



**Mental Health
Australia**



A PRACTICAL GUIDE FOR WORKING WITH CARERS OF PEOPLE WITH A MENTAL ILLNESS

Recovery-oriented practice and service delivery recognises the unique role of personal and family relationships in promoting wellbeing, providing care, and fostering recovery across the life span, and recognises the needs of families and support givers themselves

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Foreword

The 2.4 million¹ people who care for those with a mental illness, and those who work with these carers, have been, to a large extent, the unsung heroes in mental health in this country. They will remain the bedrock of the system.

This Guide recognises carers are a crucial component of any partnership approach to service delivery. It has been developed to assist staff across service settings in Australia in recognition and support of carers, to enable them to continue in their role as partners in recovery.

The Guide addresses a need identified early in the work of the National Mental Health Commission in its report *A Contributing Life: the 2013 National Report Card on Mental Health and Suicide Prevention* and more recently in its *2014 National Review of Mental Health Programmes and Services – Contributing Lives, Thriving Communities*. The 2013, Report Card made a Recommendation (14) that a practical guide for the inclusion of families and support people in services must be developed and implemented, and this must include consideration of the services and supports that they need to be sustained in their role. The 2014 Review confirmed this need which highlighted Australia's complex mental health system and a need to empower and support people with lived experience, their families and other support people to be involved in decision making and policy development.

The Australian Government's mental health reform announcement in November 2015, aligns with these strategic directions. In 2013, the Government committed to the adoption of a Recovery Framework for service delivery where all staff, consumers and carers have the opportunity to participate as equal partners in the delivery of care for people with a mental illness. The Government's reform plan recognises the need to involve and support carers.

I commend this guide to you and thank you for your commitment to helping all of those with a lived experience of mental health problems, including those who care for and support those who are unwell, to live the contributing lives we all deserve.

Yours sincerely



Allan Fels AO

Chair, National Mental Health Commission

March 2016

¹ Pirkis, J, Burgess, P, Hardy, J, Harris, M, Slade, T and Johnston, A, 2010 'Who cares? A profile of people who care for relatives with a mental disorder', Australian and New Zealand Journal of Psychiatry 2010: 44, p929–937

What If....

WHAT IF...

We can work together to:

- **recognise** who carers are and acknowledge the importance of their role
- always **welcome carers** and enquire about their reason for visiting or contacting the service
- **request information** from carers to assist with the care and support of the consumer
- **provide information about our service**, including its purpose and how it can be contacted
- provide information about **carer rights and responsibilities**
- **ask if** carers have any questions and do our best to answer them
- **explain** what can, and cannot, be discussed
- **refer carers** to separate carer information and support services
- ensure carers are **fully engaged** in all stages of care

Glossary

Carer

The term commonly used by services and governments to describe people who provide support to individuals who need help. A carer may be, and will continue to be, primarily the person's wife, husband, partner, son, daughter, parent, neighbour, friend or, in some cases, their child or children. It doesn't matter how many hours are spent each week providing support. Carers may live with the person they are caring for, providing assistance with daily needs, or may visit the person regularly. Carers are people who invest time, energy and support, generally in an unpaid capacity. However, some may receive Centrelink benefits to enable them to continue in their caring role. Carers are often 'hidden', or do not see themselves as a carer. Children who become carers face particular difficulties in being recognised and having their needs met.

In culturally diverse communities, responsibility for the provision of care may involve the entire community and may provide additional challenges during the process of identifying who is a carer.

Consumer

A person experiencing mental illness, receiving treatment and support from a GP, public or private mental health service or staff of a community-managed organisation.

Mental health service

A specialised service that provides assessment, treatment and support for people experiencing mental illness. Mental health services may be delivered in either the public or the private sectors. They include both inpatient and community-based services.

Inpatient services

When someone is admitted to a public or private specialist psychiatric hospital or unit within a general hospital, they may be cared for in either an open or a closed ward. This will depend on what is considered to be the safest option for that person and/or the community at any point in time.

Community mental health services

Specialist mental health services that deliver a range of acute interventions and ongoing support services in the public sector. These services generally serve a defined catchment area. Private hospitals also deliver a small range of short-term, community-based services for privately insured patients.

Community-managed organisations (CMOs)

Community-managed organisations are usually non-government organisations that provide a range of information and support programs targeted to specific groups, including families. They may also deliver support services to people with a mental illness to enable them to set goals and develop the knowledge and skills to achieve them. The services are recovery focussed and may include assisting with:

- daily living skills
- increasing capacity for mental health self-care and management
- social and relationship skills
- housing, education and employment.

Recovery

Recovery of the person cared for is a process of developing a new sense of self, meaning and purpose in life, despite their diagnosis and possible continuation of symptoms and the need for some ongoing support. Recovery is not necessarily the cessation of symptoms. It is also important for carers to work towards recovery.

Partnership standards

These refer to the six standards from *The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England, Second Edition, 2013*², adapted where necessary for use within this Guide to better reflect Australian practice.

Information – personal

Information that can only be shared with consent. It refers to information that is specific to the person with mental illness, and that may be regarded as sensitive.

² Worthington, A, Rooney, P, Hannan, R 2013, *The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England, Second Edition, 2013*, Carers Trust, London. The Carers Trust is acknowledged as the copyright holder of the concept.

Information – general

Information that can be shared even without consent from the person with mental illness. It refers to non-personal, factual information that builds on the carers' or close family's existing knowledge. It is still important to note in case records what information was discussed, with whom and when.

People with lived experience of mental ill-health

These can be consumers or carers. The following terms are often used interchangeably.

Peer workers

These can be consumers or carers who have a lived experience of, or care/have cared for someone with, mental illness. Peer workers are increasingly employed by mental health services to provide peer support. They can also be recognised as having completed the Certificate IV - Peer Worker (carer).

Carer consultant

A carer who is employed as a carer 'specialist' within a public or private mental health service.

Carer champion

Generally a member of staff who has taken on the specific role of liaising with, or being responsible for, working with carers. This person may also be the first point of contact for carers.

Psychoeducation

The education offered to individuals with mental illness and their carers to help empower them and deal with their condition in an optimal way.

Psychoeducation includes:

1. information transfer (symptomatology of the disturbance, causes, treatment concepts, etc.)
2. emotional discharge (understanding to promote the exchange of experiences and information with others concerning contacts, etc.)
3. support of a medication or psychotherapeutic treatment, as cooperation is promoted between the mental health professional and consumer (compliance, adherence)
4. assistance to self-help (for example, training so that crisis situations are promptly recognised and the steps that should be taken to be able to help the consumer are identified).

Wellness Plans/ Advance Directives

Are voluntary expressions of a consumer's treatment wishes and are important documents in the sense that they clarify consumers' treatment preferences and are – in some jurisdictions – required to be taken into account by mental health services when clinicians are making treatment decisions. However, they are not legally binding and, therefore, may not be followed – depending on the particular situation.

Background to the Guide

Historically, the training of professional staff and the delivery of care to people in both the acute and recovery phases of a mental illness have been organised around an individual treatment model. Confidentiality has been seen as fundamental and has sometimes become a constraining element when caring for an individual. This has resulted in many situations where carers are unable to contribute or receive information or to participate in the recovery process. This individual treatment model can be illustrated by the following diagram from the UK Carers Trust.²

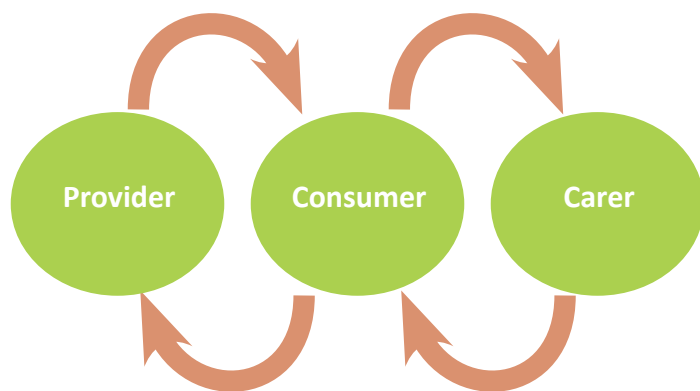


Diagram: Individual treatment model

Findings from the national consultation undertaken in 2015 to support the development of this Guide show that in current inpatient practice, in both public and private sectors, brief assessment and quick resolution of acute symptoms is the general focus of care. Reduction in length of stay, together with an under-resourcing of community-based services, has resulted in carers expressing an increase in their responsibilities.

Further findings showed that, within community-based services, staff training provided by public services and community-managed organisations (CMOs) in a partnership approach to service delivery is limited. Many staff express concerns regarding issues such as confidentiality. Information and support is not keeping pace with the responsibilities being placed on carers.

There have been changes to:

- state and territory mental health legislation
- state, territory and Australian Government carers' rights legislation
- state/territory and CMO policies and procedures
- accreditation processes
- the adoption of the Recovery Framework nationally in 2013

All encourage the delivery of services in a partnership manner. However, national consultation with representatives from all stakeholder groups tells us that:

- Current practice, across the majority of service settings, fails to meet national, state and territory policies of carer engagement.
- Staff believe that they are not trained to undertake the practice of Family Therapy.
- Carers often feel they are not recognised sufficiently or given key information or support in their role.
- Where carers persist in the quest for information, they are often labelled as 'angry', 'over-involved' or 'difficult'.

Further information from the national consultation advised that attitudes and practices vary between clinicians and across service sectors.

Mental illness and its treatment is a unique journey. Illnesses are episodic in nature and the need for care changes. People will move in and out of different stages at different times. They will also have contact with a range of service providers over time, all of whom have different skill sets.

Current programs to train specialist mental health staff and CMO employees contain components related to carer engagement. The translation of this training into action requires support from all levels of management and a desire to provide a continuum of care in a manner that recognises the lived experiences of consumers and carers.

² Worthington, A, Rooney, P, Hannan, R 2013, *The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England, Second Edition, 2013*, Carers Trust, London. The Carers Trust is acknowledged as the copyright holder of the concept and the Triangle of Care model.

A search both of current practice in Australia and of the international literature identified ideas and practical suggestions that could be considered for implementation on a national basis in Australia. Two models were identified as being particularly relevant:

- The Triangle of Care²
- The Pyramid of Family Care³

Consultation undertaken as part of this project with a wide range of stakeholders supported the UK Carers Trust model, The Triangle of Care, as representing a 'good practice', simple, evidence-based model on which to base future activity in Australia. This model has also been adopted for use in Scotland and Ireland.

The Triangle of Care model provides a practical framework that, if implemented, will meet the criteria of state and territory mental health legislation, carers' rights legislation, quality and safety guidelines and state and territory policies.

The UK Carers Trust has generously endorsed the use of the Triangle of Care model for use in Australia as a mechanism to further activities associated with meeting partnership approaches to working with carers on an international basis.

The Triangle of Care model clearly illustrates the system we are striving to achieve in Australia, where consumers, carers and service providers work together in a partnership model.

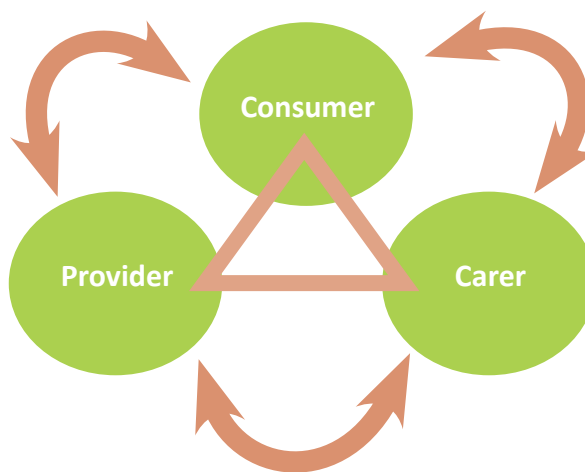


Diagram: Triangle of Care model

² Worthington, A, Rooney, P, Hannan, R 2013, *The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England, Second Edition, 2013*, Carers Trust, London. The Carers Trust is acknowledged as the copyright holder of the concept and the Triangle of Care model.

³ Mottaghipour, Y and Bickerton, A 2005 'The Pyramid of Family Care: A framework for family involvement with adult mental health services', *Australian e-Journal for the Advancement of Mental Health*, vol. 4, issue 3.

Why work in partnership?

People do not develop mental illness in isolation. It does not only impact on the person it affects.

Many people are involved in every situation. Each individual only knows part of the story.

There are three partners in the Triangle of Care:

- The **consumer**, who is living the experience of the illness and wants to move to recovery. They are experts by experience.
- The **carers**, who have the main responsibility for care when service providers are not there. They are frequently faced with providing care to consumers who are acutely unwell. They are also experts by experience.
- The **service providers**, across all settings, who have knowledge through their training and experience and a commitment to an improved outcome for the consumer.

Each of the partners has recovery as a common goal.

When service providers:

- **recognise** family and other carers
- **receive** information from family and other carers
- **respect** the needs of family and other carers
- **refer** family and other carers for additional information and support if necessary

and work together with consumers and carers as partners in care, there will be:

- improved outcomes for consumers
- reduction in family and carer anxiety
- improvement in ability and desire of family and other carers to remain supportive
- improved satisfaction for staff.

Carers supporting a person with a mental illness are generally, especially in the early days, moving through uncharted waters. Their feelings, experiences and questions may vary considerably as they encounter unexpected situations that they have little experience of and no preparation for. These may cause emotions and feelings that include:

- fear
- confusion
- grief and loss
- wondering how they will cope

- wondering what the cause of their loved one's mental illness is
- wondering why they in particular have been affected by mental illness
- wondering what other people will think
- wondering what the situation means for their family.

These reactions may appear at different stages of the diagnosis, treatment and journey towards recovery.

Family members and carers have a unique role to play in that journey because they know the person, and probably knew them before they became unwell. They are a source of information about a consumer's life beyond their diagnosis of mental illness, including information about their interests, skills, beliefs and ambitions.

The six Standards developed by the Carers Trust in the UK as part of their program of implementation of the Triangle of Care are proposed as **Partnership Standards** for Australia in this Guide. Practical examples of tasks that individuals and organisations might undertake to demonstrate they are able to work in a partnership manner have been developed for the implementation of each of these Standards.

A number of individuals and organisations within Australia have already translated some or all of these standards into practice. We look forward to the publication of their experiences and specific learnings for the Australian community.

I cried when a staff member said to me: 'Are you John's mother? How are you going?'

We have endured many changes of staff and services over the last 20 years.

No-one ever spoke to me.

After 20 years, I can now share the information I have, and together we are slowly working towards recovery – for all the family.

(Mother's comments during this project's national consultation, 2015).

Partnership Standards in Practice

The six Partnership Standards are designed to improve outcomes for consumers by combining the knowledge and skills of staff with the knowledge and lived experience of family and other carers in a partnership approach to service delivery across all settings.

The Six Partnership Standards

1. **Carers and the essential role they play are identified** at first contact, or as soon as possible thereafter.
2. **Staff are carer aware** and trained in carer engagement strategies.
3. **Policy and practice protocols regarding confidentiality** and sharing of information are in place.
4. **Defined staff positions are allocated** for carers in all service settings.
5. **A carer introduction to the service and staff** is available, with a relevant range of information across the care settings.
6. **A range of carer support services** is available.

The Partnership Standards can be applied across all settings and incorporate age-related and cultural needs.

The processes associated with identifying carers and providing basic information to them can be broken down into simple actions that can be undertaken by all staff at:

- an organisational level
- an individual staff level

All services are required to undertake a process of accreditation, either by individual professional bodies such as service agreements for CMOs responsible for service delivery or by organisational surveys via accreditation agencies against specifically agreed standards such as National Safety and Quality Standards, Australian Commission on Safety and Quality in Health Care. These processes require services to demonstrate evidence of partnering with carers in service delivery.

Implementation of the Partnership Standards will provide a framework for demonstrating organisational commitment to working in partnership and to meeting the various requirements of the accreditation processes.

Specific requirements for consideration in all settings.

The tasks associated with implementing the Partnership Standards are also applicable when working with consumers and carers who may have specific needs. Each of the Partnership Standards has been addressed individually in this Guide. However, in considering each standard, it is important to review, and take account of, consumer- and carer-specific requirements.

Remember consumer and carer requirements associated with:

- age
- gender
- Indigenous status
- culture – for example, definition of family
- language – for example, use of interpreters
- religion
- sexual orientation
- children as carers

The Partnership Standards work on the premise that the basis for a partnership is the recognition of all parties and the skills they bring to the partnership.

Each Partnership Standard is accompanied by an easy-to-use self-assessment tool with a traffic light system (Red, Orange, Green) that can be used by both individual staff and organisations to assess current practice and determine areas for change. This has been based primarily on the self-assessment tool developed by the UK Carers Trust as part of their Triangle of Care Project⁴ and the Mental Health Carer Experience of Service Provision draft measure piloted in selected sites in Australia in 2015.⁵

⁴ Worthington, A, Rooney, P, Hannan, R 2013, *The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England, Second Edition, 2013*, Carers Trust, London. The Carers Trust is acknowledged as the copyright holder of the concept and the Triangle of Care model. Self Assessment Tool, 2013 Permission provided

⁵ www.amhcn.org/special-projects/carers-experience-service-provision-project

The assessment questions listed are comprehensive and may need to be modified to fit specific service settings

General guidance - traffic light system

Red indicates significant under-performance and a need to develop action plans for improvement.

Orange indicates achievement of the activity some of the time but that improvement is required.

Green indicates positive achievement of the activity the majority of the time.

Staff who are prepared to complete these self-assessments openly and honestly and share this information with other staff are more successful in achieving positive change in culture and practice than those who are not. Doing so also enables specific action plans to be developed in situations where a number of staff may require additional training.

Any individual or organisation can complete the self-assessment. However, consistency will be improved when assessments are completed at the same time.

Ideally, self-assessments will be sent for review to an independent person such as a senior manager or a carer consultant.

Successful completion of these assessments provides evidence of completion of quality and safety initiatives for accreditation processes.

Partnership Standard 1

Partnership Standard 1: Carers and the essential role they play are identified at first contact, or as soon as possible thereafter.

'Carer' may not be a term that family and close friends are familiar with. Their role is crucial throughout all stages of care across all service settings. Their views need to be:

- recognised
- respected
- recorded

In most situations, families and close friends have a desire to be helpful and to try to solve each other's problems.

They often have lived experience in recognising:

- early warning signs of change in a person's health
- what management strategies have worked in the past
- the impact of medication.

Remember: carers have known the consumer when he/she was well.

You may have only met the consumer since he/she became unwell.

It is likely that a better outcome will be achieved if all parties work as partners in care.

Early and ongoing involvement of carers will assist accurate assessment and influence ongoing care.

Carer Nomination Form (see Appendix 1)

The inclusion of a carer nomination form as a regular part of all documentation acts as a reminder for you throughout all stages of care that it should be completed and updated on a regular basis. A discussion with the consumer regarding the identification of carers provides an opportunity for the importance of a partnership approach to care to be reinforced.

If you have a long-standing relationship with the consumer, it is still important to address the issue of identification of carers regularly and to record changes in the case notes. This will facilitate:

- continued discussion or development of plans and clarification on who will take responsibility for what
- setting timeframes and clarifying what you can and can't do
- referral of the identified carer to other groups such as Mind Australia, Helping Minds, Mental Health Carers ARAFMI Australia and Partners in Recovery for information and support
- involvement of other agencies (referral/liaison as needed).

Identification of carers allows you to provide them with information regarding their rights. The opportunities you have as a staff member to identify carers will change according to the service setting.

Examples of questions you might ask the consumer to support identification of the carers:

- Who do you rely on?*
- Who worries about you the most?*
- Who helps you the most?*
- Does anyone take you shopping or help you with banking on a regular basis?*
- Do you have any family or friends who you would feel comfortable asking for help?*

How do you achieve this Partnership Standard?

It is crucial that you, no matter what the setting:

- introduce yourself and your service
- ask anyone who is present what their name is and how they are related to the consumer; that is, that you recognise and acknowledge them
- document the contact details of all key people
- seek permission, or re-clarify in a positive manner with the consumer, that it is okay to discuss information.

What carers want to know will vary according to the place, situation and the stage of illness of the person they are caring for. It may include:

Initial presentation to any service

- the location of the consumer – are they safe?
- are they in the right place to get some help?
- why are they behaving in this way?
- what care is required?
- how long will they be in hospital/require this service?
- who do I contact to check on what is happening?
- what do you need me to do?
- who will look after any children they may have?

A certain amount of this information can be prepared in information sheets that can be personalised for your specific service.

Consumers should always be asked who they identify as the person/s who provide support to them and the level of information that can be shared with them.

A question to the consumer could be something like:

“It is important we involve your family. They are concerned about you and need to understand what is happening, or else they may react in ways that are not helpful to you.”

Sometimes the person is too unwell or distressed to provide this information. This issue can be revisited later; however, it is still important for you to obtain as much information as possible from any people who accompany the consumer.

Irrespective of what setting you work in, you can seek and receive information from carers.

Movement across settings

The process of care and recovery may occur over a significant period of time. During this time it is likely you will be involved with the transfer of the consumer, either to another service or to another staff member. This may be a temporary or permanent transfer.

Information passed on in any transfer process – even at discharge – needs to include the identification of the carer, their role in the consumer’s life and the level of information sharing that has been agreed.

It is crucial that carers are identified and given choices regarding how much and what type of care they are able to provide, taking account of their family and work commitments.

Carers are your partners in care. They have a right to be identified and fully involved at all stages of care, including the decision to discharge and making sure practical arrangements are in place. Carers are often the only ones around to support the consumer following discharge; involving carers can facilitate continuity of care. It is crucial that you identify who the carers are, have consulted with them, and understand what they might need from you. If you are discharging to a community setting or community managed organisation, has the carer been fully identified in the referral so that the subsequent intake process clearly provides for ongoing engagement with them.

This discussion must be held prior to discharge.

The other essential person to include in the process of transfer across settings is the GP.

Discharge to a community setting. Questions you need to discuss will include:

Where will the consumer live?

Who will support them and what level of support is required?

Will this support be available on discharge? If not, when will it be available?

Ask the carer what is the best way to advise them of impending discharge?

To help carers with their role, you may also wish to discuss with them:

- Will they have to cease or change their work to care for the person?
- What they might tell their family and friends.
- Do they have enough information on diagnosis and medications?
- Do they need to look for side effects of medications?
- What they can expect in the future.
- Advising the carer that they have been identified in the discharge and referral documentation.
- Discussing with the carer what they can expect from the community organisation's intake process.
- Who they contact if things go wrong.

Do not assume that carers will always want to continue their same level of involvement.

Carers have choices – and other commitments.

All staff, across all settings, need to check on a regular basis:

- Carer willingness to continue to be involved
- Carer needs for information and support

Simple strategies to consider

- Complete the carer nomination form as part of every intake or admission, preferably in a different colour to make it stand out from other forms.
- Include a check box in the admissions forms to show that this information has been given to carers.
- Seek feedback from consumers and carers of their experiences to support ongoing improvement.
- Ensure carers are recognised and respected – this is a major issue for family and friends who provide care.
- Include identification of carers in case notes.
- Establish a carer information board in the reception area of each service.
- Establish targets to meet [with rewards] for completing the carer nomination form.
- Ensure that both identified carers and the GP are recognised in any process of discharge.

Self Assessment Tool: Standard 1

Partnership Standard 1:

Carers and the essential role they play are identified at first contact, or as soon as possible thereafter.

Activities	R	O	G	Action Plan
1.1 Carers are routinely identified when carrying out an assessment				
1.2 Special circumstances of the carers are recorded, for example: <ul style="list-style-type: none"> • parent of young family • single parent • caring for parents • young carer • carer with mental illness • friend • partner • relative 				
1.3 Carers views and knowledge are sought throughout the assessment and ongoing support process				
1.4 Consent of consumer is routinely obtained and recorded re: carers involvement				
1.5 Carers are regularly updated and involved re: care plans				
1.6 Strategies for medication management are explained to the carers				
1.7 Carers have access to advice re: advocacy, rights, information and support				
1.8 There is a documented procedure for welcoming carers				
1.9 Carers are involved in the discharge process				

Red indicates significant under-performance and a need to develop action plans for improvement.

Orange indicates achievement of the activity some of the time but that improvement is required.

Green indicates positive achievement of the activity the majority of the time.

Partnership Standard 2

Partnership Standard 2: Staff are carer aware and trained in carer engagement strategies.

Awareness and engagement are everyday activities of life. They do not require you to have undertaken specialist training in family therapy.

In the Australian environment there is an expectation that health and disability organisations will deliver services in a partnership manner.

You can achieve the tasks associated with identifying and welcoming family and other carers via mechanisms described in Partnership Standard 1. Assessing ability in these areas needs to be an integral component of orientation programs and continuing education programs for staff in all capacities, including those in administrative roles.

How do you achieve this Partnership Standard?

Organisations have opportunities to reinforce partnership approaches via:

- service orientation or induction for new staff
- continuous education programs for existing staff

This may require assessment of your current abilities and provision of additional training where necessary

Simple strategies to consider

- Think about how you would expect to be treated and what you would like to know if you were a carer.
- Check to see if the carer nomination form has been completed (or updated).
- Ensure that you have listened carefully to, and understood from the carer's perspective, any issues the carer wants to raise.
- Recognise the importance of the role carers play by asking for suggestions for service staff of what works best for the person being cared for.

- Ensure that you have asked the carer about their needs, especially those concerning their responsibilities and the tasks they undertake. Areas to consider may include:
 - what emotional impact the caring role may have on the carer
 - any activities they have had to stop doing because of their caring role
 - how often they can get a break
- Use staff orientation and ongoing training as opportunities for individual staff to reflect on their level of carer awareness and also for staff to share experiences and strategies.
- Determine if individuals or groups of staff need to access additional training. This can be provided by personal development or continuous training programs. These may include:
 - organisational attitudinal values and practices and their impact on staff practice.
 - how to develop skills to manage specific situations such as:
 - how personal values, beliefs and circumstances of specific carers are identified
 - how and where to access cultural or language support when needed
 - how opportunities can be provided for carers to provide relevant information
 - how carers can be invited to participate in the development of care plans
 - roles, responsibilities and issues concerning confidentiality

Self Assessment Tool: Standard 2

Partnership Standard 2:

Staff are carer aware and trained in carer engagement strategies

Activities	R	O	G	Action Plan
2.1 Your organisation has a policy that requires you to work with carers				
2.2 All staff have received carer awareness training				
2.3 The training includes: <ul style="list-style-type: none"> • awareness of carer needs. • carer expectations re: <ul style="list-style-type: none"> o assessment, care and support o dealing with carer queries and concerns o advising on sources of help o advising on treatments, strategies and medication management o how to involve and engage with carers and consumers 				
2.4 Training is delivered by carer trainers or carers as part of the training delivery team				
2.5 Opportunities are offered to carers to participate in all aspects of assessment and the ongoing care, treatment and recovery of the consumer				
2.6 The level of support carers are able, or need, to provide is taken into account in the ongoing planning for the consumer				
2.7 Information is provided to carers regarding services and strategies available if a crisis occurs or the consumer becomes unwell				
2.8 You work in a way that supports relationships within families, and this is documented				
2.9 Carers are provided with opportunities to enhance their abilities in the caring role				
2.10 You convey hope for recovery when working with carers				

Red indicates significant under-performance and a need to develop action plans for improvement.

Orange indicates achievement of the activity some of the time but that improvement is required.

Green indicates positive achievement of the activity the majority of the time.

Partnership Standard 3

Partnership Standard 3: Policy and practice protocols regarding confidentiality and sharing of information are in place.

Great emphasis has been placed on the rights of people with mental illness in Australia. This is extremely important. Nevertheless, traditional management structures and complicated medico-legal provisions can impact severely on service delivery. Consumer confidentiality is frequently used as a barrier to avoid working with carers when often the underlying reasons for this are lack of confidence or time pressures. Some staff hold the belief that the consumer will no longer trust them if they involve family members or other carers. You need to understand that:

- Our analysis from the findings of the national consultation undertaken during 2015 showed that these beliefs and models of service delivery are outdated and not evidence based.
- That they fail to meet the requirements of state/territory mental health legislation, state/territory and Australian Government carers' rights legislation, the National Framework for recovery-oriented Mental Health Services and the National Standards for Mental Health Services (2010).⁶

Irrespective of setting:

Legislation, policies and protocols now require you to work in a partnership manner with carers.

This does not negate the need to obtain consumer consent.

Obtaining informed consent is not a one-off activity.

Consent is rarely refused if:

- it is sought at an appropriate time
- the consumer understands the reason for asking
- the information is sought in a positive manner
- it is re-checked on a regular basis

Most consumers are generally happy to work with their families or friends towards recovery. They understand, if asked at an appropriate time and in an appropriate manner, the fact that people close to them are likely to be an essential part of their recovery.

Timing is important. It might be necessary for you to revisit the issue on a regular basis as settings and relationships change.

The people who consumers nominate to be involved in their recovery may change over time.

Asking 'who are your carers?' rarely receives a positive outcome.

Many families and friends do not see themselves as carers.

Many consumers do not see family and friends as carers,

Nor do they see themselves as requiring carers.

A question you might ask the consumer could be:

“Who else is a good support for you? I want you to think of someone you trust who we could involve in helping with this issue.”

If you work in an acute inpatient unit, you might say:

“Your husband/wife/partner brought you to hospital today. They seem very concerned about you. Would it be okay to nominate them as your primary carer? We will agree what information you feel comfortable sharing with them. It seems like they will be important to have involved in any plans we make.”

⁶ Australian Government, *National Standards for Mental Health*, revised 2010.

If consent is refused, you might say:

I am happy to work with you, but when you are feeling a little better we need to agree on a plan of what to do should you become unwell again. Family and friends are important in all of our lives. We need to talk about who you would like to help you, and I would like your permission to share non-personal information with them.

If you work in community mental health services or community-managed organisations, you might say:

I notice that when I come to visit you, your friend is often here helping you. Would you like me to involve him/her in any plans we are making for the future?

A care partnership requires staff, consumers and carers to all participate in the care planning and treatment process across the journey from inpatient to community and support for recovery.

Dealing with issues of confidentiality openly and sensitively presents you with an opportunity to develop a partnership approach to care.

The majority of carers are already very much involved in the consumer's life.

- They know what their problems are.
- They know the early warning signs of mental illness.
- They frequently know how to manage situations.
- They have possibly already made a lot of adjustments or changes to their lives – they want this to be recognised.

Information

Information can be divided into general and specific or non-personal and personal.

- Specific or personal information requires consumer permission for the sharing of the information, except in certain legal situations.
- Listening, requesting and receiving information does not require permission.
- General or non-personal information can usually be shared.

You can work in a family-inclusive manner without breaching the law.

It is important to understand the difference between listening/requesting information and providing information.

How do you achieve this Partnership Standard?

Your service has guidelines and protocols developed that clearly describe what confidentiality covers – and does not cover. These will be related to the mental health and the carers' rights legislation in each state/territory. You need to be familiar with these guidelines.

In general, consumers need to provide consent for personal information to be shared. The issue of consent can be carefully framed in a positive manner and revisited on a regular basis. All staff have a role in reminding consumers of the importance that a support network plays in their journey of recovery.

It is important for you to understand that the majority of carers will have been involved with the consumer for some time. They know why they are receiving services and frequently have developed a number of coping strategies. This information may be crucial when planning ongoing care.

You can seek or receive information to assist with diagnosis and development of care plans. This does not comprise a breach in confidentiality.

Mental health legislation supports carers having a right to receive information essential for them to continue to undertake their activities. In addition, you can provide carers with information that is already in the public domain about mental health conditions, mental health legislation and availability of local services for both consumers and carers.

When a crisis occurs, particularly if it involves involuntary treatment, it may provoke consumer/ carer conflict and may temporarily prevent or limit the sharing of information. In such situations it is crucial that you revisit the issue of consent when the health of the consumer starts to improve.

It is important to remember that carers also have a right to confidentiality regarding their wishes in relation to the information they are providing to staff.

Wellness Plans or Advance Directives are important for consumers to maintain as much control as possible during their recovery journey. Such a plan or directive could detail the consumer's wishes about what should happen and which carer(s) to contact and what information can be shared.

If you work on an ongoing basis with consumers in a community setting, you are ideally placed to help them develop such plans or directives when they are well. The information needs to be regularly reviewed and carers need to know, and preferably participate in, the development of the Wellness Plan or Advance Directive. The ongoing role of the GP (where there is one) should also be discussed. You might say:

“Now you have been well for some time, I wonder if it might be a good time for us to discuss the development of a Wellness Plan/ Advance Directive to assist with your ongoing recovery. We could also consider nominating specific people you might want to have involved should things change in the future, and what information we can share with them. We can discuss this on a regular basis and change it any time you want.”

And:

“Do you have a regular GP? Would you like me to contact them to make sure we all know who is going to take care of each of the areas we have agreed is important for your recovery?”

Simple strategies to consider

- Know what information can and cannot be shared with carers.
- Ascertain what carers already know, as this supports the care provided to consumers.
- Talk with consumers to identify everyone involved in providing significant care to the consumer.
- Record information about carers in the case notes and share this information with others involved with the provision of care (with consent from the consumer and the carers).
- Talk to consumers about the level of information sharing they are comfortable with – full, partial or no disclosure. You may also need to distinguish between personal and non-personal information.
- If the consumer does not want any information disclosed, regularly revisit this decision with them over time.
- Listen to carers and offer support and general information.
- Check your organisation's compliance with mental health legislation and provision of information to 'nominated' or 'primary' carers
- Record all decisions about provision of services in the case notes. You may have existing forms to detail this information.
- Identify if there is a Wellness Plan/Advance Directive, where it is held and how to activate it and ensure this information is shared across service providers.

Self Assessment Tool: Standard 3

Partnership Standard 3:

Policy and practice protocols regarding confidentiality and sharing of information are in place.

Activities	R	O	G	Action Plan
3.1 Consumer consent to share information with the carer is sought				
3.2 Agreement is reached with consumer about the level of information to be shared with the carer				
3.3 If the consumer requests no disclosure, staff regularly revisit this decision with them				
3.4 Opportunities are provided to carers to discuss the care, treatment, recovery and support of the consumer (even if, for reasons of confidentiality, you cannot provide specific personal information)				
3.5 Carers are encouraged to share information re: consumer to inform assessment, treatment and support				
3.6 Carer notes and letters are kept in a separate section of the consumers' case notes/on IT systems				
3.7 Wellness Plans/Advance Directives are routinely used				
3.8 A Recovery Plan is in place				
3.9 Practice guidelines re: information sharing with carers are in place				
3.10 A policy is in place to support practice re: confidentiality				
3.11 Staff training is available and includes carer best practice for information sharing and confidentiality				

Red indicates significant under-performance and a need to develop action plans for improvement.

Orange indicates achievement of the activity some of the time but that improvement is required.

Green indicates positive achievement of the activity the majority of the time.

Partnership Standard 4

Partnership Standard 4: Defined staff positions are allocated for carers in all service settings.

Defined positions for carers as peer workers are increasingly being recognised as crucial components of a mental health workforce across all service settings. Initial activity in this area occurred via the appointment of consumer peer workers, and this has now expanded to encompass carers. A range of titles has been developed according to location. These include:

- Consumer and Carer Consultants
- Consumer and Carer Peer Workers
- Experts by Experience.

These positions have been created across all settings in mental health care; however, there is a particular focus on employment in the CMO sector of people with lived experience.

If no specific positions have been made available to date for people with lived experience in your service, you could consider the appointment of staff as 'carer champions'. These are responsible for modelling appropriate behaviour and promoting good practice among other staff. They may also act as the contact person for carers following case reviews if carers themselves are unable to participate.

The task of staff liaising with carers may be allocated to a person such as the carer consultant or the carer champion. It helps if this liaison can happen in person, although a phone conversation can be a useful starting point. It also provides an opportunity for you to deliver information in an appropriate and accessible way, taking account of special needs associated with age and culture. If a service operates with a partnership approach, there are a number of activities that need to be developed and coordinated. When a specific person is designated to this role, it is more likely to receive appropriate attention.

The appointment of people with lived experience (and/or appropriate skills) to these positions provides the service with credibility with both carers, consumers and other staff.

The capacity to connect with a peer with lived experience during difficult times, and to model recovery, can be powerful:

“... It is like having someone I could confide in, I feel like we have kind of been in the same boat. She also had a daughter who had a mood disorder and abused alcohol. She was able to understand when I talked about how I was afraid when the phone rang or the doorbell sounded late at night. You know it is someone with yet more bad news... She taught me how to set limits on the family being involved 24/7. Now we are working on building some healthier relationships between me and my daughter. I am not so exhausted all the time any more. The carer worker really understood my position and helped the other staff hear what I was saying.”

(The above is the testimony of a parent of a person with severe mental illness describing their experiences with a peer worker. It was provided during the project's national consultations in 2015.)

Often carer peer workers are involved in family education, which can increase their knowledge about mental illness and possible coping strategies. Carer peer workers 'have a lived experience, which many parents/carers and staff might benefit from. They can offer hope to families. They can share with the staff the vulnerabilities they experienced when they were using the mental health system. In a very practical way, they can help ease the burden for families. By sharing the load, they can empower families and staff to communicate more sensitively and to work more collaboratively' (Gerraghty et al, 2011).

The benefits of peer support and peer work are also demonstrated for peer workers themselves. For many people, work provides structure and meaning, giving an opportunity to draw on a difficult experience and assist others (Moran et al 2012; Razlaff et al 2006).⁷

“My life experience is an asset, not a liability. It is required! It really informs my work every day and it has personally helped me transform a lot of pain into meaning and fuels my passion to make the mental health system a kinder, gentler place (Maline, quoted in Bluebird).”⁸

How do you achieve this Partnership Standard?

The allocation of ‘carer responsibility’ to an individual member of staff is critical in the early days of implementing a partnership model of practice. This is not necessarily a full-time activity, although adequate resources and support are important for success. Lived experience peer workers add a great deal to this role and should be considered in any partnership model. It is envisaged that over time all staff across all service settings will see carer responsibility as a core component of their job.

Simple strategies to consider

- Ensure that orientation programs for staff across all sectors include carer awareness.
- Appoint a carer champion whose role is to promote carer engagement and support all staff to work in partnership.
- Appoint carers with lived experience as peer workers across all service sectors.
- Ensure adequate support and opportunities for skill development are provided to carer peer workers.

⁷ Health Workforce Australia [2014]: *Mental Health Peer Workforce Literature Scan*, Health Workforce Australia.

⁸ Pamphlet produced by Bluebird Care UK

Self Assessment Tool: Standard 4

Partnership Standard 4:

Defined staff positions are allocated for carers in all service settings

Activities	R	O	G	Action Plan
4.1 A carer champion is identified within the service, or there are carer consultants employed				
4.2 All staff are responsible for identifying, involving and supporting carers				
4.3 A network is in place to support carer champions, carer consultants and carer peers.				
4.4 Carer peer roles are in place				

Red indicates significant under-performance and a need to develop action plans for improvement.

Orange indicates achievement of the activity some of the time but that improvement is required.

Green indicates positive achievement of the activity the majority of the time.

Partnership Standard 5

Partnership Standard 5:

A carer introduction to the service and staff is available, with a relevant range of information across the care settings.

The early days following admission of a consumer to any mental health service can be frightening for carers. They may have many questions. If it is a first presentation to a service, you need to recognise that carers may be exhausted or fragile and may not be at their best to receive a lot of information immediately.

The provision of written information can provide a tangible resource on an ongoing basis, particularly when the family is involved in the longer term across a number of service settings.

Service-specific welcome packs need to contain a relevant range of facts that provide information regarding:

- what the service does
- contact phone numbers
- legal status of the consumer – what this means
- carers' rights and responsibilities
- the difference between personal and general information – what this means in practice
- service options
- visiting hours or appointment times.

Sometimes it takes time to settle on a clear diagnosis and program of care. The amount of information that a carer is able to absorb will change over time and may vary according to the setting.

Meeting directly with carers will provide an opportunity for them to express their concerns to you. Recognition of the issues they have been facing and their possible fears for the future may assist in reducing their anxiety. Most carers want to be reassured that their family member or friend is now in the right place to receive the care needed; carers want to be reassured they have taken the correct action to keep their loved one safe.

In the consultation undertaken in 2015 to support the development of this Guide, participants reported that working in a community mental health service or

community-managed organisation provides increased opportunities to work in partnership with carers as they are often present with the consumer and this enables the sharing of information across the care pathway, including with GPs. Many carers are actively involved in accommodation and support activities. Recovery is the shared aim of all parties.

You are well placed to monitor the updating of the carer nomination form and to discuss the development of Wellness Plans or Advance Directives. The existence and the content of these plans should also be re-checked when a consumer changes services.

How do you achieve this Partnership Standard?

All staff across all service settings need to be familiar with basic information regarding their service.

Copies of brochures outlining basic facts can be made available in all waiting rooms, admission centres, GPs' rooms and local libraries. Small, up-to-date, colourful leaflets containing basic telephone and web information are generally enough for a first presentation. This should serve the purpose of first point of contact only and should not be designed to answer all questions from all people. Additional information can be added over time, specific to diagnoses, medications and support. Some services use a welcome letter or a welcome pack with key information that is an important start to informing carers.

The main message of an initial brochure to carers is:

We recognise that you play a role in the life of a person who has become unwell. Please take this brochure. It provides some brief information for you, including information regarding legal status, rights of consumers and carers and the contact information for a number of local groups who may be able to help you with more information and support. Please feel free to contact us if you have any questions.

In a crisis situation, you will find that actually sitting with a family member or carer to go through this information is extremely important to enable you to gauge how much they are able to absorb. Sometimes reassurance and an offer of a phone call or an

appointment as soon as possible may be the best option available.

If you are unable to meet at a particular time, you might say something such as:

“Can you wait a short time and I will meet with you so that we can go through the information we have that may assist you?”

“I can't meet with you now but I will make sure you receive a call in the morning so that we can go through the information we have that may assist you. You have done the right thing in contacting us.”

This meeting also provides an opportunity for you to gather information that may be critical to the consumer's diagnosis, treatment and ongoing care.

The nature of the presentation and the setting will influence the next activity. Communicating this may include:

“Your relative/friend has been admitted to hospital. I need to explain the differences to you between a voluntary and an involuntary admission, and to give you some more information.”

“Thanks for calling me so early once you noticed there were some changes in behaviour. This gives us an opportunity to provide some additional information.”

“It is good we have a plan as a result of our last meeting; thank you for calling me so quickly. We can now ensure we stay up to date with each other to ensure we minimise the impact of this episode.”

“I think we need to organise a family meeting to share information – do you have preferences for a specific time soon?”

“How have you been managing over the last....?”

“Did you have a chance to contact the information or support group I suggested?”

“Were they helpful?”

There are a number of model brochures available. A helpful example can be found at the following web link: www.pmhccn.com.au Private Mental Health Consumer Carer Network (Australia) – *Information Booklet for Families and Other Carers, 2010.*

However, the process of developing and reviewing information resources provides an opportunity for staff to 'own' the information.

Additional information related to specific diagnoses, medications and potential side effects can be added later as these details are confirmed.

Simple strategies to consider:

- Include a welcome letter to carers in your welcome pack.
- Develop a brochure and/or a web site for carers specific to your service.
- Raise awareness of carer support services such as helping minds: www.helpingminds.org.au
- Make brochures available in, for example, GP waiting rooms, accident and emergency departments, inpatient wards' notice boards and staff rooms in community organisations.
- Ask community workers to carry information packs during visits, etc.
- Ask carers to complete the *Mental Health Carer Experience of Service Provision Measure*.
- Include information about engagement with carers in the consumer's case notes.

Self Assessment Tool: Standard 5

Partnership Standard 5:

A carer introduction to the service and staff is available, with a relevant range of information across the care settings.

Activities	R	O	G	Action Plan
5.1 Upon first contact, across all service settings, provide the carer with: <ul style="list-style-type: none"> • an introductory letter that explains the service and points of contact (for example, CMO staff names and contact numbers) • carer rights and responsibilities information • the partnership policy of the service • information regarding carer support services (for example, local groups, carer champions, carer consultants, carer peer workers) • a number to call for after-hours service 				
5.2 Offer an early appointment to the carer to hear their story/history and to address their concerns				
5.3 Ensure that the service has meeting and greeting protocols in place to minimise carer distress and address any concerns they may have				
5.4 Discuss with the carer whether they wish to bring a support person with them to meetings				
5.5 Provide locally developed carer information packs to new carers at first meeting				
5.6 Ensure that the cultural and language needs of carers have been addressed during the preparation of this pack				
5.7 Ensure that the format of the information pack is flexible and regularly updated				
5.8 Make a member of staff responsible for developing, storing and issuing the packs				
5.9 Ensure that the carer is involved in discharge planning and is clear about what to do and who to contact in the organisation in a crisis				
5.10 Ensure that the carer is asked for feedback regarding the service provided as part of quality improvement activities				

Red indicates significant under-performance and a need to develop action plans for improvement.

Orange indicates achievement of the activity some of the time but that improvement is required.

Green indicates positive achievement of the activity the majority of the time.

Partnership Standard 6

Partnership Standard 6

A range of carer support services is available.

Mental illness is episodic in nature. The path to recovery for consumers is a continuous work in progress. Carers, via their lived experience, are also on a path to recovery. The range of support they require changes over time and is related to the activities associated with implementing the Partnership Standards. The majority of the needs of carers can be met across all service settings if you:

- identify who the carers are as early as possible
- treat the carers as partners in care
- provide the carers with relevant information in a timely manner
- refer the carers for additional information and support as required.

Service providers across all service settings need to ensure that these activities are within the capacity of all staff in public and private sectors in partnership with services provided by community-managed organisations.

Many of the public and private services in which you work currently provide information and support services to the carers of existing clients via carer information sessions. Some of these services have been developed by carer champions or lived experience peer workers.

Some carers prefer to obtain information from other sources such as via programs provided by the community-managed sector. You need to be aware of the range of general and diagnosis-specific education and support services in your area to enable you to make appropriate referrals.

Web-based resources are also an important referral avenue.

How do you achieve this Partnership Standard?

It is crucial that all staff across all public and private mental health settings and the community-managed sector are aware of their local resources and work in collaboration with them where possible. This includes ensuring the availability of: community-based information/support groups; general information

about the areas they might cover; their contact numbers. Your service probably has a list of these agencies and their phone numbers. They would include organisations such as:

- Mind Australia
mindaustralia.org.au
- Helping Minds
helpingminds.org.au
- Mental Health Carers Arafmi Australia
arafmiaustralia.asn.au
- Mental Illness Fellowship of Australia
mifa.org.au
- Carers Australia
carersaustralia.com.au
- Beyondblue
beyondblue.org.au
- SANE Australia
sane.org
- Orygen Youth Health
oyh.org.au
- Multicultural Mental Health Australia
mhima.org.au
- Alzheimer's Australia
fightdementia.org.au
- Alcoholics Anonymous
aa.org.au
- Grow
grow.org.au
- Anglicare
anglicare.asn.au
- Centacare
centacare.org.au
- Carers Gateway
carergateway.gov.au

These organisations provide regular education programs as well as a range of support, advocacy and accommodation services. Development of working relationships with these organisations is an important component of your practice in order to meet Partnership Standard 6.

Once carers are identified and they have had an opportunity to provide information and discuss their concerns, it is likely that you will be better placed to provide re-assessment of the consumers' and carers' needs. On the basis of the extra information you have gained from the carers regarding the consumer, you may now need to reconsider current plans by asking yourself such questions as:

“Has the level of information and support I have been able to supply been adequate to meet the needs of the carers?”

Have the right referrals been made?

Are the family/friends ready for more information?

Do we have this information available in a form that will be easily understood by the carers?”

What if these support services are not enough?

Are there more available for example, more support or information?

What is your role in this situation?

Sometimes your experience with other consumers will tell you what works for some people. You can share these strategies – without divulging personal information for example:

“I worked with another family once who expressed similar concerns. They tried a number of things and what they found most helpful was...”

Do you think that might work in your situation?

What changes would we need to make to try this?”

I will check back with you in ... days to see how you are getting on.

Not all carers have the benefit of the partnership model of service you are now practising. Some have been managing on their own for many years, coping the best way they know how. Despite your best efforts, some will continue to struggle and will need to be referred for more specialist assistance such as psychoeducation, specialist assessment or family therapy.

Psychoeducation can take place with a single family or carer group or with a number of families and carers who are experiencing similar issues.

These services are provided by people who have undertaken specialist training. Your role is to seek advice regarding how to refer those carers who might need this specialist expertise.

How do you achieve this Partnership Standard?

A diagram representing the tasks associated with identifying and providing support to carers is included in Appendix 2, (the Pyramid of Family Care).⁹ It provides an illustration of the activities associated with working in partnership with carers across all service settings. The Pyramid represents the needs of the totality of carers.¹⁰ Provision of support is divided into five levels of increasing complexity. If you implement the Partnership Standards, you will have covered levels 1 and 2 and you will have met the majority of the needs of most carers.

Partnership Standard 6 allows provision for you to refer carers who may have more complex needs for specialist interventions.

9

1 Mottaghypour, Y and Bickerton, A 2005 'The Pyramid of Family Care: A framework for family involvement with adult mental health 'vices', *Australian e-Journal for the Advancement of Mental Health*, vol. 4, issue 3.

2 Adapted from: Bickerton, A, Hossack, K and Nair, J, 2007, *Connecting with Carers is Everybody's Business*, Working With Families Program, Sutherland Division of Mental Health, South Eastern Sydney Illawarra Area Health Service.

Simple strategies to consider

- Identify existing gaps in service delivery regarding carer support service referrals.
- Create a list of carer support services and include this in carer brochures.
- Discuss with carers available support services and make regular referrals.
- Receive feedback regarding carers' experiences of your service by mechanisms such as asking them to complete the 'Carers Experience of Care Measure'

Self Assessment Tool: Standard 6

Partnership Standard 6:

A range of carer support services is available.

Activities	R	O	G	Action Plan
6.1 A carer support service is in place locally				
6.2 Carers have access to local carer advocacy services				
6.3 Carers have access to a range of support services if required				
6.4 Carers' needs and plans are regularly re-assessed				
6.5 More specialised services such as family therapy are offered to carers and family if required				

Red indicates significant under-performance and a need to develop action plans for improvement.

Orange indicates achievement of the activity some of the time but that improvement is required.

Green indicates positive achievement of the activity the majority of the time.

Information for specific settings

This section explores information for specific settings including:

- Working with GPs
- Working in a specialist mental health acute inpatient unit
- Working in a community mental health service
- Working in a community-managed organisation

The following issues need to be taken into consideration, irrespective of the service setting.

Remember carer requirements associated with:

- age
- gender
- Indigenous status
- culture – for example, definition of family
- language – for example, use of interpreters
- religion
- sexual orientation
- children as carers

Working with GPs

GPs play a crucial role in contributing to a partnership model of care. Eighty-five per cent of the Australian population attend their GP at least once a year¹¹; and the National Mental Health Survey conducted in 2007 confirmed that GPs are the health professionals most commonly consulted by patients experiencing mental health concerns.

Presentations to the GP may be by the person themselves, but in many cases will be by a concerned relative. Concerns regarding a family member will frequently present during the course of a consultation regarding an apparently unrelated issue.

The role of the GP is complex and pivotal. Frequently GPs have known/treated the whole family over a considerable period of time, so they are ideally placed to assess changes.

They also play an important role in identifying mental illness across the life span. This includes detection of mental health issues that frequently impact carers themselves.

Appointments with people who attend the GP regularly for assistance with chronic health conditions are an ideal time to check the availability of carers, clarify their role and seek the patient's permission to involve them in ongoing care.

GPs also play a significant role in health promotion and illness prevention. As such, they can be a useful resource for:

- providing psychoeducation to consumers and carers
- monitoring for physical health complications that commonly occur in patients receiving treatment for mental illness, allowing for earlier intervention
- assisting mental health services with pro-active engagement with carers.

Such support from the GP may be enhanced when specialised mental health services ensure the provision of reliable, timely and informative communication pathways with a consumer's usual GP.¹² Such communication assists GPs in their critical role in referring to other specialised services and ensuring that the total biopsychosocial health needs of consumers and carers are addressed.

Case study:

Marcus is a 45-year-old man with major depression who has required hospitalisation four times in the past five years (usually for an adjustment to his medications in the context of severe depressive symptoms, and on one occasion for a course of ECT). He also has diabetes and several other risk factors for heart disease. He works full-time when he is well as a school teacher. His wife Kirsty has rheumatoid arthritis and is unable to work in her profession as a horticulturist due to her health. They have two teenage children in early secondary school.

When Marcus is in hospital, there are added worries re: financial matters and it is hard for Kirsty to run the household and look after the children. Other family members live interstate, with the exception of Marcus's mother, who lives in a granny flat on the family property.

Your role in this type of case is to:

- Ensure the GP is kept informed of Marcus's admission, ideally by leaving a phone message and/or sending a fax or email on the day of admission.
- Ensure the GP receives a timely discharge summary outlining all treatment changes and any investigations carried out during the hospital stay. A phone call to the general practice advising that discharge is imminent and arranging a GP review appointment soon after discharge is ideal.

It is particularly helpful for GPs to know:

- what follow-up is planned
- what to do if relapse occurs

¹¹ Britt H, Miller GC, Henderson J, Bayram C, Harrison C, Valenti L, Wong C, Gordon J, Pollack AJ, Pan Y, Charles J, 2015, *General practice activity in Australia 2014–15*. General practice series no. 38. Sydney: Sydney University Press.

¹² PMHA *Principles for Collaboration, Communication and Cooperation between Private Mental Health Service Providers*, Private Mental Health Alliance, March 2014.

- o what the planned duration of any pharmacological treatments will be, particularly with clarity around planned reduction of medications known to have a risk of causing dependency or serious side effects
- o what information has already been communicated and what still needs to be communicated to the consumer and carer. (GPs can reinforce appropriate key messages given to consumers and carers by mental health service staff, but of course require these key messages to be communicated prior to their next encounter with the consumer or carer. Sharing an individualised mental health plan with the GP would be a simple way of achieving this).
- encourage Marcus to see his GP regularly for implementation of a Chronic Disease Management Plan, which will allow access to Medicare-subsidised allied health support, such as a diabetes educator, dietician and podiatrist
- check how Kirsty is coping and encourage her to talk to the GP about additional supports she might need in her role as carer
- remind Marcus and Kirsty that, despite their limited access to family support, they can get assistance from a variety of places, all which can be discussed with the GP. Topics for discussion might include:
 - o optimising the management of Kirsty’s arthritis (which may need specialist referral)
 - o additional parenting support, for example via COPMI resources
 - o aged care services in the local area for Marcus’s mum, including help from the local multidisciplinary aged care team and the local council
 - o add-on eMental Health resources for both Marcus and Kirsty
 - o assessment of Kirsty’s mental health, to see if she would benefit from additional support via a private psychologist, MH nurse, occupational therapist or social worker.

Questions to ask a carer:

“Does Marcus attend his GP regularly for review of his diabetes?”

Does the GP know Marcus has been in hospital? Here is a letter to let the GP know what is planned for Marcus’s depression care. Can I phone the GP to discuss some issues that will need sorting once Marcus goes home?

Are you getting extra help at home? Would you talk to the GP about things you could do to help Marcus’s mum and to support the children while Marcus is getting better? Would you like me to call the GP to give her/him a heads-up re: what has been happening?”

Working in a specialist mental health inpatient setting

Partnership Standards

1. Carers and the essential role they play are identified at first contact, or as soon as possible thereafter.
2. Staff are carer aware and trained in carer engagement strategies.
3. Policy and practice protocols regarding confidentiality and sharing of information are in place.
4. Defined staff positions are allocated for carers in all service settings.
5. A carer introduction to the service and staff is available, with a relevant range of information across the care settings.
6. A range of carer support services is available.

A person with a mental illness rarely appears on their own to this type of service. They are generally accompanied by a concerned family member or friend. In some extreme situations, they may be accompanied by police and/or ambulance crews. Police and ambulance workers will have information regarding who called them and details regarding the situation they were collected from.

All of these people can offer you an opportunity to identify who the carers are (as opposed to the Next of Kin). Data systems need to make provision for this information to be recorded separately. A number of services have adopted the carer nomination form as an essential component of the admission process.

If someone is involved with, and gives support to, another person, they should be considered a carer irrespective of their living arrangements and actively involved in the care team. This applies even if the consumer is unwilling or unable to acknowledge the carer's involvement.

You need to ensure this knowledge is recorded and shared with other members of the team (as appropriate). If the consumer has a young family or is a carer themselves, this needs to be understood and responded to.

Carers possess valuable information. Their early identification will assist you to formulate an accurate assessment on which to plan treatment and assess risk. Carers need an opportunity to be part of the

development and maintenance of a treatment plan for recovery.

Consumers should always be asked who they identify as the person/s who provide support to them and the level of information that can be shared with them.

Sometimes the person is too unwell/distressed on admission to provide this information. This issue can be revisited later; however, it is still important for you to obtain as much information as possible from the people who accompanied the person to hospital.

A helpful comment to make to the consumer could be something like:

It is important we involve your family. They are concerned about you and need to understand what is happening, or else they may react in ways that are not helpful to you.

You can seek and receive information

When a specific form to nominate carers (carer nomination form) is included as a regular part of admission and referral documentation, there is a continuous reminder to every staff member throughout all stages of care that it has to be completed. A discussion with the consumer regarding the identification of carers provides an opportunity for

the importance of a partnership approach to care to be reinforced.

Carer nomination requires regular review and updating. Many people, especially family members, may not know that they are 'carers'.

Some people may be admitted to hospital on an involuntary basis. Each state and territory has separate mental health legislation. All have different requirements regarding the obligations of staff in relation to consumers and carers and the amount of information that can be shared. It is important that carers are given an explanation of what this means for them, and for the person they care for. Information regarding rights and responsibilities of consumers and carers must be made available to the carer.

Questions you might ask carers:

What led them to seek help/call the police/ ambulance today?

What changed?

Does this person have a history of this type of behaviour?

What have you tried to date?

Does everyone feel safe?

What are the most pressing needs of the family?

This time also enables you to give carers an orientation to the mental health service: what the service does, the contact person, visiting hours, etc.

Discharge from an inpatient setting

Information passed on at discharge needs to include the identification of the carer, their role in the consumer's life and the level of information that has been agreed as being able to be shared.

In the acute setting it is important to ensure on discharge that the consumer, family member and/or carer have relevant information regarding diagnosis and medication and how to deal with future issues or crises should they arise.

During an acute admission, one of the crucial reasons for identifying carers is to enable you to discuss choices regarding how much and what type of care they are able to provide, taking account of their family and work commitments.

Carers are your partners in care. They have a right to be fully involved at all stages of discharge, including the decision to discharge and making sure practical arrangements are in place.

Discharge planning allows an opportunity for you to discuss with the identified carers issues such as:

- Where will the consumer live?
- Will they be able to return to work/school?
- Information about medications – levels, compliance, possible side effects?
- The level of support required – will carers have to cease work? Has this been discussed with the carers?
- Will this support be available on discharge? If not, when will it be available?
- Ask the carer what is the best way to advise them of impending discharge?

Carers might ask you:

Will I have to change my work to care for them?

What do I tell my family and friends?

Do I need to look for side effects of medications?

What can I expect in the future?

Who do I contact if things go wrong?

Do not assume that the family/friends will always want to continue their same level of involvement.

Carers have choices – and other commitments.

All staff, across all settings, need to check on a regular basis:

- Carer willingness to continue to be involved
- Carer needs for information and support

It is crucial that you are aware of particular circumstances regarding carers and you undertake whatever action you need to in order to address them.

Children can be carers of a parent/s with mental illness and they are particularly vulnerable at this time. It is crucial that you identify issues such as,

- are they being cared for with someone they trust, especially if they are young?
- do they have somewhere they can stay?

At these time irrespective of their age, they may be very distressed. They may be the primary carer of their parent with a mental illness and will need additional support.

It is important that you refer young carers to the Children of Parents with a Mental Illness organisation (COPMI) at www.copmi.net.au and provide them with the call line of: [Kids Helpline](http://www.kidsline.net.au) on 1800 55 1800. COPMI have very good information which can assist young carers.

The other particularly vulnerable group are those carers from non English speaking countries. They may have numerous cultural issues and if they are isolated from support, this can be a very challenging time for them. It is as important to engage with interpreter services when talking to carers, as it is for consumers. Mental Health in Multi Cultural Australia have a number of resources including diagnosis specific information on their website of <http://www.mhima.org.au>.

They have a number of translated resources which would assist carers understand more. The languages catered for include: Amharic, Arabic, Assyrian, Simplified Chinese, Croatian, Dari, Dinka, English, Farsi, Greek, Italian, Khmer, Korean, Krio, Macedonian,

Polish, Russian, Serbian, Spanish, Swahili, Traditional Chinese, Turkish, Vietnamese.

Some communities such as Indigenous ones have a broader understanding of who carers are or who they may be. In some cases the entire community considers itself as the carers . This has implications when deciding who to involve in the process of care and discharge.

Remember carer requirements associated with:

- age
- gender
- Indigenous status
- culture - for example, definition of family
- language - for example use of interpreters
- religion
- sexual orientation
- children as carers

Case Study:

Janet is a 37 year old woman with a diagnosis of schizophrenia who was admitted to the inpatient unit after her parents were concerned about her increasing auditory hallucinations and inability to care for herself and her three children.

Janet was initially reluctant to give us the name of a Nominated Carer because she blamed her parents for admitting her to hospital. Staff explained that it would be beneficial to the team if we had someone who could give us history and offer support to as they were caring for her children.

Janet signed a nominated carer form and we had the first of several family meetings to discuss concerns about her excessive drinking and financial vulnerability. Janet was allocated a case manager from the service and staff were successful in obtaining a package which gave her up to 15 hours support in her home.

Unfortunately despite the support given Janet relapsed and had her children removed to foster homes as parents were elderly and unable to cope. Janet agreed to go to a service for a period of rehabilitation and on return continued with the support package and was referred to supported employment to enable her skills and independence.

Your role in this type of case is:

- Provide her parents with significant support in the community and refer them to the Carers group for individual and group follow up.
- Continue to support Janet as her 14 year old son returned to her.
- Follow up appointments with the psychiatrist, Family Centre for parenting skills, a diabetic educator and dietician and psychology referral.

Janet is an excellent example of how a partnership approach between staff at an inpatient unit, case manager from a community managed organisation and supportive parents have ensured a good outcome.

Questions to ask her carer:

I wonder how things are going with Janet.

How are you going?

Is there anything we can provide which might help you more?

Is there anything you need to clarify with us?

Working in a specialist community mental health service

Partnership Standards

1. Carers and the essential role they play are identified at first contact, or as soon as possible thereafter.
2. Staff are carer aware and trained in carer engagement strategies.
3. Policy and practice protocols regarding confidentiality and sharing of information are in place.
4. Defined staff positions are allocated for carers in all service settings.
5. A carer introduction to the service and staff is available, with a relevant range of information across the care settings.
6. A range of carer support services is available.

Following an admission to an acute inpatient service, it is likely that the consumer will be referred to a community-based mental health service provided by specialist mental health clinicians.

You will oversee the care of individual consumers in a supportive environment. Physical health is often an ongoing focus and you may need to liaise with the consumer's GP.

You will need to be aware of a range of local support groups which could assist carers and provide the carer with relevant information.

Case Study:

Melanie is a 20 year old University Student who lives with her mother. She was referred to the community mental health service by her GP as a result of concerns expressed by the mother regarding Melanie's serious loss of weight and refusal to eat.

On referral it was noted that Melanie had low blood pressure and had lost 21kg over a 15 month period. She had been eating only a crumpet and 2 apples per day and used exercise to increase her weight loss. Melanie minimized the seriousness of her illness and its physical consequences.

When interviewed, Melanie listed her mother as her nominated carer. Melanie made it very clear that she did not want to go into hospital and would work hard to modify her diet and lifestyle.

Following discussion the mental health team agreed that she could try remaining at home where her mother would care for her. The dangers associated with Melanie potentially losing more weight were discussed.

Melanie was referred to a dietician. Her weight and physical status started to improve and she was able to increase her physical activity in a monitored manner. Over time, as Melanie improved she was able to return to work and was referred back to her GP for ongoing care.

Your role in this type of case:

- Organise a family meeting to obtain Melanie's history and to form a treatment plan that would involve all parties, including the GP.
- Monitor Melanie in the home environment.
- Support Melanie's mother to understand the issues associated with eating disorders.
- Refer both Melanie and her mother to the Eating Disorders Association for additional information and support.
- Ensure that Melanie's mother feels that she also has the support of the GP for her own issue.
- Also refer them to a number of web based programs established to provide balanced information on this topic.

Questions to ask a carer:

“ Do you have enough information to assist you in caring for Melanie at home?

Do you feel confident you can monitor Melanie’s weight?

Is the GP involving and supporting you?

Do you have any questions for me?

If you are concerned don’t hesitate to contact me.”

Working in a community managed organisation

Partnership Standards

1. Carers and the essential role they play are identified at first contact, or as soon as possible thereafter.
2. Staff are carer aware and trained in carer engagement strategies.
3. Policy and practice protocols regarding confidentiality and sharing of information are in place.
4. Defined staff positions are allocated for carers in all service settings.
5. A carer introduction to the service and staff is available, with a relevant range of information across the care settings.
6. A range of carer support services is available.

Community workers are generally involved in an ongoing manner with consumers as they work their way to recovery. Working in partnership with consumers and carers is a regular practice for many community workers.

You are well placed to monitor the updating of the carer nomination form. However, this should also be re-checked if the person changes services.

Consumers present in a variety of ways, and obtaining information from the consumer may be difficult if the person is acutely unwell.

When identifying carers it is important to focus on identifying who provides the support.

Case study:

Fred is a resident of your accommodation service, and has been for three years. During this time, he has stated he does not want his family involved and that staff cannot talk to his mother. Staff are worried and unsure of what to do and say as they are aware Fred frequently contacts his mother for food and money and has dinner and other contact with family. When Fred is very anxious, he frequently phones his mother and can be quite agitated and demanding. Fred's mother, Jo, comes on site regularly to help with transport and appointments. Staff feel stuck in the middle when she asks 'how is Fred going?', and feel that she could often provide valuable information about Fred's wellness and what helps him the most.

Your role in this type of case is:

- To be aware of what is confidential and what is not confidential in supporting Fred and his mother.
- To check in and re-check in with Fred to see when and how family can be involved.
- Finding out what kind of support Fred's mother may need and make appropriate referrals for family support.
- To be clear in advising the family what is confidential and what is not confidential.
- To make sure the family knows they can reconnect with you.

What to discuss with the consumer:

“ I notice you have quite a lot of contact with your mother and other family. They seem to care about you a lot. Would it be okay if I gave them an update on how you are going? We could all meet together so you can know everything that is being talked about. ”

Questions to ask a carer:

“ What has happened since we last met? ”

How are you going?

Have you had a chance to look at the information I left with you last time?

Is there anything you don't understand/want to clarify?

What effect has the medication had from your perspective?

Do you have any questions for me? ”

Appendix 1 Carer Nomination Form

Carer Nomination Form	UR No: _____
	Name: _____
	Dr: _____
	DOB: ____/____/____
	Sex: M / F (please circle)

Close family members or other significant people in your life are often vital at all stages of your treatment and recovery from mental health conditions. We generally refer to these people as 'carers'. They often have important information that they can share with us which will assist you to receive the best possible care.

This form gives you the opportunity to identify who you would like to have involved in your care, and what and how much information you are happy for us to share with them.

Please nominate the person or persons that we can include in discussions about your treatment plan and progress and identify the level of information you would be happy for the staff to share with these people.

Name	Relationship	Level of information*	Contact details

- * 1. **Personal information** = you allow us to discuss anything with this person.
- 2. **Non-personal information** = general information that allows us to discuss your treatment, support, care plan and medications but not personal information disclosed in the course of therapy.

NB: Personal information about your thoughts and feelings or your history will not be discussed with anyone without your express permission.

Staff will check with you on a regular basis to see if you would like to change the nominations you have made.

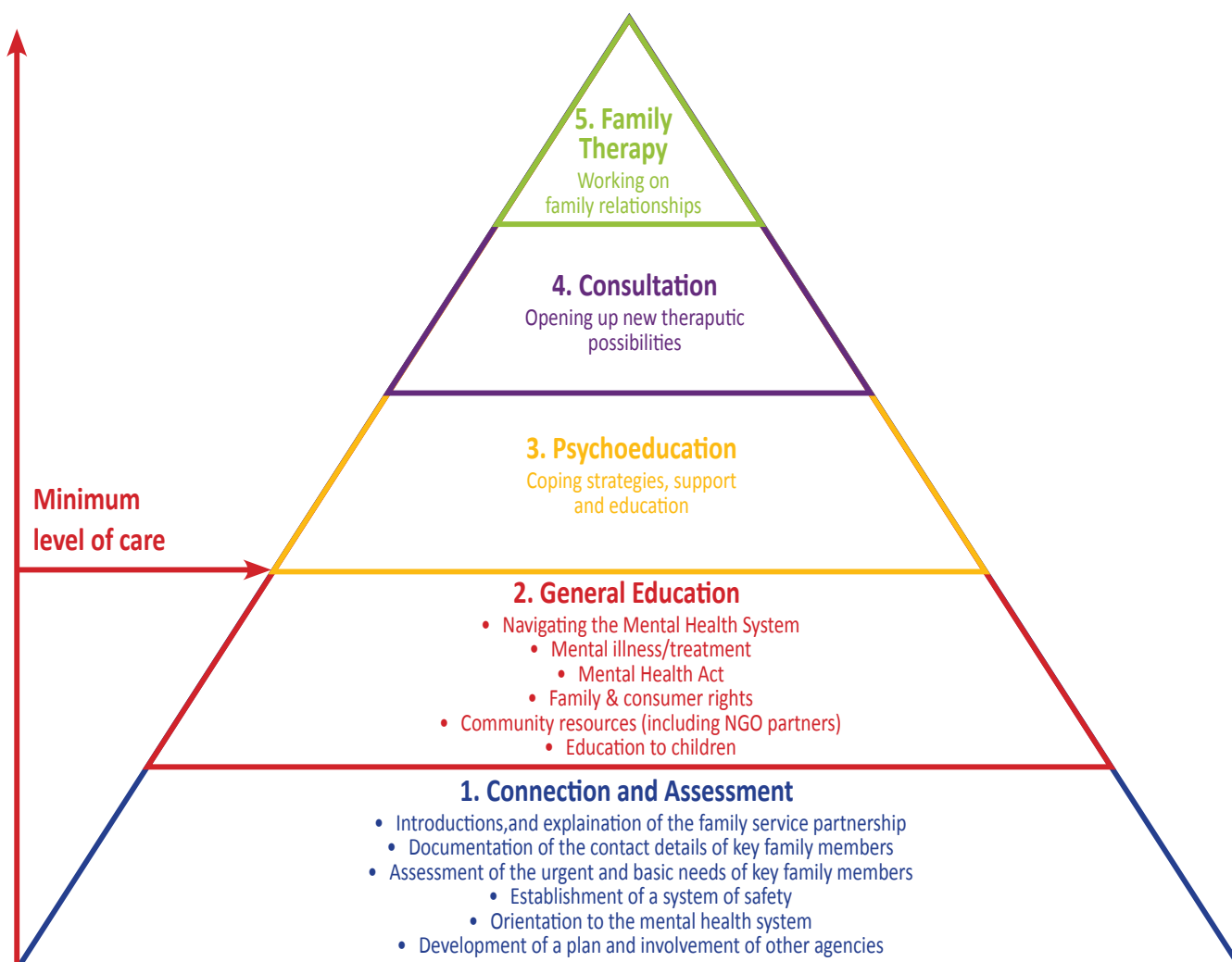
If you would like to change the nominated carer during your admission or care, please see the staff.

Name: _____ Date: __/__/__

Signature: _____

Witness: _____ Signature: _____

Appendix 2 Pyramid of Family Care



³ Mottaghipour, Y and Bickerton, A 2005 'The Pyramid of Family Care: A framework for family involvement with adult mental health services', *Australian e-Journal for the Advancement of Mental Health*, vol. 4, issue 3.

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- ² Worthington, A, Rooney, P, Hannan, R 2013, *The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England, Second Edition, 2013*, Carers Trust, London. The Carers Trust is acknowledged as the copyright holder of the concept and the Triangle of Care model.
- ³ Mottaghypour, Y and Bickerton, A 2005 'The Pyramid of Family Care: A framework for family involvement with adult mental health services', *Australian e-Journal for the Advancement of Mental Health*, vol. 4, issue 3.
- ⁴ Worthington, A, Rooney, P, Hannan, R 2013, *The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England, Second Edition, 2013*, Carers Trust, London. The Carers Trust is acknowledged as the copyright holder of the concept and the Triangle of Care model.
- ⁵ www.amhocn.org/special-projects/carer-experience-service-provision-project
- ⁶ Australian Government, *National Standards for Mental Health*, revised 2010.
- ⁷ *Health Workforce Australia [2014]: Mental Health Peer Workforce Literature Scan*, Health Workforce Australia.
- ⁸ Pamphlet produced by Bluebird Care UK
- ⁹ Mottaghypour, Y and Bickerton, A 2005 'The Pyramid of Family Care: A framework for family involvement with adult mental health services', *Australian e-Journal for the Advancement of Mental Health*, vol. 4, issue 3.
- ¹⁰ Adapted from: Bickerton, A, Hossack, K and Nair, J, 2007, *Connecting with Carers is Everybody's Business*, Working With Families Program, Sutherland Division of Mental Health, South Eastern Sydney Illawarra Area Health Service.
- ¹¹ Britt H, Miller GC, Henderson J, Bayram C, Harrison C, Valenti L, Wong C, Gordon J, Pollack AJ, Pan Y, Charles J, 2015, *General practice activity in Australia 2014–15*. General practice series no. 38. Sydney: Sydney University Press.
- ¹² *PMHA Principles for Collaboration, Communication and Cooperation between Private Mental Health Service Providers*, Private Mental Health Alliance, March 2014.

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This Guide has been developed through a partnership between consumers and carers, representative staff of public and private mental health services and the community-managed organisation sector. It reflects the desire of all stakeholders to deliver services in a manner that recognises the expertise of all partners united in a journey towards recovery.

The intended readership of this Guide is the staff of specialist mental health services and of public, private and community-managed organisations. The crucial role of the GP is acknowledged, and some sections of the Guide suggest good practices that might assist in the ongoing care of patients with mental illness and of their carers. However, it has not been developed to specifically meet the practice standards of GPs.

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This Guide can be viewed at:

- www.helpingminds.org.au
- www.mindaustralia.org.au
- www.pmha.com.au/pmhccn/Home.aspx
- www.mhaustralia.org
- www.arafmiaustralia.asn.au

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