user, representative and a partner in the delivery of care.
2. Family Carers have the right to have their role as a partner in care recognised and valued by health professionals and the broader health care system and as such family Carers have the right to be involved in processes and planning with health care professionals i.e. developing care plans and discussions about treatment options and clinical information about the person they care for.
  - 2.1. Family Carers have the right to be provided with open and honest information of a clinical nature about the care recipient from health professionals and the broader health system.
3. Family Carers have the right to raise concerns and complain on behalf of the person they care for in relation to their health and well being, treatment options, care plan and service delivery.
  - 3.1. Family Carers have the right to express their concerns about the service

delivered to the health professional delivering the service.

- 3.2. Family Carers have a right to formally express their opinions about the service delivered by health professionals to the care recipient.
- 3.3. Family Carers have the right to be involved in the evaluation of services provided to the patient whilst they are in care both in hospital care and community care.
4. Family Carers have the right to have a say and be listened to:
  - 4.1. About the health and well being of the person they care for.
  - 4.2. About their own needs in relation to providing care as a family Carer.
5. Family Carers have the right to have their own health care needs recognised as separate from those of the person they care for.
  - 5.1. Family Carers have the right to temporary and additional support while they are unable to provide care due to health problems of their own.
6. Family Carers have the right to be provided with other information about services that will assist them to continue in their role as a family Carer i.e. Carer support groups, counselling support, financial assistance, respite options, accommodation etc.
7. Family Carers as 'partners in care' have the right to relinquish care.
8. Family Carers have the right to be supported and resourced for participation through links with a Carer based organisation ie Carers SA.

#### **References**

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