



**Response to Australian Commission on Safety and Quality in Health Care on the Draft  
National Patient Charter of Rights consultation paper**

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## **1. Introduction**

### **1.1 About Carers Australia**

Carers Australia is the national peak body representing those Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia's members are the Carers Associations in each state and territory that deliver specialist information, counselling and others services to carers in the community.

Carers Australia is informed about carer issues through its member Carers Associations (the Network of Carers Associations) and its participation in national and international forums.

We believe that all carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education.

### **1.2 About carers**

There are 2.6 million carers in Australia, and nearly 500,000 of these are primary carers – the people who provide the most care (ABS, 2004).

Carers are the foundation of our aged and community care system, and the annual replacement value of the vital care that they provide is estimated to be over \$30.5 billion (Access Economics, 2005).

The impact of providing care on the carer's own health and wellbeing is well documented with many carers experiencing a significant decline in their own physical and mental health, as well as a negative impact on their employment and education prospects, their financial position, and their ability to participate in social and community life (Cummins R et al, 2007; Briggs D and Fisher H, 2000 and Gill T, 2007).

### **1.3 Submission format**

This response addresses aspects of the Draft National Patient Charter of Rights in regard to the relationship between health care provider, and patient and carer, and provides an overview of issues for carers in regard to the health system.

It is not the intention of Carers Australia to respond to all of the questions posed in the Consultation Paper.

## **2. Elements of the Draft National Patient Charter of Rights**

### **2.1 Recognition of the role of carers**

The Australian health and community care systems increasingly rely upon family, friends and neighbours who provide unpaid care and support to children and/or adults who have a disability, mental illness/disorder, chronic condition, terminal illness or who are frail. Seventy-four per cent of the

assistance required by Australian's due to disability or illness is provided by carers. Every year carers provide over 1.2 billion hours of care (Access Economics, 2005).

Carers are a vital part of the health care support team. This is a fact which is increasingly acknowledged in international literature (Performance Improvement Advisor, 2004, p58):

Family members that care for patients at home can provide valuable information and feedback to health care professionals. Educating and training caregivers can increase compliance with discharge plans and prevent readmissions. During hospitalisations, caregivers can act as quality monitors, alerting staff to potential costly problems before they happen.

That carers are a vital part of the health care support team is well acknowledged in hospital settings with regard to carers of children with chronic conditions or disabilities, for example (Wilson L and Harnett E, 2005). It is a fact that is less acknowledged within other areas of the hospital system, and then often only in relation to discharge planning. International research indicates that carer inclusion can have benefits to patient quality of care (Droes R, 2000 and Kelly M and Newstead L, 2004) and can reduce readmission rates (Bridge J and Barbe R, 2004).

## **2.2 Use of 'patient' terminology**

The Draft National Patient Charter of Rights acknowledges the role of family, carers and nominated support people in providing care. The draft charter applies the term 'patient' to include family, carers and nominated support people, acknowledging the rights and principles apply holistically to all those involved in an individual's care rather than just between patient and health care provider.

However the term 'patient' on its own implies the individual receiving the direct health care services, and so is not necessarily an appropriate term to encompass the whole range of groups to whom the draft charter and principles apply.

In addition the draft charter states that the principles apply 'wherever and whenever care is provided'. For carers that the State and Territory Carers Associations come in contact with, this is often in the home and/or community care setting. The term 'patient' is not readily used in the community care environment.

As such, it may be more appropriate to use the term 'consumer' to reflect the application of the Charter principles across health and community care settings, and also to encompass family and carers as part of the draft charter, rather than just the person receiving direct health care.

## **2.3 Carer charters**

Whilst the principles are designed to also be applicable to carers, the development of the draft charter has not included a review of existing carer charters nationally. It has included reviews of existing national and international charters, for example state and territory public patients' hospital charters.

If this charter is to be applicable to carers, it needs to be considered in the context of existing charters specifically for carers to ensure the charters are complementary to one another and not conflicting. The existing charters for carers are provided for your information:

- Northern Territory Carers Charter, and Carers Recognition Act 2006
- Queensland Government Carer Recognition Policy 2007

- South Australian Carer Recognition Act 2005
- Western Australia Carers Recognition Act 2004

The interface between the Draft National Patient Charter of Rights and these existing carers charter documents is particularly important when addressing issues in relation to Principle 4 regarding Communication, Principle 5 in regard to Information, Principle 6 in regard to Informed decision making and informed choices and, in particular, in relation to Principle 7 regarding Privacy.

## **2.4 Discussion about principles**

### **2.4.1 Principles 4 (Communication) and 5 (Information)**

It must be acknowledged that compliance with Principles 4 and 5 may be difficult for some individuals. Patients who have a disability, mental illness, acquired brain injury, who are frail and aged, or are from a CALD (Culturally and Linguistically Diverse) or indigenous background, may need additional and appropriate support to assist them to understand their own rights in health care.

Appropriate supports to the individual in providing information and support to enable communication between health care provider and patient is essential in upholding these principles. The role of the carer can be an integral part of assisting an individual with additional needs to understand the information provided, and communicate their understanding and own thoughts about their health care.

Principle 5 states that “patients are expected to follow plans that have been agreed with the health care provider and to report any changes in their condition.” Whilst it is acknowledged that this is important for the health and wellbeing of the patient, this may be difficult for individuals to uphold, particularly for people on low incomes who cannot afford to purchase medicines or other elements included in care plans.

For carers in particular, this may be unachievable for some. Evidence shows that carers often put the health needs of the care recipient before their own. The largest survey of carers’ health and wellbeing was released in October 2007. The survey undertaken by Deakin University, Australian Unity and Carers Australia found that carers had the lowest level of wellbeing of any group surveyed using the Personal Wellbeing Index measuring tool; that carers were more likely to be experiencing chronic pain; and that carers were more likely to have an injury.

In addition, access to services for people from rural and regional areas, financial limitations, and transport limitations (both for carers who are patients and care recipients who are patients) will impact on the ability to follow health care plans. The individual circumstances of patients will weigh heavily on their ability to utilise health services. For this reason, it is important that health care plans are developed with the patient (and family/carers where relevant) to ensure the plan identifies circumstances that may inhibit access to services, and provide solutions to overcoming these issues to enable access to health care.

### **2.4.2 Principle 6 (Informed decision making and informed choices)**

This principle regarding informed decision making and informed choices is dependent on the issues raised above regarding adequate and appropriate information and communication mechanisms to meet individual needs. The role of the carer needs to be acknowledged as an important contributor to assisting in information dissemination and communication between patient and health care provider.

For people who do not have the capacity to understand and make an informed decision about their own health care needs, carers often take on this responsibility on an informal basis. The role of the carer as a provider of information regarding a care recipient to health care providers must be acknowledged and utilised to enable health care providers to gain the most relevant information about a patient's care needs. Carers have indicated that they often feel their knowledge and experience of the care recipient is not sufficiently acknowledged or used in health and care planning (Carers NSW, 2005).

As indicated above, several articles about projects that examine the interface between health settings, service providers, consumers and carers have identified that carers have much practical wisdom to offer about care management, yet they are often overlooked as experts in their role. This comes at a high price when their knowledge of patient histories is untapped or ignored, and avoidable medical and social misadventures arise. Recommendations from projects state that:

- health worker training should address carer needs and contributions within the health care team
- discharge protocols need to include and respect carer views and ensure follow-up supports are in place
- government and interagency initiatives designed to streamline treatment options need to ensure that carer input is included as a valuable complementary resource (Carers Qld, 2008).

Research by Dow and McDonald illustrated the imbalance between expectations placed on family carers and the resources available to support them. They called this the 'invisible contract' that binds family members to carry out substantial care-work that was previously carried out by hospital staff. They found an expectation existed for the family members to accept a caring role with little consideration for their individual circumstances and listed examples where no consultation had occurred prior to arrangements for the transfer of care from the hospital to the home (Dow and McDonald, 2007).

#### **2.4.3 Principle 7 (Privacy)**

Similarly, this principle regarding privacy must also acknowledge the carer as 'partner in care' to ensure the flow of information where appropriate. Private information about an individual is often associated with the private information of those close to us. The extent to which we share information varies in accordance with the closeness and degree of our relationship to a person. A caring relationship is generally closer than other types of relationships. Caring relationships, by their definition, involve carers doing things for others (often intimate things) that people are not able to do for themselves due to illness, injury, or disability (Carers Australia, 2007).

The Network of Carers Association has recently provided a submission to the Australian Law Reform Commission Review of Australian Privacy Law Discussion Paper 72, providing evidence of the difficulties carers face with access to information regarding a care recipient due to the stringent nature of Privacy laws and regulation. A copy of this document can be provided on request.

Recent changes to the NSW Mental Health Act (2007) have included rights for nominated carers to have information regarding the patients treatment and be involved in health care planning. The changes to the Act recognise the integral relationship between the carer and care recipient in regard to health care needs.

Whilst the privacy of patients is paramount, Principle 7 (Privacy) needs to ensure that barriers are not created for families and carers in their attempts to support the patient.

### 3. Carers and the health system

This submission also provides an overview of specific issues that carers have raised with the Network of Carers Associations in relation to the health system. The information is relevant to provide awareness and understanding of issues that carers face, and should be used as a guide to how the charter principles should be applied in practice to alleviate some of these issues.

There is a need for health professionals to understand the vital role of carers, what carers do and the impact caring can have. The complexity of the hospital system and community service systems means that there can be a lack of understanding about carers and awareness of the toll that caring can take. It can also lead to misunderstanding about the availability of support to carers. Carers' involvement is generally based on a deep and abiding personal commitment. Carers do not have the same resources, pay or training as health service providers and therefore should not be tasked with the same responsibilities.

Second, there is a need for inclusion of the carer, as appropriate, throughout the patient journey. The pressure within hospitals is toward clinical and technical health delivery which can mean that carers are viewed as extraneous to the process, notwithstanding that the non-hospital and health care for the patient will often reside with the family.

Carers frequently do not receive the information, education and training that they need. At every level of the health system carers need to be identified and supported whether it is at the birth of a child, diagnosis of a condition, the end of life, or at any stage throughout.

Third, the need for a smooth transition between acute and community care is vital. Assumptions are too frequently made about a family member's ability and willingness to care. Carers often feel that the system moves too fast, especially in the first 36 hours after discharge. There is a gap between assessment and provision of services which causes stress to carers. Referrals can be made but services may not be available. This reflects a continued focus in strategic direction and budget allocation on acute rather than community care. Patients may not be linked back into the community adequately after discharge. Continuity of care can be improved through greater coordination across community care, acute care and residential care and between health, ageing, disability and other key sectors.

More broadly, the interface between the various sectors, health, disability, ageing and between community, residential and acute care needs to be better coordinated and developed into models of integrated care (Carers NSW, 2005).

The draft charter provides an opportunity to recognise and clearly define the multiple role carer play within the health system. Carers are often forced to accept considerable responsibilities in relation to the provision of care and support, yet provided with few rights themselves.

Carer responsibilities often include:

- providers of support and assistance to people in a range of institutional and community settings
- advocates for and with health service users
- substitute decision makers for health service users

It is necessary to ensure that carers' significant contribution to the wellbeing, treatment, and recovery of people is appropriately recognised, respected, valued, and supported (Carers QLD, 2008).

Carer rights should therefore include:

- support and participation to act with or for the health service user
- carers have their own requirements, as part of the health care system, for information, education, communication and support
- carers have access to support for their own issues that may arise from providing care
- carers have rights to exercise choice in the provision of care to another (Carers QLD, 2008).

#### **4. Conclusion**

This submission has identified key issues for carers in regard to the health care system, and the integral relationship between health care provider, patient and carer. The draft National Patient Charter of Rights provides an opportunity to recognise the role of the carer within the health system, and the information of this submission provides an overview of how carer recognition could be applied in practice to better meet the health care needs of both patient and carer.

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