



**Private Mental Health  
Consumer Carer Network (Australia)**

*engage, empower, enable choice in private mental health*

**SUBMISSION  
Towards a National Carer Strategy  
A discussion paper from the Australian Government**

We thank the Australian Government for the opportunity to provide comment on the National Carer Strategy.

The *Private Mental Health Consumer Carer Network (Australia)* (hereafter Network) represents Australians who have private health insurance and/or who receive their treatment and care, and those that care for them, from private sector settings for their *mental illnesses or disorders*. As our title implies, the Network is the authoritative voice for consumers and carers of private mental health settings.

The Network is committed to working with the Australian Government and relevant others in addressing the needs of carers of people with a mental illness. We bring to the Discussion Paper a private mental health consumer and carer perspective.

Mental health brings with it many challenges. As a consumer and carer organisation we are in a position to provide direct lived experiences to the Australian Government and would welcome the opportunity to engage in further consultations, either independently or with other relevant organisations.

**Question 1: Do you think the Strategy as outlined in this discussion paper sets the right direction to meet the vision and aim to better support carers?**

Our Network was funded by the Department of Health and Ageing, in 2007 and again twice in 2009 to conduct three Projects which involved national consultations of mental health carers around how carers are *identified* by service providers.

It is clear from those Projects that unless there is a clear process, clear policies and clear protocols around how carers are identified in the first place, *Goals 1 through 5* of this Discussion Paper would be hard to implement.

It is not a difficult process with GPs being the first 'port of call' in many instances with referrals coming from them to various specialist practitioners, allied health and health services. Nor is it difficult to identify carers when the person they are caring for is admitted to a health facility, in our case mental health services.

What the three projects identified was a lack of engagement with carers because they are not appropriately identified.

We would be pleased if you were to view the three Carer Projects and the recommendations for action in regard to the identification of carers on our website of [www.pmhccn.org](http://www.pmhccn.org) Many of the recommendations are still relevant today.

In terms of the direction to meet the vision and aim to better support carers the Network strongly supports the National Strategy. Carers of people with a mental illness have added difficulty in accessing carer support allowances/benefits because

of the episodic nature of mental illness and the criteria in terms of physical requirements of the caring role. This is often not recognised.

Our Network is of the belief that with the shift of mental health consumers' care into community settings brings with it, additional responsibilities for their carers. Engagement and inclusion is a first priority for them and this is not done well.

**The first important goal we believe should be the identification of carers.**

**Question 2: Do you agree with the five goals outlined in this discussion paper?**

### **Goal 1 – Better recognition for carers**

Our Projects identified a very simple task that could be undertaken easily in the following:

1. Mandatory use of a designated A4 ***Nominated Carer Form***
2. Nominated Carer Forms should be of a different colour to ensure they are not lost within any paper based medical records.
3. Nominated Carer Forms should be situated at the front of any paper based medical record.
4. This form should be completed at every point of entry to a health service.
5. The carer must be identified thereon.
6. Care should be taken as not all primary carers are necessary the next of kin.
7. The amount and to what extent carers should be provided with information should be detailed. ie. Medication information only, care plans only, sharing of full information.
8. Regular audits of Nominated Carer Forms should be undertaken on regular basis as part of good quality improvement processes.

Additionally, with the move to electronic based medical records data development must be an integral component.

9. Mandatory carer identification fields to be built into data collection software. This would include the following:

Modification of State and Territory health data systems to make collection of 'carer' identification mandatory and separate to data related to 'next of kin';

Inclusion of carer identification fields in General Practice software; and

Development of suitable questions for inclusion in data collection protocols to inform identification of the carer.

Further, policies, protocols, guidelines must be developed with consistency across Australia.

10. Nationally consistent carer identification and participation policies and good practice protocols must be developed for implementation in all public and private health services.

**Our Network strongly believes that this work must be undertaken if any National Carer Strategy is to be taken forward.**

### **Goal 2 – Better support to help carers work**

Our Network absolutely agrees that Carers require far better support for their caring role. Carers often have their caring role thrust upon them and must be better recognised for the work that they do.

### **Goal 3 – Better information and support for carers**

The one consistent theme coming from all the consultations with carers is that they are crying out for information. Much is not provided to them yet within mental health, there is a plethora of information held by mental health services which are not supplied to them.

Carers require information about health services, where to go for assistance, who to contact in a crisis situation, information about the diagnosis, information about medications including side effects, how to handle confronting behaviour and how to take care of themselves within their caring role.

*This is one of the most important tasks that any national strategy must undertake.*

### **Goal 4 – Better education and training for carers**

Because of spiralling health care costs, much energy is being expended into how that health care can be undertaken within the community setting. Care is now being increasingly shifted from acute services to hospital in the home services.

Carers come from all walks of life with differing life experiences including levels of education and professional credentials. Many carers are not in the main health professionals and health and in our area is mental health, therefore they are manifestly unprepared for the increasing responsibilities required for their caring role.

Education and training is paramount to good outcomes for carers and the person they are caring for. As mentioned previously, education around access to the health system and who to go to, training for handling crises, confronting behaviour and medication side effects is of critical importance.

### **Goal 5 – Better health and wellbeing for carers**

*The carer of today is the consumer of tomorrow.* How many times have we heard this comment and it is extremely important that carers are educated and informed about how to care for themselves.

As articulated within the Discussion Paper, carers have a right to employment, good lifestyles and choices in their lives. In reality, this is not the case as many carers forgo these rights not by choice, but by requirement.

Actions must be expanded by the Australian Government to offer more places for respite care, more practical assistance and support for the carers' own needs.

If we are to seriously care for our carers and address their needs and good health and well being, our Network recommends that a *Carer Outcome evaluation measure* be undertaken once per year of all carers involved in full time caring roles. An outcome measure such as this would highlight areas in which carers are struggling, needing support and provide routine health checks. This must be supported by a Medicare Number to assist GPs undertake this critical work.

### **Question 3: Tell us if you have any suggestions about how the goals could be improved.**

Please see our comments under each of the five goals articulated previously.

**Question 4: What should the Australian Government focus on under the goals to better support carers now and into the future?**

Please see our comments under each of the five goals articulated previously.

**RECOMMENDATIONS**

The Private Mental Health Consumer Carer Network (Australia) makes the following recommendations.

**1. Changes in Clinical Practice**

- *Public and private health services are encouraged to identify carers through the development and distribution of nationally consistent information packages to carers as a compulsory component of the admission procedure.*
- *Admission procedures to public and private health services be modified to include development of standardised forms that:*
  - *highlight the benefits of consumers involving others in their care;*
  - *seek specific permission to identify family members or significant other persons who have ongoing input to their lives;*
  - *nominate the level of information to be shared;*
  - *are colour coded, updated on every admission and remain in the health care notes; and*
  - *make note of the distribution of information packs to carers, family members or significant other persons.*
- *All public and private health services to review their admission, discharge and referral policies to ensure carers are identified, supported and allowed to make informed choices.*
- *Clinical practice standards which promote an inclusive approach to identifying and working with carers are established by all public and private health services. This approach will promote identification and engagement to enable carers' strengths to be promoted, their difficulties to be acknowledged and to encourage empowerment.*
- *Public and private health clinicians to encourage consumers with long term illnesses to develop Relapse Prevention Plans and Advance Directives regarding care preferences, identification and involvement of carers. This process should occur when the consumer is functioning at the best possible level, become part of the health file and the information be transferred to other services as appropriate.*
- *Carer Consultants/Liaison Officers to be appointed to all public and private health services to assist with carer identification and assessment, staff support and training, linkages to carer support mechanisms and to be a specific point of contact for carers following discharge of the consumer.*

**Education/Training and Skill Development**

- *Comprehensive training to be provided for health specialist and primary health care professionals about legislative provisions, associated policy and practice guidelines, carers contribution to consumer wellbeing, and the experiences and needs of families and carers.*
- *Recognition of additional training modules in family/carer oriented practice by relevant Colleges as a component of skill maintenance.*

## **2. Data Development**

*Mandatory carer identification fields to be built into data collection software. This would include the following:*

- *Modification of State and Territory health data systems to make collection of 'carer' identification mandatory and separate to data related to 'next of kin';*
- *Inclusion of carer identification fields in General Practice software; and*
- *Development of suitable questions for inclusion in data collection protocols to inform identification of the carer.*

## **3. Implementation of Nominated Carer Form**

- *Mandatory use of a designated A4 **Nominated Carer Form***

## **4. Nationally consistent policies and protocols**

- *Nationally consistent carer identification and participation policies and good practice protocols must be developed for implementation in all public and private health services.*

## **5. Nationally consistent Information Packages for Carers.**

- *Our Network has developed a draft Information Package for Carers of people with a mental illness. Something similar in more generic wording must be published by the Australian Government to inform all carers.*

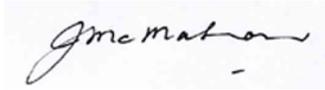
## **6. Carer Outcome measure**

- *Our Network strongly recommends the development and routine use of a carer outcome measure in all health settings most particular within General practice.*

We are grateful for the opportunity of having input into this critically important focus on carers.

Our Network is well placed to bring the 'lived experiences' of carers to Government and we have articulated our concerns within this Discussion Paper.

We would welcome the opportunity of further discussion with the Australian Government and in particular sharing the outcomes and recommendations from our three Carer Projects which we believe are crucial to the development of a National Carer Strategy.

A handwritten signature in black ink, appearing to read 'J McMahon', with a small dash or underline at the end.

Ms. Janne McMahon OAM

Independent Chair

23 December, 2010