Position Statement 76
Supporting carers in the mental health system
December 2012

Purpose
Carers play an important role in the mental health system. The Royal Australian and New Zealand College of Psychiatrists (RANZCP) recognises the importance of this role and that carers require specific support. This Position Statement has been written to inform carers, consumers and mental health professionals in Australia and New Zealand. It defines the role of a carer of a person with a mental illness in the mental health system, the challenges they face and the support that should be provided to assist them to perform their role and to maintain their own health.

Background
In 2009, over 2.6 million Australians identified themselves as carers [1]. In 2006, 420,000 New Zealanders identified themselves as carers [2]. Many carers are spouses, parents, family/whānau members, children or friends and many face difficulties with their own health, employment and finances. Since 2009, governments in Australia and New Zealand have introduced policy initiatives to raise the profile of carers and to address their particular needs.

Definition
The RANZCP defines a carer as:

a family member, friend or another whose life, because of their active caring and supporting role, has been affected by their close association with an individual who has, or who has had, experience of mental illness.

This definition aligns with current definitions used by the Australian and New Zealand governments [3, 4].

Caring may include the following:

- Help and support in any activities of daily life for the person being cared for
- Responsibility for physical and personal care
- Assisting with things such as showering, feeding or providing transport
- Responsibility for the management of medication
- Providing emotional, social or financial support; and
- Attending appointments and dealing with emergencies with the person being cared for.

A person with a mental illness may also have other carers, who are regarded as secondary carers. These may include family members or whānau, who along with primary carers may provide care to the consumer. It is important that health practitioners are able to work effectively with both the consumer's primary carer and secondary or extended care network [5].

Identification and engagement of carers
Accurate identification of carers is important to ensure that all carers have access to support and services to assist them in their role and to maintain their own social and emotional well-being. Early identification of people who are young carers is particularly important to ensure that their childhood development is not impeded. However, many carers may not identify themselves as such and some people with a mental illness may not notify health practitioners that they have a carer. Consequently, carers are under-reported in official data and service providers may be unaware of their presence.

There are many reasons why carers might not be identified or avail themselves of services available in the health system. Some people may not wish to self-identify as carers and some may have difficulty recognising that they are carers. This may be because they feel conflicted viewing their caring...
responsibility as part of their continuing role as a parent, spouse, partner or daughter/son \[6\]. These attitudes are more apparent in younger carers, Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse (CALD) communities \[7,8\]. In addition, some people with a mental illness decline to identify a carer or allow medical staff to contact their carer concerning treatment.

Australian and New Zealand governments have introduced legislation and policy initiatives that give formal recognition to the role of carer by requiring their involvement as "partners" in the development of treatment plans. Workplaces and schools are also increasingly recognising the importance of carers. The RANZCP supports initiatives such as these and encourages people who have not identified themselves as carers to do so. Carers who are minors require extra support.

The RANZCP also recommends that people with a mental illness should be encouraged to complete Advance Directives or living wills as this will enable medical staff to alert carers about medical issues in a timely manner \[6,15\] and to complete a Carer Nomination form identifying their carer and specifying information that may be shared \[6,9\].

Reducing the barriers to accessing services and support

It is important that carers are able to access appropriate information, services and support so that they can perform their role. However, there are several challenges that carers face in accessing support.

Complexity of the health system

The health system is complex and many carers do not know how to obtain support. In Australia and New Zealand, services are provided by individuals and community, government and non-government organisations across multiple health care settings in the primary, public and private health care sectors. These are complex systems and there is a lack of public information to assist carers, consumers and the general community to access the correct services when required.

Stigma

Many consumers and their families are reluctant to contact mental health services because of the stigma associated with mental illness. Raising public awareness and understanding of mental illness will help to create an environment where stigma is reduced, making it easier for carers to seek support \[10\]. Providing education for those who are most likely to meet people with a mental illness can encourage people in the community to provide support. It also increases the potential for early intervention and prevention of mental illness.

Privacy legislation

Carers rely on health practitioners to provide them with information about their family member’s diagnosis, the rationale for treatments and the likely outcomes. However, many health practitioners refuse to release information due to fears of breaching patient privacy and confidentiality \[5\]. Carers should be aware that The Australian Carers Recognition Act 2010 \[3\] and the New Zealand Health Act 1956 \[11\] both include provisions that health service providers must give carers sufficient information to assist them in their carer role.

Education and training

Carers are now formally recognised in government policy as partners in the development of recovery treatment plans. Education and training programs should be developed for carers on “how to care” and should include developmentally appropriate information for young carers. Education for health practitioners should incorporate training on how to include carers as partners in the ongoing treatment and how to utilise mediation skills when handling situations involving conflict or tension between carers and consumers.
Communication and services

It is clear from various inquiries and reports that many carers are unaware of services and resources available to them [7, 12]. Even those who are aware may still be confused about eligibility and how to apply for services [12]. For example, questions that carers must complete in order to qualify for Carer payments in Australia focus on a clinical diagnosis and give no consideration to the particular needs of a person with a mental illness that are being provided by the carer. Creating processes and protocols that reduce confusion for the carer requires a whole-of-government approach, gaining a better understanding of the support provided by carers of people with a mental illness, and accordingly, identification of the support that carers themselves need. Service organisation and integration is also required to minimise boundaries and enhance cross-sector support and collaboration.

Information on services and resources should be made available in a variety of formats and languages tailored to the needs of particular carer groups, for example; young and old, Indigenous (Aboriginal, Torres Strait Islander and Maori) and Culturally and Linguistically Diverse (CALD) carers. Carers living in rural and remote locations may have difficulty accessing information on the Internet. Therefore, information should be disseminated in a variety of mediums to ensure equality of access for all carers.

The RANZCP provides information on services for carers in Australia and New Zealand, which may be obtained by visiting its website (www.ranzcp.org).

Health and well-being of carers

There is considerable evidence that carers suffer adverse physical and mental health [7, 12, 13]. It is important that health practitioners recognise this, and that in addition to providing treatment for the person with a mental illness, they provide support and advice to the carer/s so that they know how to maintain their own health and wellbeing. Health practitioners, particularly general practitioners and psychiatrists, can provide advice to assist carers cope with stress and anxiety that may arise as a consequence of their caring role. In addition, carers should ensure that they have regular physical and mental health checks and that they seek medical assistance when they are in difficulty.

Issues for specific groups of carers

Carers in specific population groups face additional challenges, which must be acknowledged and managed. People in this category include young carers, older carers, Indigenous communities, CALD communities and people in rural and remote locations.

Young carers

Young carers face barriers within the mental health system due to the fact that many health practitioners and allied health professionals fail to recognise or adequately acknowledge that young people are carers. In addition to having poorer physical and mental health than their peers, young carers experience difficulty completing their education and many experience financial difficulties [8]. Carers who are minors are often socially isolated and the demands of caring may affect their social and emotional development and life opportunities.

Older carers and carers of older people

Older carers and carers of older people face particular challenges. Increasing age may be associated with increased resilience but is also associated with physical, social, cognitive and developmental changes that can affect their role and support needs as carers. The ‘carer’ may have significant health problems of their own and ‘co-caring’ is not uncommon. If the person with a mental illness also has dementia this may pose additional challenges [14].

Carers in Indigenous communities

Indigenous communities face multiple barriers to accessing services and support. Frequently, they may not identify themselves as carers regarding the care they provide as they see this as an extension of their community or familial role. Many Indigenous carers suffer adverse physical and mental health...
themselves. Further, as many Indigenous communities live in rural and remote locations, additional resourcing from government and health providers is required in order to address geographical isolation.

The RANZCP has released the following position statements and guidelines related to mental health issues in Indigenous communities:

- Guidance for involving families and whānau of mental health consumers/ tāngata whai ora in care, assessment and treatment processes
- Principles and guidelines for Aboriginal and Torres Strait Islander mental health, and
- Aboriginal and Torres Strait Islander mental health workers.

(These can be accessed on the College website www.ranzcp.org)

**CALD communities**

Many Culturally and Linguistically Diverse (CALD) carers have limited knowledge of services available to them. As with Indigenous carers, many may not self-identify as carers because they view their role as an extension of familial or spousal responsibilities. It is very important that information and support is made available in different languages and communicated through CALD organisations to ensure that CALD carers receive information and support in their own language and in a manner that is culturally relevant.

CALD carers should not be expected to act as translators during medical consultations. Both health professionals and CALD communities need to be aware of their rights and responsibilities with regard to accessing quality interpreter services. Translating and interpreting services require training to equip translators with a greater understanding of and sensitivity towards mental health, which is also another way of reducing stigma about mental illness within the community.

**Rural and remote communities**

Carers in rural and remote locations face problems accessing mental health services, information and resources to support them in their roles. Because of workforce shortages in rural and remote locations, maintaining continuity of service is difficult, and this leads to the need to re-engage health practitioners to ensure carers remain partners in the treatment plan. Because of accessibility problems carers often travel considerable distances to assist consumers attend their appointments with health practitioners. The important place that rural and regional carers play in achieving the best possible health outcomes should be recognised by provision of targeted assistance in meeting transportation costs and where possible, transport services.

**Accessing marginalised groups**

Finally, there are many groups who do not receive adequate mental health treatment. These include homeless people, asylum seekers in detention and people in prison. It is unlikely that these groups will have a carer or an advocate to ensure that they receive proper physical and mental health treatment. Therefore it is important that governments find ways to ensure that these marginalised groups receive adequate mental health services and are provided with an advocate to assist with their care.

**Recommendations**

The RANZCP makes the following recommendations to ensure that carers receive appropriate support and services to assist them in their role as carer:

1. Development of processes and protocols to ensure early identification of carers
2. Private and public practitioners should encourage self-identification through the distribution of information packs and promotional material on the role of carers and supports available to them
3. Provision of accessible public information to encourage people to self-identify as carers
4. Encourage consumers to develop Advance Directives, or similar documents, to assist medical staff, alert carers and provide prompt treatment when required
5. Encourage health practitioners to offer consumers or parents a Carer Nomination form to identify who, and to what extent, information-sharing is permitted.
6. Better mental health training of primary health staff and frontline hospital staff, with priority training given to emergency health staff

7. Investment in a national mental health literacy campaign to promote recognition of early signs of illness, the need to seek help and the value of early action

8. Better education and training of health practitioners on the role of carers in assisting the treatment and recovery of consumers and in mediation when conflict and tension arises between consumers and carers

9. Encouragement of health practitioners to recognise the need to provide support and advice for carers, as well as consumers, esp. young carers, so that they maintain their own health

10. Increased funding and support services for young, Indigenous, CALD, rural and remote carers and relevant family/whānau members

References


11. Privacy Commissioner Te Mana Matapono Matatapu, Guidance material for health practitioners on mental health information, H.M.H.C. Te Toihau Hauora, Editor.


14. Social Care Workforce Research Unit, Update for SCIE best practice guide on assessing the mental health needs of older people, 2005.

15. The Clinical, Technical and Ethical Principal Committee of the Australian Ministers’ Advisory Council, Advance Care Directives 2011.

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