Private Mental Health
Consumer Carer Network (Australia)
engage, empower, enable choice in private mental health

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Carers Identified?

FINAL REPORT
OF THE PROJECT TO DEVELOP

Nationally consistent policies and good practice protocols to identify carers of people with a mental illness

and

Nationally consistent information for carers on admission to a service

FOR

THE COMMONWEALTH DEPARTMENT OF HEALTH AND AGEING

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“It is not morally defensible to continue to allow families to carry the burden of care without giving them the information, training and support necessary to bring about better outcomes for the patient, as well as better outcomes for the carers themselves.”

Dr. Margaret Leggatt in her chapter *Meeting the Challenges* in *Families as Partners in Mental Health Care, 2007*

APPENDICES

EXECUTIVE SUMMARY AND RECOMMENDATIONS

In 2007 the Australian Government funded the Private Mental Health Consumer Carer Network (Australia), (hereafter the Network) to undertake a project *Identifying the Carer*, examining issues associated with identification of carers as a precursor to the future development of a burden of care measures for carers.

In addition, a number of other activities at national, state and territory levels have occurred in recent years that mandate carer engagement in all levels of service delivery. These changes include the following.

- Development in some states of state–based Carers Recognition Legislation.
- Development of the national *Carer Recognition Act 2010*.
- Development of a specific Carer Standard in the revised *National Standards for Mental Health Services, 2010*.
- Revision of mental health legislation in some States and Territories to mandate identification in a variety of forms.
- Revision of the *National Mental Health Policy [2009]* and funding of the *Fourth National Mental Health Plan, an agenda for collaborative government action in mental health 2009–2014*.
- Publication of the Royals Australian and New Zealand College of Psychiatrists (RANZCP) Guidance Notes, *Involving Families,* 2000.

The needs and rights of carers of people with a mental illness have now been very comprehensively described in both legislation and policies. Following such comprehensive description one would expect a plethora of information and activities designed to meet these needs. This does not appear to be the case and while some States and Territories have developed guidelines for consumers, family carers and mental health professionals to work together in collaboration and partnership few changes have occurred at a practical level. Many have argued this relates to lack of processes to identify who carers actually are.

In an attempt to progress these issues the Australian Government in 2009 funded the Network to undertake a further short term project with the following deliverables.

- **Development of draft nationally consistent identification policies and good practice protocols.**
- **Development of draft nationally consistent information packages for carers.**
- A search of the international literature revealed a continued focus on carer needs and rights for engagement. Increased evidence is available that

substantiates the benefits of carer engagement in all processes of care and treatment. However information related to managing the complexities associated with carer identification is limited with the Network's Report of the *Identifying the Carer Project,* 2007 prepared by the same author appearing as the primary new work in this area. Some literature is also available regarding identification of general carers in GP practice in the National Health Service in the United Kingdom that has relevance to the carers of people with a mental illness.

For completeness the literature search has been updated and re–describes the following.

- The rationale for carer identification and engagement, including:
  - Carer rights; and
  - Impact of carer identification and engagement in relapse prevention for consumers.
- Impediments to identification, including:
  - Use of the term carer;
  - Privacy and confidentiality;
  - Workforce education and training; and
  - Organisational and cultural issues.
- Advance Directives.

Consultation was undertaken nationally by way of face to face focus groups in Melbourne, Adelaide, Brisbane and Launceston. Specific invitations were provided to carers identified as having interest and expertise in pursuing this topic as well as carer focused non–government organisations. Service providers and consumers from both public and private services were also invited to participate in this process to achieve balanced views. Telephone consultation was undertaken with Carer groups in other States and Territories and specifically identified individuals with a long history of working with carers. In recognition of their time and expertise, participants were paid a per diem rate for their participation in the focus groups.

In addition, individual meetings were held with representatives from the Royal Australian College of General Practitioners, Medicare Australia, Australian Council of Health Care Standards (ACHS), senior staff from MIND in the United Kingdom and representatives from relevant professional and non–government organisations such as the RANZCP and the Association of Relatives and Friends of the Mentally Ill.

The input of the many carers, consumers and health professionals who gave us their time and wisdom during the consultation phase of the project has been invaluable in exploring the issues.

The overwhelming experience of consultation participants was that, despite the existence of legislation and policies, health services continue to make little or no effort to identify or involve carers. Some stated they felt that the majority of clinicians did not seem to know how to go about this process. Organisational structures and culture were also reported to be counter productive to the processes of identification and engagement.

In addition, in situations where consumers voluntarily identified their carers or carers self identified there continues to be significant reluctance by many clinicians to include them in care processes. '*Consumer confidentiality* or *privacy legislation'* continues to be cited as reasons for non engagement. It was the experience of participants that individual clinician attitudes and practices prevail in contravention of existing service policies.

This report presents the findings of the project. The literature search, summary of Australian mental health and carer recognition policy and legislation, and report of the consultations provide the evidence base for the following.

- The draft policies and protocols regarding carer identification.
- The content of the information brochure for families and other carers.

Both products are contained within this report and with minimal editing can be re–produced as stand alone documents suitable for further consultation on a national basis with service providers, carers and consumers.

This report presents the findings of the project and summarises these into a series of recommendations for consideration by governments, professional organisations and public and private services. The recommendations are designed to strengthen the identification of, and support for, the important group of people who provide significant and sustained contribution to the care of people with a mental illness.

FINDINGS

- All participants were of the view that identification and engagement of carers is crucial in any recovery based approach to care. This position is substantiated by the literature. They also agreed that change in clinical practice will only occur if it is mandated by legislation, well grounded in policy and protocols, compliance is audited on a regular basis and incentives are associated with positive changes in practice.
- Research that recognises that carers play a critical role in the process of recovery and relapse prevention is continuing to be largely ignored by both public and private specialist mental health services.
- The professional judgement of clinicians is recognised, however no single clinician or carer can meet all the needs of all consumers. A partnership and recovery approach to care will improve consumer outcomes and decrease the burden on services and carers.
- The ideal process for identification is by the consumer. These discussions together with the degree of involvement should be negotiated, documented and regularly reviewed. The experience of staff currently working in a carer inclusive

manner is that if approached in this manner then the majority of consumers recognise and welcome the involvement of their support network.

- Some carers who self identify are not necessarily the best people to be involved in the ongoing care and recovery of consumers, either because of their past history with the consumer, or their own particular needs. However, these carers continue to have rights and mechanisms need to be developed to ensure their needs are met.

- Some consumers will, from time–to–time, because of the nature of their illness, refuse to identify or to involve carers. All professional interactions with them and written information provided to them needs to reinforce the importance of their support network being actively involved in their care.

- Consumer refusal to identify does not lesson the burden on carers. It may in some cases increase the burden of care.

- Consumer refusal to identify carers and privacy legislation is NOT a basis for preventing clinical staff across a range of settings from having a working relationship with the family/carer. Carers still have a right to give information to clinical staff to assist in assessment, treatment and ongoing care.

- Identification is not a one–off process. Service providers at all levels, on the basis of existing policies, Carer Recognition Legislation, mental health legislation and National Standards for Mental Health Services have a responsibility to identify and support carers. Cultural and organisational change, policies, protocols, education and support will be necessary to encourage changes in clinical practice.

- Policies and protocols to identify carers are essential and will vary according to service setting. The following settings provide opportunities and “trigger points” for identification to occur.

  - Primary care – specifically GP practices.
  - Public and private assessment services.
  - Formal Admission to a specialist public or private mental health service.
  - Formal discharge from a service.
  - Continuing care in both the public and private sectors.

- A nationally consistent information brochure for families and other carers is highly desirable as it will improve mental health carer literacy and opportunities for engagement. It was acknowledged that on first admission to a mental health services the information required needs to be simple, specific and practical however given that all carers are at different stages in their journey when the opportunity arises to obtain this information it was considered important to develop a brochure that was more comprehensive that could be referred to as carers were able to absorb the information. It was decided that this should be presented primarily in one booklet however should refer people to additional information related to specific diagnosed and medication once these were established. The brochure has been developed on the basis of information provided by carers, consumers and service providers, all of whom are participating in the varying stages that accompany in the treatment and recovery process.

The brochure will:

- Provide an introduction to the mental health service, explaining the processes that would be followed;
- Provide some general information about what the symptoms of mental illness might be;
- Outline in question and answer form some of the concerns they may have;
- Provide examples using the stories of family members and friends to assist them to feel less alone;
- Introduce the new language, eg ‘consumer’, ‘carer’;
- Introduce the concept of carers rights and complaints processes;
- Introduce the issues associated with the consumers rights to confidentiality and what this might mean for the sharing of information; and
- Provide information on where to go for additional information and support.

- This information brochure could be augmented by the diagnosis specific guidelines prepared by the RANZCP once a specific diagnosis is agreed and a treatment process implemented.
- Carer identification and support will be enhanced by the appointment of a nominated person/Carer Consultant/Family Support Worker on staff, with whom they can personally interact, discuss and clarify information needs as required and generally use as a point of contact for future needs.

RECOMMENDATIONS

The recommendations have been grouped according to the following headings.

DRAFT IDENTIFICATION POLICIES AND PROTOCOLS

The following policies and protocols to identify carers during all stages of care be distributed widely to public and private sector mental health services for comment and feedback on the feasibility of introduction on a progressive basis.

Policies

Identification and participation of carers in a partnership approach will be acknowledged and respected as crucial to the facilitation of early intervention, treatment and recovery of people with a mental illness.

Carer identification and levels of participation in ongoing care will take account of social and cultural differences and will be reviewed with consumers and carers on a regular basis.

Carer levels of identification and satisfaction with their engagement will form part of the regular reporting of all mental health services.

Protocols

Identification of Carers in Primary Care Settings

1. The following protocols to identify carers be discussed with the Royal Australian College of General Practitioners (RACGP) for consideration during the 2010 review of Standards.
    - Provision of general information encouraging self identification on electronic and paper notice boards including posters and leaflets.
    - New Patient Forms to identify carers.
    - Utilise normal practice appointment consultations.
    - Practice newsletters to feature articles regarding carers.
    - Utilise patients' personal health checks to identify if they undertake care for another person.
    - Have a named member of staff responsible for maintaining the practice's procedure for identification of carers – a carer specialist or champion.
2. Medicare Australia be asked to consider the placement of messages to assist with the identification of carers on benefit cheques issued during Carers Week held annually in Australia.
3. Pharmacists be asked to consider the placement of messages to assist with the identification of carers on all folders containing repeat prescriptions during Carers Week held annually in Australia.

Identification of Carers in Assessment Settings

- Generic information encouraging self identification by carers be provided in waiting areas on electronic and paper notice boards including posters and leaflets.
- New patient questionnaire data systems be expanded to include carer identification by a series of questions phrased in a positive manner designed to encourage consumers to recognise who their carers are and the importance of their ongoing contribution.
- Triage processes ask appropriately worded questions emphasising the positive aspects of family/carer participation in all aspects of care.

- Interviewing doctor/nurse ask appropriately worded questions to determine identification of carers and their level of involvement.

- A specific member of staff be allocated responsibility for maintaining procedures for identification of carers – a carer specialist or champion.

- Information packs be provided for both consumers and carers that include rationale and encouragement for identification of carers.

- ‘Carer corners’ be established in waiting rooms.

- Identification of Carers during Formal Admission to a Public or Private Mental Health Service.

- Generic information encouraging self identification by carers be provided in waiting areas on electronic and paper notice boards including posters and leaflets.

- Colour coded forms inviting consumers to identify carers and nominate the level of involvement be included in all admission procedures. Forms to be completed as soon as practicable and audited on a regular basis.

- In circumstances where a consumer refuses to identify their carer(s), the Mental Health Service will review this status at regular intervals during the episode of care in accordance with Australian and state/territory jurisdictional and legislative requirements.

- A specific member of staff be allocated responsibility for maintaining procedures for identification of carers – a carer specialist or champion. This may be a carer consultant/liaison officer/family support worker with the following responsibilities.

Staff support and training

- Liaison point between staff, consumers and carers, for example, assistance with completion of admission protocols regarding identification of carers; advocacy for individual carers with staff/services.

- Information and linkage to alternative options for information and support for carers such as referral to carer support organisations.

- Provision of carer specific perspectives to staff meetings.

- Assistance with carer assessments.

- Specific point of contact following discharge for carers.

- Ensure accreditation and reporting systems in health and community sectors incorporate the National Standards for Mental Health Services and, in particular, Standard 7 relating to the identification and participation of carers at all areas in service delivery.

- Consumer information packs to include a rationale and encouragement for identification of carers, including the identification of children who are carers.

- Services to report on the provision of information packs to carers.

- Staff to receive ‘carer sensitivity’ and skills development training.

Identification of Carers during Discharge Processes

- Generic information encouraging self identification by carers be provided in waiting areas on electronic and paper notice boards including posters and leaflets.

- Colour coded forms requesting consumers to identify carers and the level of involvement they want them to have be checked for completion.

- Ensure carers have personalised information packs including:

  - Diagnosis;
  - Medication – dosage, purpose and possible side effects;
  - This is what you can expect;
  - Who to contact to discuss concerns; and
  - What supports are available to you locally, eg your GP, Carers Australia, ARAFMI.

- Encourage the routine identification of carers, including children, in the development of relapse prevention plans emphasising the benefits of information sharing and support.

- A specific member of staff be allocated responsibility for maintaining the Service’s procedure for identification of carers to inform carers of continued points of contact for information and support.

- Ensure accreditation and reporting systems incorporate the National Standards for Mental Health Services and in particular Standard 7 relating to the identification and participation of carers at all areas in service delivery.

- Discharge letters, with the permission of the consumer and the carer, to identify carers, their willingness to continue in this role and an outline of potential support required.

- Services to undertake regular satisfaction surveys regarding their level of engagement with carers.

Identification of Carers in Continuing Care Settings

- Relapse prevention plans to emphasise the benefits of information sharing and support and contain a specific component for identification of carers. Carers need to give permission for their names and contact numbers to be included in the Plan.

- Encourage the identification of carers in the development of Advanced Directives.
- Ensure the development of Ulysses Agreements in situations where children are carers.

Information Brochure for Families and other Carers

1. The Information Brochure contained within the report:
    - be edited to a ‘plain English’ format; and
    - be edited by a graphic designer for transmission by email and to be web based; to enable wide distribution nationally to carers for consideration and feedback.
2. The revised brochure be published in hard copy and placed on the DoHA website for national use.

Good Practice Checklist

The following ‘good practice checklist for identification and engagement of carers’ be adopted nationally by public and private services.

CARER IDENTIFICATION AND ENGAGEMENT
A GOOD PRACTICE CHECKLIST FOR STAFF

Choice

Allow carers time to make choices about:

- Taking on the role of carer;
- Whether to continue caring; and
- How much and what type of care, taking into consideration family and caring commitments, health, work education, social activities

Identification

- Throughout the service admission and discharge process and at the earliest opportunity, ensure there are triggers in place to identify carers.
- Be aware that carers may not view themselves as carers but as partners, parents, sons, daughters, etc.

Information

Actively seek permission from consumer to share information with the carer and provide carers with information about the following.

- Discharge plan in writing and verbally.
- Medical condition of consumer.
- What is likely to be involved in caring
- Benefits.
- Financial implications of caring.
- Other sources of help and other organisations, such as ***Carers Australia*** and self help groups.
- Access to interpreters to enable effective understanding and communication.
- Challenging decisions and complaints procedures.

Assessment

- Involve carers in assessments, including those carried out by allied mental health professionals' and community nurses.

Planning for future service delivery

- Ensure carers feel fully involved at all stages of service delivery including the decision to discharge the person and making sure practical arrangements are in place
- View carers as partners, respect and listen to their views – longer term carers are likely to have considerable expertise and skill in how to care for the consumer
- Acknowledge carers' individual needs, consider cultural differences, age, race, disability, health, religious background, sexual orientation, gender assumptions, geography
- Ensure carers have been involved in drawing up, monitoring and reviewing policy and its implementation
- Develop different types of consultation procedures

Support

- Be flexible: provide services that carers want, when they want them
- Ensure practical help is in place prior to discharge
- Offer information on how to care safely: eg administering medications, dealing with difficult behaviour
- Improve co–ordination between health and ***Centrelink*** and other government agencies to ensure carers receive a seamless service
- Refer carers to support groups

Monitoring

Find out whether carers' outcomes were met by the service delivery process.

Methods of carrying this out could include:

- Carer satisfaction surveys;
- Audits of discharge documentation provided to carers;
- Carer outcome measures; and
- Review policies regularly in consultation with carer consultants, ***Carers Australia, ARAFMI*** etc.

1. CONTEXT

The *Mental Health Statement of Rights and Responsibilities* for consumers and carers was published and adopted by Australian Health Ministers in 1991. This became a key component of the *National Mental Health Strategy*. The Strategy has seen a number of changes over time and now comprises the following.

- The revised *National Mental Health Policy 2009*
- The *Fourth National Mental Health Plan, an agreed agenda for collaborative action in mental health 2009–2014*
- National Health Funding Agreements (current)
- *Mental Health Statement of Rights and Responsibilities* for consumers and carers – flagged for review and updating during the Fourth Plan.

The content of the Statement particularly as it relates to carers has maintained its currency and despite the best of intentions by successive governments remains yet to be implemented on any comprehensive basis.

This can be attributed to the following issues.

- Focus of changing attitudes and practice of service delivery staff has been on recognition of consumer rights and development of mechanisms for consumer participation.
- Assumptions that service delivery standards would be applied equally to consumers and carers and that there would be no need for a carer specific standard.
- Carers would seek to self identify.
- Consumers would understand the role played by their carers and seek to include them in their care.
- The incorrect assumption that health professionals would actively seek to identify carers and develop partnership arrangements with them to improve outcomes for consumers.
- The minimal development of carer specific information, support and advocacy groups with capacity to focus on the specific needs of mental health carers.

In reality many of these issues stem from the lack of clear policies and processes to identify carers. Lack of identification has resulted in a culture at service the delivery level where it is frequently considered just “too difficult” to identify carers. Privacy legislation is also cited in many cases as justification for not identifying and including carers. As a result carers receive little information and are frequently actively excluded from the treatment process. Research indicates that consumer outcomes improve where carers are provided with information, support and are actively involved in the treatment process.

An attempt has been made to address some of these issues over the last three years by:

- The adoption by most States and Territories of Carer Recognition Legislation;
- The commissioning of a project focused specifically on Identification of Carers undertaken by the Network (2007);
- A project to examine the feasibility of development of a routine measure for carer outcomes to add to the National Outcomes and Casemix Collection (NOCC) measures;
- The funding of an extensive Carer Engagement Project conducted by the Mental Health Council of Australia (MHCA);
- The development of a carer specific standard in the revised version of the National Standards for Mental Health Services;
- The 2007 National Mental Health Survey that brought to government attention the significant size of the number of carers caring for people with mental health problems and disorders;
- The 2009 Report on the Inquiry into better support for carers, *Who Cares…? Report on the inquiry into better support for carers*, undertaken by the House of Representatives Standing Committee on Family, Community, Housing and Youth; and
- The development of Key Performance Indicators for mental health service delivery.

The Network's 2007 Identifying the Carer Report found that:

- Carers have an important role to play in all situations where a person has an illness;
- Practice varies significantly from one location to another. In general, health services make little effort to identify or involve carers;
- Identification is hampered by lack of Policies and protocols to guide practice and appropriate information to provide to carers;
- Clinical practice standards which promote an inclusive approach to identifying and working with carers need to be established by all public and private mental health services. This approach will promote identification and engagement to enable carers' strengths to be promoted, their difficulties to be acknowledged and to encourage empowerment; and
- Change in clinical practice will take time and may be assisted by the following:
  - Development of carer identification forms for inclusion as a standard component of all health records;

- Development of a specific carer standard for inclusion in the revised *National Standards for Mental Health Services*; and

- Development of carer packs of information for distribution by public and private mental health services, carer organisations, non–government organisations, pharmacies, and for downloading by carers from identified web sites.

As recommended the revised *National Standards for Mental Health Services* does contain a specific Carer Standard. Both public and private mental health services will now be required, as part of the implementation of this Standard, to provide carers with information. The development of nationally consistent packages of information would provide guidance regarding the range of topics to be covered and pro-formas for adaption to meet the needs of specific services.

These are issues of concern to all mental health carers using either private or public mental health services.

It is recognized that the whole area of carer involvement is very complex. It is known that consumers can sometimes feel very differently about whether they actually want a carer involved in their treatment, who that person should be, and in what capacity, and to what extent someone can, or should, act on their behalf. This is particularly relevant when a consumer is subject to mental health legislation.

It is also recognized that most carers currently view their involvement within mental health service processes as very inadequate.

1.1 CURRENT ACTIVITY

The Australian Government has funded the Private Mental Health Consumer Carer Network (Australia) [the Network] to undertake a further short term project which will encompass the following activities:

- **Development of draft nationally consistent identification policies and good practice protocols, and**

- **Development of draft nationally consistent information packages for carers.**

It is anticipated that the implementation of recommendations from this Project will facilitate more extensive carer identification and participation as equal partners in the delivery of mental health services in both public and private sectors.

2. METHODOLOGY

A variety of mechanisms were used to obtain information to fulfil the terms of reference leading to the following deliverables.

(A) Draft nationally consistent identification policies and good practice protocols.

(B) Draft nationally consistent information packages for carers

Mechanisms included the following.

- An international literature search to examine both current policies for identification and good practice protocols in regard to the process of identification. A search to determine the nature of the information sought by carers at the time of admission to services was also covered.
- Identification of current policies and practice in regard to identification of carers.
- Examination of current policy and practice in the public and private hospital sector regarding identification of carers.
- Identification of Australian examples of 'good practice' regarding information currently provided to carers at the time of admission.
- Development of a draft policy and clinical practice protocols for consultation.
- Consultation to ensure the necessary input of both the public and private sector, support of key peak carer organizations, service provider and consumer input. Issues examined in consultations included the following.
  - Areas to be covered by identification policies and protocols.
  - Who should be responsible for identification?
  - What processes should identification involve?
  - Timing, eg at referral, admission, discharge.
  - How should this information be recorded?
  - Processes for maintaining information up to date.
  - Process for managing situations where consumer permission is not given.
  - Content of permission forms.
  - Suggested areas to be included in information packs required by carers.

Face–to–face focus groups were held in Melbourne (17 February, 2010), Adelaide (23 February, 2010), Brisbane (2 March, 2010) and Launceston (5 May, 2010). Specific invitations were provided to carers identified as having interest and expertise in pursuing this topic as well as carer focused non–government organisations. Service providers and consumers from both public and private services were also invited to participate in this process to achieve balanced views.

Telephone consultation was undertaken with carer groups in other States and Territories and specifically identified individuals with a long history of working with carers.

In recognition of their time and expertise, participants were paid a per diem rate for their participation in the focus groups.

The focus groups were conducted by the Project Officer with the assistance of the Chair of the Network.

In addition, individual meetings were held with representatives from the Australian Divisions of General Practice, Medicare Australia, Australian Council of Health Care Standards (ACHS), senior staff from MIND in the United Kingdom and representatives from relevant professional and non–government organisations such as the RANZCP and the Association of Relatives and Friends of the Mentally Ill.

The personal and emotional needs of carers were acknowledged. However, participants were encouraged during consultation to focus on the process of identification, and requirements for information at the time of admission, as much as possible.

All participants had an opportunity to comment on draft policy and protocols developed on the basis of information obtained from the consultations and the literature search.

3. LITERATURE REVIEW

3.1 RATIONALE AND METHODOLOGY

As part of the current project, the Department of Health and Ageing requested an update of a previous review related to the '*Identifying the Carer'* project. This review was undertaken of international literature and focussed on current policies and good practice protocols in regard to the process of identification and to determine the nature of the information sought by carers at the time of admission to services.

The literature search encompassed both peer–reviewed journals and other published literature. The search methodology incorporated the following elements.

- **Electronic database searches.** Subject and text words were used in searching databases for relevant research concerning Carer identification with English language limits and a publication date from 1990 to present (2010) being applied.
- **Internet searches.** A search was made of internet resources in Australia and internationally using search criteria, such as Carers, carer identification, hidden carers, carer rights and provision of information to carers of people with mental illness.
- **Scanning of reference lists.** Reference lists of publications (primary studies and reviews) found through database searches were scanned to identify further studies for consideration.
- **Grey literature and conference proceedings**. The internet was also searched for examples of recent conference proceedings that discussed the topic.

The review strategy involved a detailed examination of the material that had been identified as part of the search strategy. In this stage, the literature was excluded if the subject matter was insufficiently described and therefore the documentation did not contribute important information to the project.

Key words used in the literature search were:

- carer;
- carer identification;
- carer recognition;
- mental health; and
- carer information.

3.2 LITERATURE FINDINGS: KEY THEMES

Literature available on identification of the carer continues to be extremely limited both within Australia and internationally. Information related to rights and needs is well documented however the process of identification is generally not addressed. Definitions are many and varied and they primarily require self identification by way of relationship to the consumer or by the tasks undertaken for the consumer. Some of the literature explores the difficulties associated with the process of self identification particularly for carers of people with a mental illness.

Some of the information presented in this section is an update of that presented in the Network's '*Identification of the Carer'* Project completed by the same author for DoHA in 2007.

Literature searches of the United Kingdom (UK) literature provided the most recent information regarding processes for identification. These relate primarily to identification of all carers, not specifically those who care for people with a mental illness. The literature also almost exclusively related to general practice rather than mental health services. Nevertheless, the practices are worth examining as they could be applied across a range of sectors. The good practice protocols identified in the search also related to general practice.

GPs practice in Australia is significantly different than that delivered by the National Health Service (NHS) in the UK. However, the 'good practice' protocols that have been implemented, albeit in a rather ad hoc manner in the UK, could form the basis for discussion with the College of GPs in Australia.

The UK National Strategy for Carers (1999) identified the NHS as being the most important point of contact for adult carers and it specified some key roles for primary care staff. They recognised that the most important point of contact for young carers was within education, but, acknowledged that primary care staff working with families/parents offers obvious opportunities for identifying young carers. The strategy highlighted the primary care roles as being ideal for identifying patients who are carers or who have a carer; checking carers' physical and emotional health; informing carers of their rights to an assessment and other support services; sign–posting and referring carers to other sources of support and developing carer friendly practice based services.

Both carer specific and mental health legislation were also re–examined however there has been minimal changes over the last two years and the majority continue to be dependent on people self identifying, or assume a process has already taken place.

For completeness this section of the project report has been updated and re–describes the following.

- The rationale for carer identification and engagement
  - Carer rights.
  - Impact of carer identification and engagement in relapse prevention for consumers.
- Impediments to identification
  - Use of the term carer.
  - Privacy and confidentiality.
  - Workforce education and training.
  - Organisational and cultural issues.
- Advance Directives

However, given the areas of overlap it continues to be difficult to address these topics in isolation.

The issues examined specifically in the literature related to processes for identification and have been categorised into the following broad themes.

Key findings around each of these themes are provided below.

3.3 THE RATIONALE FOR CARER IDENTIFICATION AND INVOLVEMENT

3.3.1 Carer rights

Australian and international policy and legislation support carers as a partner in the delivery of services to improve outcomes for people with a mental illness.

The contribution that carers make to the support and care of people with mental illness was recognised by the Australian Government in the *Mental Health Statement of Rights and Responsibilities* (1991). This document, together with the *National Mental Health Policy* (1992, revised 2008), has been the cornerstone of the *National Mental Health Strategy* since its inception in 1992. The *Mental Health Statement of Rights and Responsibilities,1991* acknowledges that caring and advocacy roles are complex and the relationship between carers and consumers can change frequently and may also vary according to the age of the consumer. The following statement, taken directly from the document, assumes identification but clearly states it as a right that:

> *"With the consent of the consumer, carers and advocates are entitled to:*
>
> - *have access to the consumer;*
> - *be consulted by service providers about measures under consideration for treatment of the consumer or for his or her welfare;*
> - *arrange support services such as respite care, counselling and community nursing facilities;*
> - *exchange information with those providing treatment concerning the consumer's lifestyles and their relationships with others."*
>
> [Page 17, Mental Health Statement of Rights and Responsibilities, 1991]

The document also acknowledges that there may be circumstances where the consumer is unable to give consent or may refuse consent because of their disturbed mental state. In such cases it may be appropriate for service providers and carers to initiate contact and involve those who may be able to assist with the consumer's diagnosis and care.

> *"Carers and advocates have the right to put information concerning family relationships and any matters relating to the mental state of the consumer to health service providers.*
>
> *Carers and advocates have a right to help with their own difficulties which may be generated by the process of caring for or acting as an advocate for a person with a mental health problem or mental disorder."*
>
> [Page 17, Mental Health Rights and Responsibilities, 1991]

This Statement has been flagged for review as part of the *Fourth National Mental Health Plan – An agenda for collaborative government action in mental health – 2009 – 2014.*

A search of available literature continues to reiterate these rights. However, the reports of various projects undertaken over the last fifteen years highlight not only the extensive roles played by carers and their ongoing needs; but also the fact that services continue to ignore, and in some cases actively exclude, carers from assessment and care processes.

A study undertaken jointly by Carers Australia and The Mental Health Council of Australia (MHCA) in 2000 detailed the extensive role played by carers of people with a mental illness and comprehensively described their needs in relation to their caring role. This was subsequently reinforced by the extensive consultations undertaken nationally by the MHCA in 2009 resulting in the report *'Adversity to Advocacy'.* It is tragic to read that in 2008 and 2009, more than 1500 carers consulted on a national basis at 116 locations, including those in rural and remote areas and carers as young as nine years old reported the same issues that were identified in the following reports.

- The *1993 National Inquiry into the Human Rights of People with Mental Illness* ('the Burdekin report').
- The 2005 *Not for Service Report*, undertaken by the MHCA.
- The report of the Senate Inquiry in Mental Health, *From Crisis to Community, (*2006).
- The 2007 *Identification of the Carer Report,* undertaken by the Private Mental Health Sector Consumer and Carer Network.
- The 2009 House of Representatives *Inquiry into Better Support for Carers*.

Only Australian reports have been specifically listed. The content of these reports is reflected in the international literature.

Carer rights have also been recognized both internationally and in Australia in the form of Carer Recognition Legislation.

The needs and rights of carers of people with a mental illness have been very comprehensively described over a number of years both in Australia and internationally. However, the literature indicates that the rhetoric far outweighs the action. In the UK, carers have been entitled to an assessment of their own needs since 1995. However, numerous reports indicate that in the majority of cases, carers are still not even offered this opportunity. Many would argue this relates to lack of processes to identify who carers actually are.

3.3.2 Impact of carer identification and participation in relapse prevention for consumers

The literature is clear that the support needs of consumers and carers are interdependent. There is now good evidence to demonstrate that providing support and education to families/carers provides direct health benefits to consumers.

Dr Margaret Leggatt, a key figure in carer issues, both in Australia and internationally, in 2009 summarised the current evidence for inclusion of families and other carers in delivery of care, in the following statement:

> *"We now have powerful evidence from over 40 randomized controlled trials carried out over 30 years that supports the inclusion of family and other carers in the treatment and care of their unwell relative, leading to better outcomes for consumers, their carers and for clinicians. These studies meet the 'gold standard' for research; meta–analyses of these studies are included in Pharoah et al (2006), Pitschel–Walz et al (2001) and Cuijpers.P (1999). Briefly summarised, the evidence reveals:*
>
> - *a reduction in relapse rates (up to 20%) – resulting in a reduced number of hospitalisations*
> - *better adherence to medication*
> - *reduced psychiatric symptoms*
>
> *Further research studies show other significant outcomes, such as:*
>
> - *improved social functioning of the consumer*
> - *increased employment rates*
> - *increased involvement in community*
> - *reduction in the burden experienced by family carers*
> - *improved relationships between family members, including improved relationships with the consumer*
> - *cost effectiveness*

Leggatt also reports that studies in China, Spain, Scandinavia and Britain have demonstrated that family interventions are effective across different cultures. This is important for consideration of our own culturally and linguistically diverse (CALD) communities in Australia.

> *All of the research studies utilised three important techniques not usually found in clinical settings. Consumers, family carers and clinicians met together and worked on plans of action that were mutually agreed by all parties. Working together was carried out over an extended period of time until effective communication styles and problem–solving techniques had been achieved. This process combined the experiential knowledge of the consumer and carers with the professional knowledge of the clinician/s. This method of working together overcame situations where fear of breaching confidentiality was used by clinicians to avoid communicating with family carers.*

It is surprising then to find that these research findings are not generally known about, let alone implemented into routine clinical mental health care. The late

Professor Ian Falloon (2001), a pioneer and international champion of ‘integrated’ mental health care, has commented:

> *‘All recent authoritative reviews of this body of research have reached a consistent conclusion that further delays in implementing these methods in clinical practice can no longer be justified, either on the grounds of insufficient scientific evidence for their effectiveness, or on account of problems with securing additional manpower resources for implementation.’*

3.4 CONTINUED IMPEDIMENTS TO IDENTIFICATION

The literature acknowledges the importance of carers as partners in the delivery of services to people with a mental illness and primarily focuses on impediments to inclusion. These continue to include:

- Use of the term carer;
- Privacy and confidentiality;
- Lack of training in a carer oriented approach to clinical practice; and
- Organisational structures and cultures that impede ‘carer friendly’ practice.

3.4.1 Use of the term carer

Becoming a carer is usually not based on a conscious decision of the carer but on an event in the life of someone else. Sometimes the onset of caring is very sudden, for instance when one’s partner, child or parent is involved in an accident and is seriously injured. In other cases, especially with the development of mental illness, it may be a slower process, particularly in situations complicated by substance abuse where diagnosis can take some time. Here the carer begins by giving slight assistance but may end up with a heavy care load. For most people caring is a matter of course.

Carers do not tend to think of themselves as carers but rather as the mother of a person with a mental illness or the child of a parent with a mental illness who has never known any other situation. They are often referred to as ‘hidden carers’ and are not identified by schools or health services. That makes it difficult to reach them and to provide them with the recognition and support they need. This situation is compounded when the carers are children.

In undertaking both this and our previous *Identifying the Carer Project* in 2007 the practical difficulties that can arise when using the term ‘carer’ were highlighted. The term carer was seen as controversial. It was reported that some carers disliked it because it implied they did not ‘care’ before the person they support became unwell or because it unhelpfully professionalised the relationships. Others did not recognize that the ‘regular and substantial’ support they provided entitled them to specific ‘carer’s rights’ such as carer assessments. Others queried as to when their role of a mother, father, wife, husband, partner, neighbour or friend ended and the role of ‘carer’ began? Equally, it was noted, there are consumers who do not recognise their carers as such and who do not want them involved with their mental health care.

This position was reported as far back as 1997 in the Pfizer Journal, *Perspectives on Health care and Biomedical Research* which was devoted to care-giving in America. This document describes how carers define themselves differently depending on their relationship to the consumer. The adult child will come to see himself as a carer before a spouse does, because the spouse will see their role as a good husband or wife, and the parent will see the role as that of a good parent. The carer designation often does not come in until a crisis changes the situation. It clicks in at different times for people in different relationships.

The Journal goes on to state, "Carers do not self–identify or seek out carer organizations because the word is not well recognized."

Identification is a major issue for young carers. If young carers do not identify – or are not identified by others as carers – they and the person for whom they are caring, can miss out on the support that may be available.

The 2009 Carers Australia Budget Submission states:

> *In most countries community awareness of young carers is very limited, even among those in the health, education and social service professions who have most regular contact with the families of young carers. The idea that young people, even children under age 10, are undertaking caring responsibilities goes against general societal norms where children should themselves be looked after, rather than looking after someone. As a result those administering adult services often fail to recognise that a young person is taking an active caring role in the family, often excluding them from discussion about patient treatment or services for the family and, as a result, their particular needs are ignored...*
>
> *...Young carers have also reported that they are often not recognised as carers 'by adults in authority'. Increasing identification of young carers requires legislative frameworks of equity and fairness with developed welfare support, community awareness and respect. It also requires clear pathways of referral to supporting organisations for those most likely to be in contact with families.*

Use of the term 'carer is also a problem for Indigenous communities. Carers Australia convened a roundtable with Indigenous elders and Indigenous support workers. The report of these discussions indicated that identification of carers is difficult because:

- Indigenous carers are more likely to be women and less likely to see themselves as 'carers' because caring 'for their own' is what they do;
- an individual carer is likely to be caring for several people across generations; and
- often people with a disability or mental illness have low status in Indigenous communities, and consequently carers also have a low status

Other issues that impact on identification of Indigenous carers are:

- the cultural background of Indigenous carers , including their kinship relationships; and
- lack of cultural awareness and competent practices of many mainstream services, which means in urban centres Indigenous people are unlikely to access the service.

However there are few services and supports in communities to call on, especially in regional and remote centres. This makes identification even more important as it is likely to result in significant increases in carer burden.

The Social Policy Research Centre at the University of New South Wales has been commissioned to determine what information is known about Indigenous carers and what further information is needed. It is hoped that this study will also examine mechanisms for identification.

3.4.2 Confidentiality

The issue of confidentiality is frequently cited as an impediment by Australian clinicians as a reason for not sharing information. If this position is adopted it negates the need to identify people with whom one might have concerns about sharing information.

It appears that the protection and use of information in general, and specifically in relation to carers, is deeply embedded in ethics and professional codes, policy and law, values and professional practice.

Health professionals believe in the right of an individual's privacy in relation to his or her psychiatric condition, and are trained in 'patient confidentiality' rather than information sharing (Leggatt, 2001). They are concerned to keep the trust of the patient (British Medical Association, 1999) and fear being sued (Montgomery, 1997; Leggatt, 2001), although litigation is rare (Department of Health, 2001). Yet rights to confidentiality are not absolute, may be breached in cases of societal and public interest (W v Edgell, 1990), and need to reflect social responsibilities (Etzoni, 1999). Backlar (2001) contends that although in Western societies confidentiality in healthcare is implied and broadly assumed, providers should be clear about what information can be divulged to families and under what circumstances the patient has privacy rights. Furlong and Leggatt (1996) suggest a conceptual framework is needed to balance the rights and interests of patients with the needs and responsibilities of carers. Confidentiality is seen as a particularly taxing ethical issue when the family's involvement appears justified but the service user is withholding consent (Szmukler and Bloch, 1997).

Mental health service consumers face particular restrictions on their private lives. The right to privacy is essential in the interests of maintaining self–respect and enabling human interaction without constant social breakdown (Nagel, 1998 cited in Backlar, 2001).

Patient privacy and autonomy are frequently espoused as vital components of mental health recovery. However, privacy and autonomy principles are subject to restrictions when there are:

- Doubts about an individual’s capacity to make rational judgements;
- Public and personal safety considerations;
- Treatment criteria of mental health legislation (where a person is detained on an involuntary basis); and
- Groups of people with severe mental illness who could not survive without significant assistance from others.

The carer’s need for information to support the caring role further threatens consumer autonomy and privacy. Firstly, the consumer may have no choice about the identity of the carer, or the right to refuse to have one. The position is further complicated by the following.

- Disaffected and abusive relationships.
- Connotations of overprotection associated with the term carer, that conflict with the ethos of independence fostered by community care.
- Potential vested interests exist in close relationships (Brazier,1992).

Beauchamp and Childress (1994) observe that professional organisations impose obligations to ensure the trustworthiness of their members. However, traditionally, professional codes have been generated without scrutiny or acceptance by patients and the public (Beauchamp and Childress, 1994). Many are now being revised with stakeholder assistance (namely consumers, carers and mental health professionals). As a result, professionals with entrenched attitudes could be seen to be breaching the new guidance of their own professional bodies.

The Australian Law Reform Commission undertook a review of privacy law in 2008 and recognized that disclosure of information to ‘a person responsible for an individual’ can occur within privacy law. The need for legislative reform in this area was also recognized by the 2009 House of Representatives Inquiry into Better Support for Carers. Recommendation 14 of that report called for investigation of whether privacy and mental health legislation ‘adequately allows carers to be involved in the treatment of the individuals for whom they care’.

In theory, clinicians now run the risk of carer litigation where harm to carers (Zinn, 2003) or depriving carers of information to enable them to exercise their role (S v City, 2002) can be shown as a result of failures to communicate appropriately.

SANE Research investigating the effects of caring for someone with a mental illness, 2007 produced the *SANE Guide for Families, the essential resource for families, friends and other carers of people with a mental illness*. The Guide explains how everyone in a family can be affected, the services available, and the skills needed to help support their relative’s recovery.

The Guide does not address the issue of identification per se, however, drew attention to the need for this and the role that ‘confidentiality’ plays in excluding carers from services. The report states:

> *"Many health professionals still exclude family carers from treatment planning, and withhold information, inappropriately citing confidentiality. This is despite changes to legislation and new policies on inclusion of carers. Health professionals need training and supervision to ensure these attitudes to family carers are improved."*

Diane Froggat, in examining issues of confidentiality and privacy in *Families as Partners in Mental Health Care* states:

> *The difficulty arises when those who are caring for a severely ill person are told by the clinician that he or she cannot discuss the patient. In most cases carers are not looking for personal details of the clinical relationship, but only for information that will help them carry out their responsibilities as caregivers. This is not privileged information unless the patient has specifically asked the clinician not to talk to his/her relatives about anything, a circumstance that is very rare in the families who bring their relative to treatment.*

The concept of confidentiality is often a concern to clinicians training in mental health. One effective way of raising the profile of the needs of carers that has been reported, has been to involve carers directly in the teaching and training process to 'tell their story' of their own experience. Carers are usually very willing to do this and clinicians repeatedly report this has major impact on how they go on to engage families following the training in family interventions. One main component of the model is information sharing between the consumer and the family members.

This often takes the form of the consumer describing to the other family members their experience of being unwell. During this process, information about the service and the particular difficulty the consumer identifies is discussed. With this approach both the consumer and the carer have control over what information is divulged. However, the evidence base for this work maintains that, by encouraging greater effective communication between people who significantly influence each other, outcomes for both parties are dramatic. Service satisfaction through a positive experience is well known to enhance future relationships between consumers, carers and clinicians.

The development of a specific carer standard in the revised National Standards for Mental Health, 2010, that requires services to actively engage with carers highlights the urgency of finding mechanisms to address this situation.

3.4.3 Lack of training in a carer oriented approach to clinical practice

Public mental health services in Australia are generally delivered by teams of people from different disciplines subject to different professional codes. The literature acknowledges that little examination or discussion has occurred regarding these differences. Given the critical impact of the carer and consumer relationship, professional skill in managing the interface is of utmost importance, particularly in situations where consent for involvement is an issue.

This stance is supported by Experts by Experience (EbE), a group of service users and carers who advise National Institute for Mental Health in England on their concerns. An unpublished discussion paper (2003) noted:

> *…Handling tensions between users and carers should be regarded as a core skill for mental health professionals and included in all qualifying training programmes and continuing professional development.*

Staff training remains primarily individually focused however the evidence in the mental health area for adopting a partnership approach to care that is inclusive of the consumer and their carers is overwhelming. Changing training and practice to a partnership approach is not a simple matter. Legislation and standards now mandate behaviour that clinicians are not adequately trained to provide at this point in time.

Changing training programs is a protracted activity and whilst it will have benefits in the long term, the literature indicates that strategies are required to facilitate change in current clinical practice to be more carer and family focussed.

Recent literature from centres that have incorporated ‘Family Interventions’ (the name given to programs that utilise the methods used in the research), now document the barriers to implementation and how they are attempting to meet these challenges.

While some patients and families reject this intensive form of help, most welcome it. The major challenges to be tackled for new models of evidence–based mental health service delivery to be implemented, relate to the training of the workforce and changing the organizational culture to accommodate a radically different way of working.

Carers Australia in their submission to *the Senate Inquiry into Mental Health, (2007)* highlight the fact that a major plank in the successful implementation of any carer participation policy is the planned and coordinated education of mental health professionals and service providers driven by governments and professional bodies.

They clearly state that the present level of education provided in some states and territories through staff orientation, in–service seminars, targeted workforce training, psychiatric trainee education and general practitioner education under the Better Outcomes in Mental Health program is inadequate to achieve and sustain culture change regarding carers. They were optimistic however, that with the funding now available through the COAG National Action Plan on Mental health (2006–2011) across national and state and territory levels this may now improve. Also, DoHA and the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) are funding local and community programs through the COAG national action plan.

Workforce training for professionals who deliver mental health care need to address a number of key barriers carers encounter. Formal protocols for identification are considered key in overcoming these barriers.

Carers Australia acknowledge that general practitioners, mental health professionals in public and private sectors, and other key primary and acute health care providers need skills, knowledge and the right attitude to build partnerships with carers. This will require an ongoing education strategy through undergraduate, postgraduate and continuing education programs targeted to professionals delivering specific programs or employed in public and private mental health systems.

There are now excellent and effective training programmes that have been developed in the UK and America, where mental health clinicians – psychiatric nurses, psychologists, occupational therapists, social workers, a few psychiatrists and family carers – have been trained in the methods developed from the research studies. These programs have also been tried in Australia but have been largely unsupported, and have not developed to any great extent.

Set out below, are two models of working with families that have developed from the evidence–base reported in the literature and for which training manuals ('Family Work Manual' – Falloon et al, 2006 and 'The Management of Major Mental Illness with Families in Group Interaction' – Lambert and Leggatt, 1999) are now available.

- Behavioural Family therapy. This model has been adapted and is being implemented as 'Building Family Skills Together,' in conjunction with North West Area Mental Health Service, the Centre for Psycho–Social Research and the Bouverie Centre. All of these services are located In Victoria.

- Multiple Family Groups. A research project was implemented through the Inner West Area Mental health Service in Victoria, and the results of this work have been published (Bradley G et al, 2006). Multiple family groups have been commenced in two other Victorian Mental Health Services.

3.4.4 Organisational change necessary to accommodate new ways of working

Margaret Leggatt in her article, *New thinking and acting for turbulent and challenging times, 2010,* sees organizational change as probably the greatest challenge to identification and engagement with family members and other carers.

> *In brief, the major barriers that have to be overcome are:*
>
> - *changing outdated clinical attitudes to families as the cause of mental illness*
> - *implementing better methods of case–load management*
> - *finding resources, both in terms of funding but significantly more important has been the need to gain the support of management. Once this occurs, funding seems to become available.*
> - *finding 'culture change carriers' who will advocate and push for innovation*
> - *making time available to implement the change process*
> - *finding ways to ensure sustainability; this has happened primarily through ongoing clinical supervision to build and maintain confidence and expertise.*

Leggatt goes on to say that there is now substantial literature from clinical researchers in other countries where family work has been implemented, who have confronted and overcome the barriers to this implementation (Brooker C, 2001; Drake et al, 2001; Fadden G, 2006; Grol and Wensing, 2004).

One method for overcoming these barriers is to undertake a ‘Barrier Analysis’ as described by Leggatt in the chapter *Meeting the Challenges* in *Families as Partners in Mental Health Care.*

A ‘barrier analysis’ enables major individuals and groups that are critically important in making changes within an organization to be identified. This type of analysis can be undertaken by groups comprising clinicians, consumers and carers.

When the National Institute of Clinical Studies (NICS) used this process in Australia they identified the following individuals and groups as most important to making change succeed:

- Area managers;
- Directors on clinical services;
- Team leaders/program managers;
- Frontline clinicians (interdisciplinary case managers);
- Doctors; and
- “Known obstructors”.

It is clearly very critical that known obstructors are identified and involved if change is to occur. Focus groups with frontline clinical staff were also seen as an important tool in addressing the barriers to implementing changes in clinical practice towards a partnership model of care.

Leggatt also notes the importance of involving experts in family interventions when making changes in clinical practice. Dr Grainne Fadden, in a workshop in Melbourne in 2005 emphasized the following key principles to ensure change occurs:

- *Evolving family work into routine clinical practice is a practice that takes time and perseverance.*
- *Central funding is needed to get family work started – not necessarily to have it in the longer term.*
- *Model of intervention should be relatively simple and part of the workload of all clinicians.*
- *Ongoing supervision of clinicians after training is vital.*
- *Uptake of the intervention by clinicians will be minimal at first (working in depth with only one or two families if working with a single family model, or one group if a “multi–family group” model is adopted.*

The literature reports that consumers, family or carers and clinicians working together collaboratively, provide an excellent opportunity for incentive–based learning. Staff start to find that they are ‘thanked‘ by families, rather than having to cope with families that are angry, frustrated, and therefore seen as difficult and ‘dysfunctional.’ Less staff burn–out, less absenteeism, and fewer resignations have also been reported. Including the family and other carers is much more satisfying in that they are now ‘allies’, and not ‘enemies.’ Clinicians also find that issues such as confidentiality disappear when carers become part of the treatment and care team. Cost effectiveness of these interventions has been reported in several cases, including in Australia (Mihalopoulos, 2004).

Family Interventions are a proven way of helping families stay together. Rather than focussing treatment solely on the consumer, new ways of thinking and acting must incorporate the consumer’s social network, most particularly his or her family and friends. This is undoubtedly in the consumer’s best interests for optimum recovery.

Diane Froggatt in her introduction to *Families as Partners in mental health Care, A Guidebook for Implementing Family Work (2007)*, provided the following quote:

> *Asked about what single change would substantially improve quality of psychiatric care, Professor Julian Leff replied: “Listening to and implementing what patients and their carers want.” In answer to what single area of psychiatric practice was most in need of development, he replied: “Including the family in any consideration of the patient’s problems, needs and strengths”*

3.5 ADVANCE DIRECTIVES/STATEMENTS/CARE PLANNING

An exploration of the literature to determine mechanisms for identification indicated that Advanced Directives and Ulysses Agreements have some potential for use in this area.

Advance care planning refers to the process of preparing for likely scenarios and usually includes assessment of, and dialogue about, a person’s understanding of their medical history and condition, values, preferences, and personal and family resources. An Advance Directive, sometimes called a ‘living will’, is a document that describes one’s future preferences for medical treatment in anticipation of a time when one is unable to express those preferences because of illness or injury.

Advance Directives are most commonly used in situations towards the end of life. However, there are some anecdotal reports of an increasing use in the mental health area as a means for consumers to have more input into their care at times when they have acute episodes and are considered unfit to make decisions on their own behalf.

They have been used successfully to help people to plan ahead and maintain a degree of autonomy and control during crisis (Diggins, 1993) with beneficial outcomes on rates of hospital admission (Sutherby *et al*., 1999). They also enable the consumer to nominate people to have control over their affairs. This may enhance the carer’s position in decision–making where he or she is nominated.

They have received widespread international support and, in the United States, Advance Directives now have a statutory basis in all 50 States. Three Australian States (Victoria, South Australia and Queensland) and two Territories (the Northern Territory and the Australian Capital Territory) now have legislation which provides for

Advance Directives. Although New South Wales, Tasmania and Western Australia do not have similar legislation, Advance Directives may still be valid under common (judge–made) law in these States.

Recommendation 18 of the Australian Government Senate Select Committee on Mental Health (2006) also states:

> *“That the HREOC be requested to complete its important work on advance directives and protocols that would recognize the rights of consumers to, for instance, identify substitute decision makers, appropriate treatments and other financial, medical and personal decisions, particularly for the care of children.”*

However, despite their prevalence in the United States, Advance Directives have, in many instances, failed to guide clinical decision–making, and their utility has been questioned. Of particular concern is the dilemma facing clinicians when the AD rules out treatment which the doctor believes is in the patient's best interests. Currently in Australia, mental health legislation can over–ride an Advance Directive.

In the UK, Advance Statements are recommended by the Expert Committee (Department of Health, 1999d), and actively promoted as part of a reformed Mental Health Act by the 60 organisations of the Mental Health Alliance (2003). However, as yet advance statements are not recognised in mental health law in the UK. Prudent professionals may of course choose to state why they have acted against an individual’s wishes. Advance statements are recognised in UK case law and healthcare policy and usefully promote consumer values and autonomy. They can also avoid the problem of paternalism associated with best interests.

Families and others often shoulder significant burdens when consumers are acutely psychotic. Reflective discussion in a non–crisis situation can identify options regarding treatment and the role that carers will play. This process, if carried out as part of the development of a relapse prevention plan, would justify the identification of carers and publicly acknowledge their role in future treatment.

3.6 CONCLUSION

The literature is mostly silent on how to achieve identification, however there is plenty of evidence to support the activities that flow from identification. Existing literature focuses on the problems associated with implementing these processes. One can assume the resistance that exists in current practice relates to implementation of activities that flow from identification. Therefore it appears necessary to address impediments to implementation of existing policies if the issue of identification is to be addressed.

In summary the literature identifies that a substantial commitment is required from all stakeholders across the mental health system in years to come if the widespread current poor practices in identification and support of carers are to be rectified. Improvements in practice depend on the following.

- Clear policy guidance and service delivery protocols.
- Improved knowledge and training regarding confidentiality.

- Routine identification of carers preferably by consumer consent via Advance Directive or relapse prevention plans.

- A cultural shift within mental health services, including a change in attitude towards identification and working with carers.

- A process for addressing practical constraints that restrict professional involvement with carers within services.

- Increase in carer mental health literacy via access to specifically tailored information packs.

- Carers self identifying and becoming pro–active in the development of effective relationships with professionals.

4. AUSTRALIAN POLICY, LEGISLATION AND PRACTICE IN REGARD TO IDENTIFICATION OF CARERS

4.1 CONTEXT

Australian policy and legislation support carers as partners in the delivery of services to improve outcomes for people with a mental illness.

The contribution that carers make to the support and care of people with mental illness was recognised by the Australian Government in the *Mental Health Statement of Rights and Responsibilities* (1991). This document, together with the *National Mental Health Policy* (1992, revised 2009), has been the cornerstone of the National *Mental Health Strategy* since its inception in 1992.

The *Mental Health Statement of Rights and Responsibilities* acknowledges that caring and advocacy roles are complex and the relationship between carers and consumers can change frequently and may also vary according to the age of the consumer. The following statement, taken directly from the document, talks of the rights of carers but can only be fully realised through a process of identification:

> *"With the consent of the consumer, carers and advocates are entitled to:*
>
> - *have access to the consumer;*
> - *be consulted by service providers about measures under consideration for treatment of the consumer or for his or her welfare;*
> - *arrange support services such as respite care, counselling and community nursing facilities;*
> - *exchange information with those providing treatment concerning the consumer's lifestyles and their relationships with others."*

Page 17, *Mental Health Rights and Responsibilities, 1991*

The document also acknowledges that there may be circumstances where the consumer is unable to give consent or may refuse consent because of their disturbed mental state. In such cases it may be appropriate for service providers and carers to initiate contact and involve those who may be able to assist with the consumer's diagnosis and care.

> *"Carers and advocates have the right to put information concerning family relationships and any matters relating to the mental state of the consumer to health service providers.*
>
> *Carers and advocates have a right to help with their own difficulties which may be generated by the process of caring for or acting as an advocate for a person with a mental health problem or mental disorder."*

Page 17, *Mental Health Rights and Responsibilities, 1991*

This Statement has been flagged for review as part of the *Fourth National Mental Health Plan – An agenda for collaborative government action in mental health – 2009 – 2014.*

A number of activities at national, state and territory levels have occurred in recent years that mandate carer engagement in all levels of service delivery. These changes include:

- Development in some states of state based Carers Recognition Legislation;
- Development of the national *Carer Recognition Act 2010*;
- Development of a specific Carer Standard in the revised National Standards for Mental Health Services, 2010;
- Revision of mental health legislation in some States and Territories to mandate identification in a variety of forms;
- Revision of the *National Mental Health Policy (2009)* and funding of the *Fourth National Mental Health Plan, (2009–2014)*; and
- Publication of the RANZCP Guidance Notes, *Involving Families,* 2000.

In addition, the 2007 National Mental Health Survey brought to government attention the significant size of the population caring for people with mental health problems and mental illness. This survey found 40% of the adult population have at least one relative with a mental illness and 15% of the Australian adult population (approximately 2.4 million individuals) provide care for one or more people with a mental illness.

These carers provide a range of emotional and practical support to people who may be unlikely to access support elsewhere. This support makes a crucial difference to the wellbeing, ability to cope and likelihood of recovery of the person with the mental health problem or mental illness.

The size of the carer population and the impact that the caring role has on people was reinforced by data contained within the 2009 *Report on the Inquiry into better support for carers, Who Cares…?* undertaken by the House of Representatives Standing Committee on Family, Community, Housing and Youth.

The revision of the National Standards for Mental Health Services, 2010, has resulted in the development of a specific carer standard. Standard 7 states:

> ***'The Mental Health Service recognizes, respects, values and supports the importance of the role of carers to the wellbeing, treatment, rehabilitation and recovery of people with a mental illness.***
>
> ***In the context of this Standard 'carer' refers to family members or friends of people with a mental illness whose life is affected by the mental illness and includes the partner, parent, friend or child of the consumer.'***

The needs and rights of carers of people with a mental illness have been very comprehensively described. Following such comprehensive description one would expect a plethora of information and activities designed to meet these needs. This does not appear to be the case and while some States and Territories have developed guidelines for consumers, family carers and mental health professionals to work together in collaboration and partnership few changes have occurred at a practical level. Many would argue this relates to lack of processes to identify who carers actually are.

4.2 STATE AND TERRITORY POLICIES AND PRACTICE

States and Territories in their policies support the position that 'Carers are partners in the provision of healthcare to those they care for. Identifying and supporting them is a sound investment in continuity of care.'

Some jurisdictions have developed practical Guidelines on how to work with carers. However, it is difficult for these guidelines to be implemented in the absence of mechanisms to identify carers and to seek permission from consumers for the involvement of their carers in ongoing care.

These documents support involvement of carers at both individual and organisational levels. Over this period there has been an increase in consumer specific activity at local and state levels. However, opportunities for carer participation in activities that impact on them at local and state levels have not continued to develop in the manner initially hoped.

At the individual care level the policies require carer participation in all aspects of care with the consumers consent or at the clinician's discretion in certain circumstances such as involuntary detention. These policies require that services assist carers to manage their caring role and the impacts of mental illness on them and their family.

The policies also recognise carers as key stakeholders in the planning, development, delivery and evaluation of mental health services at a system–wide and local service level. Some distinct policies and programs exist in some states and territories including the one–off training of variable length and content offered to mental health staff to assist them to engage with carers. These programs have positive impacts, but generally appear to lack the capacity to reinforce practice changes though follow–up training, in–service sessions or consultation.

Feedback from carers indicates that both public and private mental health systems have been slow to implement these policies.

Engagement of carers to enable the implementation of legislation, policies and programs continues to be dependent on:

- **Identification of the carer by the consumer;**
- **Self identification as a carer; or**
- **Identification by a service provider**

4.3 SUMMARY OF STATE POLICIES AND LEGISLATION

4.3.1 Queensland (QLD)

In 2003 the Queensland Government released a Carer Recognition Policy. This was a whole of government policy that was followed by a *Carers (Recognition) Act, 2008*. A Consumer, Carer and Family Participation Framework is currently in the final stages of review. This aims to provide public mental health services across Queensland with clear guidelines regarding consumer and carer participation. An audit tool is included to ensure carers are identified and engaged by the mental health service.

The *Mental Health Act 2000* mandates that each consumer provided for under the Act, is to be linked with an Allied Person to ensure that their wishes are made known to the mental Health Review Tribunal. However, it is not a requirement for the Allied Person to be the consumer's carer, nor is it considered always desirable.

The Mental Health Directorate's Statutory Administration Policy Unit (SAPU), which leads mental health legislative policy analysis and development, is currently piloting the Audit Tool 7 – Carer Survey. SAPU has also agreed to investigate alignment between The Carer (Recognition) Act 2008 and the Mental health Act 2000. Additional work is also underway to ensure alignment with the Consumer, Carer and Family Participation Framework.

Queensland has identified that there are barriers that exist in identifying carers, especially in rural and remote areas. Carer workers from across the State were recently asked to detail strategies they have employed to identify and engage with carers. Their responses were collated and widely circulated to promote and improve consistency across the State. These strategies have been reported as Good Practice Examples at the end of this section.

In 2008 Queensland Health introduced a Carers Matter component to their web site. This was reviewed in 2009 and contains a range of information regarding mental illness, access to services, issues carers may face etc. It has been supported by the development of a range of brochures. This development is ongoing.

There is also a commitment to increasing carer involvement in mental health services as reflected in the following practice guidelines.

- Carer involvement should be negotiated at the earliest possible stage between the consumer, the carer and the mental health service.
- Carers should be engaged in a partnership with the consumer and the mental health service to support and assist the consumer in their recovery from mental illness.
- Carers should have access to a mental health professional who has been designated as a contact person.

- Carers should be provided with information, support and options that will enhance and maintain their own well–being.

The web site contains a number of practical tips for carers, however neither the web site nor the pamphlets address the issue of identification.

However, some very interesting work has been undertaken in Townsville, Northern Queensland where practice standards have been developed for family/carer participation in mental health care. The standards are based on a recognition that mental health outcomes are improved when there is full sharing of information in partnership between consumers, families/carers and clinicians.

Flow charts have been developed to assist clinicians in decision making regarding sharing of information in situations where consumers do, or do not give consent.

4.3.2 New South Wales (NSW)

Mental Health Services in NSW are currently delivered within the context of the five year plan launched by NSW Health in 2006 and summarised in the document: *NSW: A new direction for Mental Health – a five year plan to improve care for people with mental illness*.

Individual Area Mental Health Services generally have specific local policy documents associated with carer participation although it is not known if these specifically address the issue of identification.

In addition, NSW has a whole of government approach to identifying, recognising the needs of, and supporting carers. This is documented in the *NSW Carers Action Plan 2007–2012*. As part of the funding allocation to Carer Support Services, Area Health Services are required to develop a local Carer Action Plan that outlines the carer support strategies it will implement to address the five priorities for action outlined in the Plan.

As part of this approach NSW Health funds four Non Government Organisations (NGOs) to provide Mental Health Family and Carer Support Services across NSW. There is one NGO service provider in each Area Health Service. It is the role of these NGOs to provide:

- Education and training packages which teach families and carers about mental illness and its management and help to build coping skills and resilience;
- Individual support and advocacy services for families and carers of people with a mental illness; and
- Infrastructure support for peer support groups.

A key role for the NGOs delivering support services under this program is to provide support and information to families and carers during the early stages of diagnosis and treatment.

The *Mental Health Act 2007* (NSW) also recognised the notion that families and carers of someone with a mental illness need greater access to information about the consumer. This legislation recognises how important it is that carers, including family members, are given access to information that would assist them in providing care. However, the legislation also acknowledges the need for consumers to maintain control regarding who is to be provided with information about them.

The 2007 Act balances these views by:

- Enabling consumers to nominate a particular person to be their 'primary carer' so this person can receive information and be involved in treatment planning;
- Establishing a process for identifying who will be the primary carer when the consumer is not able to or does not nominate a particular person; and
- Enabling consumers to exclude a person or persons who they do not wish to receive information about them or their treatment.

4.3.3 Australian Capital Territory (ACT)

ACT Mental Health Services are currently directed in their service delivery by *Mental Health – Building A Strong Foundation: A Framework for Promoting Mental Health and Wellbeing in the ACT, 2009–2014.*

The purpose of this framework is to guide investment in the development and implementation of activities to promote mental heath and wellbeing in the ACT over the next five years. The framework does not specifically address the issue of carers.

Mental Health ACT undertook a project to develop a model for engaging consumers and carers across all levels of Mental Health, ACT.

The Framework that has been developed sets out principles for participation and the structures required for continuous improvements to the quality of relationships between consumers, carers and staff of Mental Health ACT, and the quality of services. The Framework also acknowledges the need for systemic change that will support genuine consumer participation and carer participation, with a focus on organisational development, workforce development and re–sourcing that will build capacity within Mental Health ACT and the community.

The Framework details strategies for consumer participation and carer participation in policy development, service planning, implementation and evaluation, individual advocacy and systems advocacy, staff development and research. It does not address the issue of carer identification.

The Mental Health (Treatment & Care) Act 1994 is also being reviewed to ensure the Act reflects best practice in mental health law as it has developed over the last 10 years.

4.3.4 Northern Territory (NT)

The Mental Health and Related Services Act (2006) has provided significant impetus for changes in attitude and clinical practice regarding the identification and engagement of carers in the delivery of services in the Northern Territory.

Under the Act, in most situations, the same information is provided to a person's primary carer as is provided to the person receiving treatment. Generally carers can expect to be provided with this information unless the consumer says they do not want this to happen and their doctor believes that it is not in their best interests to do so. In situations where the consumer actively refuses consent the doctor responsible for his/her care will decide if providing the information is in the person's best interests. If it is, the information can be given to carers. However, if it is not, the doctor can withhold the information. If this happens, the doctor is required to inform carers of their options, which may include applying to the Mental Health Review Tribunal for a review of the decision.

Carers have wide ranging options to information including that they are:

- Notified of an involuntary order;
- Given information about how make an application to or give evidence to the Tribunal;
- Given information about rights under the Act;
- Notified of a Tribunal decision following a review;
- Given information regarding the availability of legal and support services;
- Provided with information about medication under **s88**;
- Included in discussions regarding treatment options;
- Provided with information about discharge planning under **s89**;
- Given information on how to make a complaint; and
- Given information on how to contact the Community Visitor.

Carers may also seek information from NTMHS about their relative/friend and where this information is provided, they can expect that the information will be in a form that they can understand.

In 2009 a *Carers Guide to The Mental Health and Related Services Act (2006)* was released. This is a very comprehensive document that currently sets the benchmark within Australia. This guide has drawn on existing documents including some excellent stories that were included in a publication produced by *Lifeline* for carers of people with a mental illness. More information regarding this document can be found in the section on Good Examples. The NT Guide for carers has contributed to the development of the welcome pack for carers developed as part of this project.

The term ‘carer’ is defined in a very inclusive manner reflecting the Northern Territory population profile.

It would appear from discussions undertaken during consultation that there has been significant change in clinical practice towards a more carer inclusive partnership approach to service delivery since the introduction of *The Mental Health and Related Services Act (2006)*.

4.3.5 Western Australia (WA)

WA was the first State in Australia to pass the Carers Recognition Act in 2004. This legislation recognises the significant role that carers play in the community and provides a mechanism for their involvement in services that impact on them. All public health services are obliged to comply with the Act.

The following information guides, specifically for use in the mental health area, were published in 2007 as part of the implementation of the Act:

- *Carers guide to information sharing with mental health clinicians;* and
- *Communicating with Carers and Families.*

These Guides have contributed to the development of similar information in some other states.

In 2009 the WA Government announced the establishment of a Mental Health Commission (MHC) as a separate department from March 2010. In order for the MHC to lead reforms of the mental health system throughout the State, minor amendments will be required to the draft *State Mental Health Strategic Plan and Policy, 2010–2020.*

The MHC will undertake work on the draft Plan to agree on priority actions for mental health reform. It is proposed that the draft Plan document previously developed by Pricewaterhouse Coopers is considered a ‘green paper’/consultation document and placed on an internet website for public comment.

In 2004 Service Standards for Non–Government Providers of Community Mental Health Services was released. Standard 5 relates to ‘Participation of Carers and Significant Others’. In order to achieve this Standard services are required to have in place a range of policies and practices including 5.1 which states:

> *Processes to Identify and Inform Carers*
>
> *The service has a process in place to identify carers/significant others when the consumer enters the service, and to make information about carers’ rights and responsibilities available to them.*

The degree to which this standard is audited is not known.

Carers are also recognised by the Carers Recognition Act 2004 and Carers Charter. There are government agencies and non–government advocates that can assist with complaints of discrimination or inequity.

Carers WA is funded to support the representation of carers' perspectives on mental health issues. This is primarily achieved through carers' participation in governmental committees or advisory groups for the planning, development and delivery of mental health services.

4.3.6 Victoria (VIC)

Specific Victorian State Government policy or protocols regarding the identification of carers has yet to be developed however the issues are discussed in: *Review of the Mental Health Carer Support Program and carer support and resource workers (mental Health), Final Report – 2008* and *Caring together – An action plan for carer involvement in Victorian public mental health services – 2006.*

The *Mental Health Reform Strategy 2009–2019, Implementation Plan 2009–2011* provides a succinct statement of actions to be undertaken by government and key partners over the next two years. The plan forms the basis for an annual reform activity report and a three–year progress report covering 2009–2012.

A whole–of–government mental health outcomes framework (with agreed measures) is being developed and is expected to be available in early 2010. The purpose of the framework is to provide a shared basis for planning and monitoring progress across government and the various levels of the service system that impact on, or are directly targeted to, people affected by mental illness. This includes people with or at risk of mental health problems, their families and the broader community.

The Victorian *Mental Health Act 1986* has recently been reviewed and in July 2009 the Government made a commitment to repeal the current Act and to introduce a modern Act that improves safeguards, protects human rights, promotes supported decision making and greater carer involvement. The Government is currently finalising its policy for new mental health legislation. It is anticipated that the Mental Health Bill will be considered by Parliament in 2010 with full implementation expected to occur from 2012. The likely changes in the treatment of involuntary clients will reflect the strategy's emphasis on supporting consumer participation in decision making and the more meaningful involvement of carers and families in treatment and recovery planning.

The recently developed *Caring Together: a Carer Participation Action Plan* reaffirms the importance of effective and responsive partnerships between consumers, carers and professionals. A key strategy to improve carer participation described in the Action Plan is the identification of best practice examples in clinical mental health services and the psychiatric disability rehabilitation and support services.

In addition specific information for carers is distributed via area mental health services in the booklet*: Information for families and carers of people with a mental illness – 2004*. This may be supplemented by additional local carer support information compiled by individual area mental health services.

Victoria has established approximately 30 part–time Carer Consultant positions. It was reported to us however that this program requires further development by way of increased training and support to minimise turnover and to ensure consistency in approach across services.

Examples of 'good practice' were found in Victoria in the form of *Psychiatric Medication Information, A Guide for Patients and Carers* at St Vincent's Mental Health Service.

4.3.7 Tasmania (TAS)

Tasmania's *Mental Health Consumer and Carer Participation Framework* was developed in 2006. This provides the overarching policy framework for engagement with carers. The Department of Health and Human Services' (DHHS) *Consumer and Community Engagement Strategy and Policy*, which is still in draft, identifies who carers are and in what circumstances they should be included. Once endorsed, the DHHS Engagement Policy will inform the development of specific mental health policies.

At a service delivery level, Mental Health Services does not currently have policies and procedures that identify a person's carer and the information to be shared with this carer, as part of the admission process. It is envisaged that such matters will be considered as part of the implementation of the recommendations of the Consumer and Carer Participation Review.

The *Tasmanian Mental Health Act 1996* provides 'persons responsible' with a number of roles including the ability to apply for a person's involuntary admission to hospital. A person responsible may also give consent to medical treatment on behalf of a person with a disability who is incapable of giving his or her own consent to the treatment, by virtue of the *Tasmanian Guardianship and Administration Act 1995.*

Tasmania is in the process of drafting a new Mental Health Act. It is anticipated that the new legislation will refer to 'support persons', rather than 'carers' to ensure broader inclusion of all relevant support people. It is also envisaged that the new legislation will clarify the role of support persons by, for example, requiring them to be provided with a range of information at key points along the person's treatment pathway.

Separate information packs are not currently provided to carers at the time of admission to services.

4.3.8 South Australia (SA)

The *SA Health Consumer and Community Participation Policy Directive, 2009* defines carers, and clearly indicates that "for the purpose of this policy, "carers" are included in the category of consumers." There is not such a distinction made for particular identification and participation of carers within treatment and care processes. This policy emphasises Consumers (including Carers) and community.

South Australian Mental Health Services emphasise and recognise more specifically the distinct role of carer in *the Southern Mental Health Consumer and Carer Participation Framework May 2009*. There is also an acknowledgement within the Framework that:

> *Recognises that working in partnership with our consumers and carers requires a cultural change, and that different strategies are required to support the partnership.*

There is also a clear expectation that services will adhere to, and report on, the principles of the *"SA Carers Recognition Act 2005 and Carers Charter"*, by "involving carers in the planning, delivery and evaluation of policies, programs and services".

In Mental Health some good carers packages of information have been formulated for provision to carers. Currently distribution is reliant on self identification as a carer.

The State also supports the inclusion of the specific Carer Standard (7) in the revised National Standards for Mental Health Services.

The report *Stepping Up: A Social Inclusion Action Plan for Mental Health Reform 2007–2012*, by the South Australian Social Inclusion Board made the following recommendation relating to carer participation.

> *The carers and families of consumers must be seen as partners in the care process. They should be included in care planning processes and, with the agreement of the consumer, receive timely and appropriate information and support.*

The issue of how carers are identified in order to be given this information or to be engaged as partners has not been addressed.

A number of part–time Carer Consultant positions have been established in South Australia. Over the last year the role and function of these positions has been reviewed and increased support structures put in place. This has lead to greater stability for people appointed to these positions.

4.4 PRIVATE HOSPITAL SECTOR

Letters were sent to Chief Executive Officers (CEO's) of all private psychiatric hospitals seeking information regarding current policies and practice regarding identification of carers. Responses were received from a small number of hospitals.

Admissions to the private hospital sector are primarily voluntary. As a result, State and Territory Mental Health Legislation has little impact in this sector. There has also been a reluctance within this sector to undertake accreditation processes against the National Standards for Mental Health Services. Private hospitals are also not under an obligation to meet State policies regarding carer participation.

However it is pleasing to note, as recommended in the *Identifying the Carer Report 2007*, that a number of private hospitals have included as part of their formal admission process, a form based on the one developed by the Ramsay Health Care New Farm Clinic. This form is colour coded and audited on a regular basis. It invites consumers to identify people they would like to have involved in their care, and to nominate the level of involvement they endorse. Some hospitals then seek separate consumer permission to contact family members/carers to invite them to participate in Support and Education Programs.

One hospital also informed us that as part of their admission procedure consumers are asked about their living arrangements, the existence of carers, as well as the health and willingness of the carer to assist the consumer post discharge. These questions are documented in the admission assessment format.

In some hospitals, carers have access to resources located in patient’s lounges and brochure stands with some information provided in a number of languages other than English. These brochures have primarily been developed on an individual basis by hospitals and rely heavily on information supplied by the Commonwealth Respite and Carelink Centre. A specific Carers Lounge is offered in one private hospital. This area allows carers a space for some time out and offers privacy for attending to any phone calls that need to be made.

Identification of carers in the private hospital sector appears to hinge almost exclusively on consumer consent. Little assistance is provided to encourage carers to self identify.

Consumer/carer participation has been slow to develop in the private hospital sector. The recommendations and materials produced during the course of this project may provide examples to encourage and increase the identification and engagement of carers And reinforce the role that carers have in consumer recovery in both the public and private sectors.

4.5. SUMMARY OF STATE AND TERRITORY LEGISLATION

JURISDICTION	MENTAL HEALTH ACT REVIEW	NAME	CARER RECOGNITION ACT
QLD	Completed 2000. Minor amendment 2007 related to forensic patients and victims of crime	Mental Health Act 2000	Carer (Recognition) Act 2008 Carer Action Plan 2006–2010
NSW	Review completed.	Mental Health Act 2007	Whole of Government Carer Action Plan, 2007–2012
ACT	Currently being reviewed	Mental Health (Treatment and Care) Act 1994	No Act, principles included in *Mental Health – Building A Strong Foundation: A Framework For Promoting Mental Health And Wellbeing In The ACT, 2009–2014.*
VIC	Act reviewed 2009, new legislation being developed	Mental Health Act 1986	*Caring together – An action plan for carer involvement in Victorian public mental health services – 2006.*
SA	New Act is due to be proclaimed on 1 July 2010 and will replace the Mental Health Act 1993 from midnight on 30 June 2010	Mental Health Act 2009	Carers Recognition Act 2005 Whole of Government Carer Policy Implementation Plan 2006
WA	Review ongoing	Mental Health Act 1996	Carer Recognition Act 2004
TAS	Amended 2005	Mental Health Act 1996	Mental health Consumer and Carer participation Framework 2006
NT	Review completed	Mental Health and Related Services Act as in force 1 February 2010.	Carer Recognition Act 2006 *Carers Guide 2009, to The Mental Health and Related Services Act (2006)*

As indicated in the Network's Identifying the Carer Project 2007 Report, the purpose of the various Mental Health Acts is primarily to protect the rights, articulate treatment, assessment and care provisions of the consumer. The purpose of these Acts is not primarily to identify or address the needs and rights of carers, even though they are integral to the care and safety of the consumer. Recent reviews of the Acts have increasingly identified the importance of the role of carers and their access to information, which allows them to provide care, but do not address the issue of identification.

Some Mental Health Acts specifically define carers, however, provisions that allow for information to be shared with other people, or for treatment to be initiated, are drafted in ways that do not adequately define a process for identifying or defining a "carer." For example, these include the concept of an "allied person" (*Queensland Mental Health Act 2000*), or "a person assuming the responsibility" for the care of the patient (*Western Australia Mental Health Act 1996*). These provisions focus on notification of information, usually after an event such as an involuntary admission and do not say how carers will be identified in order to fulfil this provision of the legislation.

The Northern Territory's *Mental Health and Related Services Act 2006,* is somewhat different in that it addresses the issue of carers' rights in relation to information, admission, treatment and discharge of the patient. This legislation, is first in Australia to balance the rights of both carer and consumer.

The *NSW Mental Health Act (2007)* makes provisions for a primary carer to receive information. The primary carer is defined primarily according to their relationship with the consumer with the emphasis on family, however, the concept of that relationship being 'close and continuing' was introduced which was an important innovation

The Queensland Mental Health Act 2000 does not specifically identify carers although involuntary patients are entitled to nominate an 'allied person'.

All legislation defines carers but none address the issue of identification.

4.6 IMPACT OF LEGISLATION ON CARERS

4.6.1 Carer Recognition Legislation

There is now a move towards a whole of government approach to recognise, support and meet the needs of carers. The table above illustrates the fact that some states and territories have enacted Carer Recognition Acts and carer recognition policies are in place or about to be introduced in others. This ensures a whole of government approach to ensuring that policy, program and service development meets the needs of carers. However, while these Carer Recognition Acts provide legislative recognition for carers they do not address the issue of identification, particularly in the mental health area where there is a balance that has to be achieved between the right to privacy for the consumer, and the carers' need for information in order to achieve better outcomes for the consumer.

The National Carer Recognition Bill 2010 was tabled in Parliament in March 2010. The Bill establishes a definition of *carer* and sets down ten principles, including the fundamental principle that all carers should have the same rights, choices and opportunities as other Australians.

The Bill also means that all public service agencies will need to make sure staff have an awareness and understanding of the principles. Any public service agencies with responsibility for policies, programs and services that affect carers and the people they care for will need to ensure their staff take actions to reflect the principles, report on how they meet the principles, and consult with carers and representative bodies on issues.

While this is a crucial piece of legislation, it does not address the issue of identification.

4.6.2 Privacy Legislation

The Carers Australia Senate Inquiry submission [2007] states:

> *An unexpected outcome of the complex interaction of the Privacy Act 1988, the Freedom of Information Act 1988 and Mental Health Acts is that carers denied information about a consumer are still "expected" to care for and support the consumer upon discharge.*

They go on to say:

> *…systemic misunderstanding of the rights, obligations and responsibilities of carers, consumers and service providers exists within all relevant services. This lack of understanding leads to inconsistencies in application and frustrating interactions between carers and mental health service providers.*
>
> *There is an urgent need for programs to ensure that carers' rights, obligations and responsibilities are understood and that mental health service providers comply.*

Attempts have been made in the public sector in Victoria in the Chief Psychiatrists Guidelines regarding confidentiality and in the private sector by way of the *Privacy Kit for Mental Health Service Providers* to clarify issues regarding confidentiality for clinicians. This issue has also been addressed by other states and territories by the development of policies and guidelines however it appears that this has resulted in little change in practice at service delivery level. Current practice indicates that the legislation continues to be used as the reason for not sharing information with carers.

The Australian Law Reform Commission undertook a review of privacy law in 2008 and recognized that disclosure of information to 'a person responsible for an individual' can occur within privacy law. The need for legislative reform in this area was also recognized by the 2009 House of Representatives Inquiry into Better Support for Carers. Recommendation 14 of that report called for investigation of whether privacy and mental health *legislation 'adequately allows carers to be involved in the treatment of the individuals for whom they care'.*

Identification is a pre–cursor to sharing information and providing support.

Some states and territories already support carers and provide information to assist them understand their rights to access information within the existing legislative framework. **However, these processes pre–suppose identification.**

4.7 CONCLUSION

Government legislation, policy and standards clearly mandate that services are expected to engage with carers. There is increasing pressure on services to demonstrate they are able to meet these requirements. Clear identification of carers is central to this process if services are to fulfil requirements

5. SUMMARY OF CONSULTATION

5.1 PROCESS

Issues regarding areas to be covered by policy and protocols associated with the area of identification of carers of people with a mental illness together with suitable content for nationally consistent information requirements were discussed in focus groups and during telephone consultations with a wide range of stakeholders and key individuals [see 2. Methodology]. The following information emerged during this process.

5.2 CHANGES IN CARER EXPERIENCE SINCE 2007

The majority of participants from the public sector reported that they were generally unaware of any existing policies regarding identification of carers and that current practice continues to vary significantly from one location to another. Some exceptions to this were identified and followed up during the project. A description of these services can be found in the State and Territory Practice Section 4.

A number of carers and staff from private hospitals reported they have implemented one of the recommendations from the 2007 *Identifying The Carer* report related to the inclusion of a colour coded form as part of formal admission procedures that asks consumers, at an appropriate time to identify their carers/people they would like involved in their care and specifies the level of that involvement. We were unable to find any examples of public services implementing this process however service providers from the public sector who participated in consultations supported this process.

Many participants were unaware of the 2007 report and its availability on the DoHA web site. All felt that this information is only used by people specifically researching particular topics and that other mechanisms are necessary if the content of such reports is to be brought to the attention of service delivery staff in both public and private settings. The production of hard copies together with an implementation plan was suggested to accompany the placement of the report on the web site.

In general, participants acknowledged that there is evidence at the policy and legislative level of increased acknowledgement of carers rights for participation however, with a few exceptions, these policies are not being implemented.

In fact, the overwhelming experience of participants was that they felt health services continue to make little or no effort to identify or involve carers. Some stated they felt that the majority of clinicians did not seem to know how to go about this process. Organisational structures and culture were also reported to be counter productive to the processes of identification and engagement.

In addition, in situations where consumers voluntarily identified their carers or carers self identified there continues to be significant reluctance by many clinicians to include them in care processes. '*Consumer confidentiality* or *privacy legislation*' continues to be cited as reasons for non–engagement. It was the experience of participants that individual clinician attitudes and practices prevail in contravention of existing service policies.

Changes to Mental Health Legislation in the Northern Territory (2006) and NSW (2007) do appear to have had some impact on clinician practice.

Some changes were also reported in locations where Carer Consultants/Family Liaison Workers have been appointed. Unfortunately, it was reported to us that these appointments have been hampered by the following.

- Part–time nature of the appointments.
- Lack of training and support for the individuals appointed to these positions.
- Attitudes within units they have been appointed to; for example:
    - *You are not a clinician – how can we trust you with confidential information?*
    - *Thank goodness you are here – we wont have to deal with those difficult relatives anymore.*
- Exclusion from team meetings.
- Organisational structures that prohibit the person actually doing their job.
- Burnout leading to high turnover in people in these positions.

Use of the term ‘carer’ is not well understood by either consumers or the people who care for them. Alternative terms were discussed however all acknowledged the need to continue using the term ‘carer’ because of its common usage within government. The similarities that mental health carers share with ‘general carers’ is not well understood by people early in their experience of being the carer of a person with a mental illness. At the same time, the differences that apply to people who care for a person with a mental illness (e.g. the episodic nature of the tasks) continues to be poorly understood by government departments responsible for developing funding criteria to facilitate access to the supports required.

Participants also continued to express the view that asking consumers to identify their carers was frequently counter productive as, if they were to do this, it would be an admission that they were unable to care for themselves. Consumers’ identifying their children as their carers was also considered to be problematic as some believed that by revealing this it may lead to the involvement of child protection agencies.

Organisational systems are not conducive to ongoing education and whilst attitudes of staff to consumer participation are very slowly changing this change has been at the expense of carer engagement. Existing staffing practice and systems do not facilitate young clinicians practicing in the manner in which they have been trained.

Substance abuse is increasingly pervasive and it was felt that this may further complicate family relationships and impact on the level to which people wish to be identified as caring for a consumer who may have the double stigma of mental illness, and substance abuse. This was particularly noted in situations where the consumer’s behaviour has resulted in contact with the law. It was also mentioned that significant numbers of young children are the ‘hidden carers’ of people, in particular single mothers, who have substance abuse problems. The issue of co–morbidity also impacts on access to services for consumers thus potentially increasing the burden of care for family and carers.

Participants noted that stigma and discrimination towards both consumers and carers is reducing in the general community and within government departments outside health at a greater rate than it is within mental health services.

Some participants mentioned the carer inclusive delivery of some of the FaHCSIA services supporting people with long–term mental illnesses to live in the community.

All participants were of the view that identification and engagement of carers is crucial in any recovery based approach to care. They also agreed that change in clinical practice will only occur if it is mandated by legislation, well grounded in policy and protocols, compliance is audited on a regular basis and incentives are associated with positive changes in practice.

Participants in the consultations also queried why there continues to be such reluctance within the mental health sector to identify carers when research clearly demonstrates that better outcomes are achieved for consumers, carers and mental health clinicians by informing and engaging carers early in the planning and on–going delivery of service.

They felt that this research that recognises that carers play a critical role in the process of recovery and relapse prevention is continuing to be largely ignored by both public and private specialist mental health services.

5.3 SUMMARY OF DISCUSSIONS OF CONSULTATIONS

- Carers have an important role to play in all situations where a person has an illness. However, specific identification of carers is most important in situations where their role is likely to be ongoing over a long period of time such as when they are caring for a person with a long term mental illness.

- The professional judgement of clinicians is recognised however no single clinician or carer can meet all the needs of all consumers. A partnership and recovery approach to care will improve consumer outcomes and decrease the burden on services and carers.

- The ideal process for identification is by the consumer. These discussions together with the degree of involvement should be negotiated, documented and regularly reviewed at times when the consumer is well. The experience of staff currently working in a carer inclusive manner is that if approached in this manner then the majority of consumers recognise and welcome the involvement of their support network.

- Some carers who self identify are not necessarily the best people to be involved in the ongoing care and recovery of consumers either because of their past history with the consumer or their own particular needs. However, these carers continue to have rights and mechanisms need to be developed to ensure their needs are met.

- Some consumers will, from time to time, because of the nature of their illness refuse to identify or to involve carers. All professional interactions with them and written information provided to them needs to reinforce the importance of their support network being actively involved in their care.

- Consumer refusal to identify does not lesson the burden on carers. It may in some cases increase the burden of care.

- Consumer refusal to identify carers and Privacy Legislation is NOT a basis for preventing clinical staff across a range of settings from having a working relationship with the family/carer. Carers still have a right to give information to clinical staff to assist in assessment, treatment and ongoing care.

- Identification is not a one–off process. Service providers at all levels, on the basis of existing policies, Carer Recognition Legislation, Mental Health Legislation and National Standards for Mental Health Services have responsibilities to identify and support carers. Cultural and organisational change, policies, protocols, education and support will be necessary to encourage changes in clinical practice.

- Changes need to occur in all settings however specific opportunities for identification of carers exist in the following circumstances:

5.3.1 Primary care – General Practitioners (GPs)

- Participants identified the need for a poster that facilitates generic identification of all carers, including mental health carers. These could be placed in waiting rooms/locations where people are already congregating. Development of a form such as that developed by the Princess Trust in the UK was supported.

- It was suggested that similar messages could be used for TV and hard print ads with information for a single point of contact such as Carers Australia.

- The UK Greenwich Primary Care Trust protocols for carer identification were supported as important for discussion with the College of GPs to determine if they could be included as part of the Standards for General Practice in Australia. It was acknowledged that this would require incentives to be attached. Modification of the Better Outcomes and Better Access Programs was suggested as one option to further the process of identification.

5.3.2 Referral to specialist MH Care

- The GP referral to specialist mental health care, with the approval of the consumer, could specifically include carer identification including a request for contact.

5.3.3 Assessment/Admission

- Emergency Departments may be the first point of contact with the mental health system. While many Departments have introduced specific responses to concerns regarding the appropriateness of this environment to manage people who are distressed and agitated, participants indicated that little has been done to date to use this as an opportunity to identify carers.

- Participants reported that people referred, or being brought on an involuntary basis to an Emergency Department, are frequently accompanied by family members or friends. This exercise mostly involves long waiting periods and provides an ideal opportunity for identification of carers and initiation of a partnership approach to the care of the person with mental illness.

- It was considered that the same opportunities exist in first and subsequent presentations to private psychiatrists.

- Service providers consulted stated that the paperwork associated with the formal admission of a person with a mental illness to a public or private mental health service also provides an opportunity for identification of carers. The use of colour coded forms, as recommended in 2007, requesting permission from the consumer to identify carers via a structured set of questions was supported. They noted however that it may take some days for the consumer to be well enough to answer the questions.

- Consultation participants felt the completion and review of this form should be an ongoing process that is used as the basis of discussion between all parties. The form should highlight the benefits of involvement of a wider range of people in the care and support of the consumer and seek to clarify the level of involvement that the consumer feels comfortable with each person having. It was acknowledged that these levels may change over time.

5.3.4 Discharge Process

- All participants agreed that decisions and discussions regarding discharge of a consumer from an inpatient service should ideally focus on practical issues regarding availability of ongoing care and support, accommodation, future appointments and linkages to other services. They indicated that this discussion presents a further opportunity to remind service providers to ensure that carers have been identified and to emphasise to consumers the importance of continued support for their recovery.

- Carer participants strongly agreed that in undertaking these discussions staff need to be aware that carers may not view themselves as carers, but as partners, parents, sons, daughters etc.

- It was agreed that it is important that carers feel fully involved at all stages of care, including the decision to discharge the consumer. This is a process of handing over care and carers are critical partners in this process. Ideally, time should be allowed for carers to make choices about:

  - Taking on, or continuing to fulfil, the role of carer; and
  - How much and what type of care they are prepared to provide, taking into consideration family and caring commitments, work, education and social activities.

- Participants felt that some people feel they have no choice but to continue to provide care even when their personal and physical resources have been exhausted, where they are afraid of the consumer, or where the consumer continues to refuse to acknowledge the role they play. This is an untenable situation for carers who self identify, and the National Standards for Mental Health 2010 and Carer Recognition Legislation now require services to listen to concerns and refer for support to meet the needs identified.

5.3.5 Continuing Community Contact

- Participants felt that this was the most important time for service providers to discuss with consumers the importance of ongoing support and to work with them to identify who provides support to them and to seek permission for these people to be actively involved in future care. This should be recorded in the notes and updated on a regular basis. The following processes were also noted as possible times to specifically identify carers.

5.3.6 Relapse Prevention Plans

- It was agreed that more emphasis needs to be placed on the development of Relapse Prevention Plans when the consumer is functioning at the best possible level. Ideally this would involve discussion with case managers and clinicians including private psychiatrists and would involve the identification of carers, including the level of involvement the consumer would like them to have. Participants stated that the majority of people with a long term mental illness know they need to have varying levels of support at different stages of their illness and are mostly happy to acknowledge this when they are well. Relapse Prevention Plans could ensure that both consumers and carers could have more say in what happens during acute episodes of illness.

5.3.7 Advance Directives for Treatment/Ulysses Agreements

- It was acknowledged that some states also have legislation in place that allows the development of Advance Directives. Historically these have been used primarily for specific instructions regarding treatment for physical illnesses and ageing, however, participants felt they could also be used by people with ongoing mental illnesses to identify who their carers are and the role the consumer wants them to play in any crisis situations and in their ongoing care.

- Ulysses Agreements were proposed by participants representing children as carers of people with a mental illness as a clear mechanism for identifying carers. A draft for such a document has been included in the appendix. Ensuring such agreements are maintained within all casenotes and kept up to date is particularly important when the caring role has been taken on by children.

- It was acknowledged by participants that not all States have this legislation available and even where it does exist it can be superseded by Mental Health Legislation. However, it was hoped that as Relapse Prevention Plans and Advance Directives support consumer driven care they are likely to receive more focus over time.

5.4 SUMMARY OF DISCUSSION REGARDING IDENTIFICATION

- Participants unanimously supported the need for policies and protocols to identify carers and stressed that no single process could achieve this. The following settings were identified as opportunities and “trigger points” for identification to occur.
    - Primary care – specifically GPs
    - Emergency Departments
    - Formal Admission to a service
    - Formal discharge from a service
    - Community care.
- For many consumers and their carers this is a rotational sequence that continues sometimes like a whirling dervish. Participants felt that adoption of a partnership approach to care between all parties would impact on the speed of rotation.

5.5 CONSUMER CONSENT

Participants also acknowledged that the process will be different in each setting depending on whether the consumer has given informed consent or not for identification and engagement. The following situations were described in the 2007 report. Participants in the 2010 consultations continued to agree with the groupings described. They also recognised the additional obligations that are potentially placed on clinicians charged with the responsibility for identifying and engaging with carers. It was also agreed that the processes developed by the Townsville Mental Health Service (see Policies and protocols – section 6) provided a useful tool to guide clinicians through this process. The 2007 descriptions have been updated on the basis of information collected in 2010 and re–presented for completeness. They have been incorporated into the policies and protocols.

5.5.1 The consumer voluntarily identifies carers

This continued to be seen as the ideal although it was felt that this could only be achieved under the following conditions:

- Development of standardised lists of question prompts to identify who provides support in an ongoing way to the consumer;
- A willingness to ask the questions and record the information when the consumer is well. Many consumers will need to develop a trusting relationship with service

delivery staff if they are to reveal sensitive information, particularly if their carer is a child or young person;

- A willingness to update the information regularly;
- A recognition by clinicians of the value of seeking to obtain this information;
- Staff possess the appropriate knowledge and skills to work with carers. This is particularly difficult when providing care to people whose carers may come from culturally and linguistically diverse backgrounds;
- Mandatory requirements such as legislation and standards that would require this (now in place); and
- Regular monitoring by way of accreditation surveys to examine compliance with the process of identification.

5.5.2 The consumer refuses to identify carers with whom information can be shared.

Identification of carers in order to obtain information from them to assist with assessment and diagnosis and to refer them for support, continues to be seen as separate from identification in order to share personal information.

Participants continue to feel that it is a staff responsibility to identify people involved in supporting the consumer via a sensitive set of questions and then to initiate contact to obtain information that could assist with development of plans that would lead to a positive outcome for the consumer. It was also felt that this was a role that could be facilitated by Carer Consultants.

Staff should also clarify with the carers what information they would like shared with the consumer. Carers also have a right to respect for their privacy and confidentiality.

It was acknowledged that consumers have the right to refuse to identify carers, however, all participants felt that obtaining this information is part of a process, not a one off event. It is necessary to regularly review these views with consumers. It was also considered important to inform carers that consent for involvement would be reviewed on a regular basis and the consumer may change their view as the treatment progresses.

It was interesting to note that it was the experience of service providers who participated in this project, as in the previous one, that consumers rarely refused to identify people who supported them. Identification depended rather on when and how the questions were asked and the reasons provided for asking.

Consultation participants were also clear that even if consumers continue to refuse to identify ‘carers’ it does not prevent mental health staff from working with families who self identify via their presentation or continued relationship with the consumer. The family/carers are still entitled to information of a general nature, support and referral to carers support organisations. Many examples were provided of the support obtained by carers from being referred to NGOs.

Some mental health legislation requires that carers be notified regarding specific events or clinicians are required to show just cause as to why they have not done so. This is difficult to do until they have been identified. Even where this exists, , participants felt that only minimal changes had occurred in practice. These changes were primarily seen as a result of greater carer empowerment.

In addition, it was felt that at any stage of the treatment process carers who self identify should be entitled to provide information to staff to assist with diagnosis and treatment.

5.5.3 The consumer is unable to identify carers because of their mental state

Participants felt that many such situations could be avoided if Advanced Directives, Relapse Prevention Plans or Ulysses Agreements identifying carers and the desired roles they are to play had been negotiated and documented at an appropriate earlier stage of the consumer’s illness. Where this had not occurred participants suggested staff should make a decision in the best interests of the consumer. In such situations it is essential to obtain information to assist with diagnosis and the development of a treatment plan.

It was noted that in some cases if the consumer has no history with the service and they were transported to the hospital by the police it may be difficult to actually identify who the carers are unless they accompany the person. Information may be obtained from the GP if one can be identified. This issue is of particular concern in situations where the carer is a young person and there are no mechanisms in place to identify and inform them what has happened to their parent.

Participants felt that in situations where the consumer’s mental state is not stable staff should err on the side of caution regarding sharing of information until the consumer becomes well enough to hold an informed discussion regarding this matter. However, the same conditions should apply as in 5.5.2 above regarding provision of support to carers.

5.5.4 The consumer is a child and their ability to consent is in question

Mechanisms have been in place for some time within child and adolescent services to address this issue. These situations are governed by a range of legislation. Issues arise, however, when the age of consent varies or when the child lives independently despite being considered a ‘minor’. This issue is currently being addressed in some jurisdictions where legislation is being considered to introduce the concept of a mature minor i.e. a person aged 14 to 17 years who is deemed to be able to accept responsibility for their own welfare and presumably "identify" their carer who may not be their legal guardian. In this situation, a child is then defined as a person under the age of 14.

Participants suggest that the same principles contained in the report relating to adults identifying carers should be applied except where legislation specifically provides otherwise.

5.6 SUMMARY OF DISCUSSIONS REGARDING NATIONALLY CONSISTENT INFORMATION FOR CARERS ON ADMISSION TO A SERVICE

Consultation participants suggested that the amount of information required depends on where carers are in their journey. The onset of mental illness in a family or friend can be a frightening event and even more so if it becomes necessary to involve police in transportation to hospital. Carers reported they were unable to take in a lot of new information at this time and what they were primarily looking for was reassurance that help was now available. Some reported a sense of relief that something had finally happened. Most wanted to be recognised and included in any decisions that were to be made. They wanted to be given some understanding about what would happen from now on and most of all they wanted a specific person to be nominated to maintain contact with them. All agreed they could only absorb information as they were ready for it. However a brochure containing more comprehensive information would be useful to refer back to. Carers reported finding themselves in a state of confusion and fear when recalling their first contact with a mental health service.

Participants suggested services should provide the following information to carers at the admission stage.

- Welcome message, we are here to help, outline of the processes to be followed, preferably including options for a follow up call from a designated person within the service to answer immediate concerns.
- Confidentiality – explanation of legislative requirements and re–assurance regarding options if the consumer is currently refusing in depth involvement
- Prompt questions they may use in seeking information from staff.
- Contact numbers for the hospital, ward
- Legislative status of the consumer – what this means
- Carers rights
- Complaints process
- Some general information about what the symptoms of mental illness might be
- Information as to where they might go to obtain additional information and assistance.

It was agreed that the information provided at this stage should be specific, and practically based.

Some participants also supported the provision of additional information that could be referred to as carers were able to absorb the information. Discussion ranged from including this all in one brochure to development of a total package comprising several brochures. It was also acknowledged that a lot of information already exists from Carers Australia however people generally need time to recognize themselves as a ‘carer’ so it may not be the first avenue accessed when looking for information.

It was also acknowledged that some excellent diagnosis specific information has been prepared by the RANZCP. It may, however, take a number of admissions before a specific diagnosis is agreed and everyone is willing to accept and come to terms with what this actually means. It was reported to us that in the first instance family and friends are more concerned about:

- Symptoms;
- Behaviour;
- How they (carers) should behave when their family member returns home;
- What can they expect from the person with the mental illness?
- Will they ever be like they were before? and
- What is the medication and does it have any side effects.

The terms of reference for this project required the development of nationally consistent information to be provided at admission. Following consultation it became apparent that the information needed to:

- Provide an introduction to the mental health service, explaining the processes that would be followed;
- Provide some general information about what the symptoms of mental illness might be;
- Outline in question and answer form some of the concerns they may have;
- Provide examples using the stories of family members and friends to assist them to feel less alone;
- Introduce the new language, eg ‘consumer’, ‘carer’.
- Introduce the concept of carers rights and complaints processes;
- Introduce the issues associated with the consumers rights to confidentiality and what this might mean for the sharing of information; and
- Provide information on where to go for additional information and support.

The information has been developed on the basis of these suggestions.

Participants also re–iterated the importance of having a nominated person/Carer Consultant/Family Support Worker on staff, with whom they could personally interact, discuss and clarify information needs as required and generally use as a point of contact for future needs.

5.7 MECHANISMS SUGGESTED TO ENCOURAGE IDENTIFICATION

Participants continued to support the recommendations of the Network's previous *Identifying the Carer Report, 2007*. They sought information regarding the status of implementation of these recommendations. This information together with participants current suggestions has been summarised as follows:

5.7.1 Update of the Network's Identifying the Carer Report 2007 Recommendations

Recommendation:	**Carers Recognition legislation be developed by all States and Territories.**
Current status:	Legislation currently exists in WA, SA, NT, Qld but not in Victoria, NSW, Tasmania or ACT. However all States and Territories have carer participation policies. Implementation processes developed for this legislation are currently not paying particular attention to mental health carers. National Carer Recognition Legislation has also been drafted.
Recommendation:	**Amend State and Territory Mental Health Legislation to mandate identification and support of carers/primary support persons.**
Current status:	Mental Health legislation is progressively changing around the country to provide more consistency however this is a long and arduous process and of the eight separate Acts, *the NT Act 2006* currently mandates more engagement than any other mental Health legislation in Australia.
Recommendation:	**Revise the *National Standards for Mental Health Services* to include a carer specific standard.**
Current status:	Carer specific standard now included**.** An implementation process for Standard 7 has yet to be developed. Mechanisms for specific measurement will also need to be built into accreditation survey processes such as ACHS EQuIP. This requires additional training for surveyors.
Recommendation:	**Develop nationally consistent packs of information for carers similar to those given to consumers.**
Current status:	This will be a product of the current project. Consultation participants continue to believe that admission protocols should require noting that carers have been identified and information packs provided. The availability of a Carer Consultant to support new carers to 'talk through' this information was seen as highly desirable.

Recommendation: **Develop carer identification and participation policies and protocols for implementation in each service to support changes in clinical practice**

Current status: This will be a product of this current project. Participants in this round of consultations have emphasised that opportunities for staff to receive ‘carer sensitivity’ and skills development training will be essential if any change is to be made in clinical practice regarding identification of carers.

Recommendation: **Appoint Carer Consultants/Liaison Officers to all services**.

Current status: Participants reported that the number of these positions has increased. It was noted that where these appointments have been made they have contributed significantly to:

- Staff support and training;
- Liaison between staff, consumers and carers, e.g. assistance with completion of admission protocols regarding identification of carers; advocacy for individual carers with staff/services;
- An increase in linkages to alternative options for information and support for carers such as referral to Carer Support Organisations;
- Provision of carer specific perspectives to staff meetings;
- Assistance with carer assessments; and
- Providing a specific point of contact for carers following discharge of the consumer.

The desirability of locating Carer Consultants in Emergency Departments, where this is the main point of entry to mental health services, also continued to be highlighted as being important in the process of identification of carers.

However we were informed that there has been high turnover in these positions primarily due to the reasons listed above.

Recommendation: **Introduce at point of entry a specific colour coded form to enable consumers to identify carers together with the level of involvement they wish them to have.**

Current status: This has been introduced by a number of private hospitals but, as yet, not by public hospitals. Participants in the current round of consultations continue to support this suggestion as outlined above under Assessment.

Recommendation: **Recognise and expand the importance of the potential role that GPs could play in the identification and support of carers.**

Current status: Participants continue to see GPs as potentially having a crucial role to play in the identification of carers as they frequently treat the whole family. It was felt that they are also well placed to keep this information up to date and to transfer the information when making referrals. The *Better Access to Psychiatrists, Psychologists and General Practitioners through the Medicare Benefits Scheme* (Better Access) initiative, was seen as potentially playing a positive role in identification of carers.

Participants continue to highlight the need for all referral processes/forms to identify carers. This information should be an integral component of all referrals including:

- GP to psychiatrist;
- Psychiatrist to hospital; and
- Hospital to community service.

Recommendation: **Modify data systems to make collection of 'carer' information mandatory.**

Current status: Participants strongly support this recommendation however also felt that a short list of 'sample' questions would need to be developed to assist this process. Asking about 'carers' will not illicit the information required.

Participants noted that Child and Adolescent Services are required to collect information regarding parents/guardians/etc. Electronic data collection forms are frequently organised in such a way that it is not possible to move on to the next section until this section has been completed. Participants continue to support a similar process being developed for all admissions. It was also considered important that these questions be re–asked at every admission as just copying the information from the last admission would lead to situations where clinicians are left trying to contact relatives or friends who are no longer involved, or who have moved.

It was also felt that asking for Next of Kin does not cover this issue.

This proposal was considered by the MHISS following the publication of the Network's 2007 Identifying the Carer Report. States and Territories had varying reactions to this recommendation. Some felt there were other mechanisms for collecting this information and others had different priorities for amendments to data collections. All noted that additional changes to data systems would entail significant cost implications.

Recommendation: **Encourage people with long term illnesses to develop Relapse Prevention Plans and Advance Directives regarding care preferences and identification and engagement of carers.**

Current status: The development of such Plans has been slow to be implemented in any systemic manner. Their development continues to be supported. An example of such a Directive has been included in the Appendices together with a draft Ulysses Agreement which was also supported by participants.

Recommendation: **Develop legislation to provide for separate Carers Assessments as is currently available in the UK.**

Current status: Participants continue to support this option as they recognise it would require services to identify carers.

6. NATIONALLY CONSISTENT POLICIES AND PROTOCOLS FOR THE IDENTIFICATION OF CARERS OF PEOPLE WITH A MENTAL ILLNESS

‘Carer’, as used in this document, refers to any family member, relative or friend who provides ongoing care and support for a person with a mental illness without payment.

6.1 INTRODUCTION

A number of activities at national, state and territory levels have occurred in recent years that mandate carer engagement in all levels of service delivery. These changes include the following.

- Development in some states of State-based Carers Recognition Legislation.
- Development of national Carer Recognition Legislation.
- Development of a specific Carer Standard in the revised *National Standards for Mental Health Services, 2010*.
- Revision of mental health legislation in some States and Territories to mandate identification in a variety of forms.
- Revision of the *National Mental Health Policy (2009)* and funding of the *Fourth National Mental Health Plan, an agenda for collaborative government action in mental health, 2009–2014*.
- Publication of the RANZCP Guidance Notes, *Involving Families,* 2000.
- Funding by the Australian Government of a wider range of programs for carers.

In addition, the 2007 National Mental Health Survey brought to government attention the significant size of the number of carers caring for people with mental health problems and illness. This was reinforced by data contained within the *2009 Report on the Inquiry into better support for carers, Who Carers…?*, undertaken by the House of Representatives Standing Committee on Family, Community, Housing and Youth.

Research demonstrates that better outcomes are achieved for consumers, carers and mental health clinicians by informing and engaging carers early in the planning and on–going delivery of service. It is increasingly recognised that carers play a critical role in the process of recovery and relapse prevention.

Engagement of carers to enable the implementation of legislation, policies and programs is dependent on:

- Identification of the carer by the consumer;
- Self identification as a carer; or
- Identification by a service provider.

Many different health clinicians may be involved in the care of a consumer with a mental illness. Legal, ethical, and professional codes of conduct protecting the privacy of the consumer, have previously only allowed for relevant information to be shared among other clinicians as required for the treatment and care of an individual. However, recent legislation now makes it a requirement of law that health clinicians share with carers information necessary for their role as a carer. This is a balancing act.

On most occasions, this balance of privacy and sharing information is something that should be decided by consumers. Sometimes though, service providers need to make a decision about this balance without a consumer’s agreement. This especially happens when a person is too unwell to give consent for the sharing of information. It also happens when there are safety and duty of care issues involved.

Confidentiality is NOT a reason for not identifying or engaging with carers. Staff have contact with consumers for very limited periods of time. The people who are doing the caring for the rest of the time have a right to be treated as partners in the care process and adequately equipped to undertake this process.

The following policies and protocols have been developed to provide guidance to services across a variety of settings in relation to identification of carers. The processes are multi–layered and may change according to the service delivery setting. The partnership approach needs to be supported at the most senior levels within every service setting. Protocols need to be embedded in every day clinical practice. Structures within organisations may need to change to accommodate these practices.

The policies and protocols aim to reinforce current training for professional staff and support clinicians and organisations to explore a more flexible approach to implementing evidence based practices that adopt a partnership approach to service delivery. This will result in improved outcomes for consumers as they undertake their recovery journey.

6.2 SUGGESTED NATIONAL POLICIES FOR IDENTIFICATION OF CARERS

It is recommended that the following policies to identify carers be adopted on a national basis in the public and private sectors.

1. **Identification and participation of carers in a partnership approach will be acknowledged and respected as crucial to the facilitation of early intervention, treatment and recovery of people with a mental illness.**

2. **Carer identification and levels of participation in ongoing care will take account of social and cultural differences and will be re–viewed with consumers and carers on a regular basis.**

3. **Carer levels of identification and satisfaction with their engagement will form part of the regular reporting of all mental health services.**

6.3 GOOD PRACTICE PROTOCOLS

Research demonstrates that better outcomes are achieved for consumers, carers and mental health clinicians by informing and engaging carers early in the planning and on–going delivery of service. It is increasingly recognised that carers play a critical role in the process of recovery and relapse prevention.

Identification is not a ‘one off’ process. The relationship between consumers and carers is frequently complex, and likely to change over time. Identification and level of participation will need to be continuously re–negotiated in a positive and inclusive manner at all stages and in all settings during the diagnosis, treatment and recovery of the person with a mental illness.

6.3.1 General points regarding identification of carers

- Staff in all service settings should be trained and encouraged to avoid stereotypes. Carers come from a variety of social, financial, religious, racial and cultural backgrounds. The people they are caring for may be of any age and may or may not live with the person they are caring for.

- Carers can be young people caring for parents, brothers, sisters, parents, partners, including same sex partners, or whole communities in the case of Indigenous people. Most frequently carers define themselves by their relationship to the person with the illness rather than their role in supporting that person.

- There may be more than one carer involved with a particular person with a mental illness. Those carers may have very different needs and views. They may even be in conflict with each other.

- The main, or only, carer may not necessarily be the next of kin.

- The carer may also be receiving treatment themselves for a mental or physical illness. This, of course, does not stop them being identified as a carer and this information being communicated to other services with their permission.

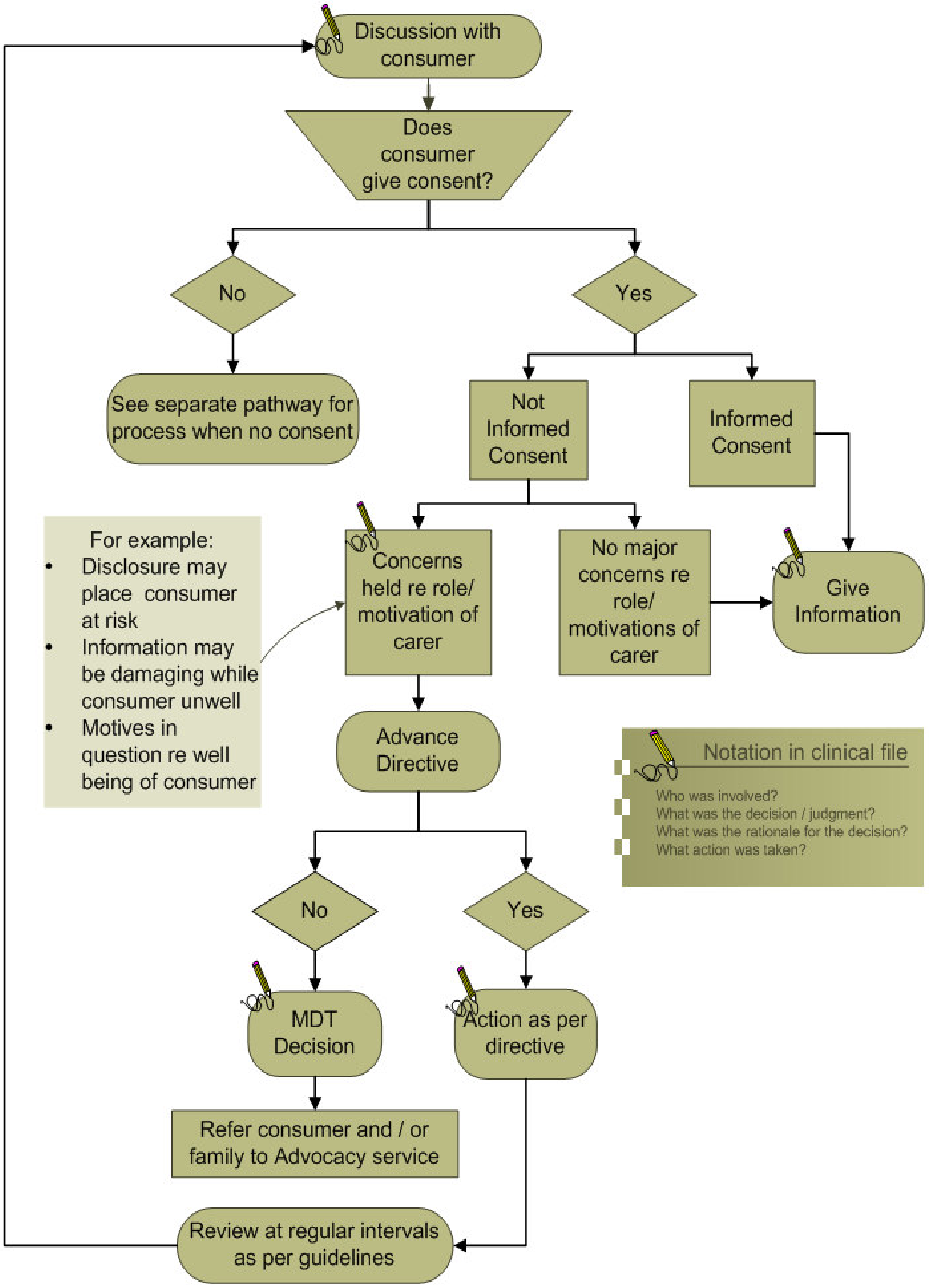
- Sometimes the person with the mental illness may not be keen on their carer being identified and classified as such, for various reasons. Consumer identification of carers will remain the preferred option however staff need to be aware of their role in the implementation of carer recognition and mental health legislation.

Carers need to be seen as individuals with different problems, different needs and different ways of coping. Some groups of carers are more difficult to reach, and others have particular needs, so specific strategies to identify and engage with carers may vary according to service settings and level of consent by the consumer.

The following charts, adapted from some developed in Townsville are presented to provide guidance to clinicians in situations where consent for sharing information is given, or with–held.

Family / Carer Participation Guidelines:

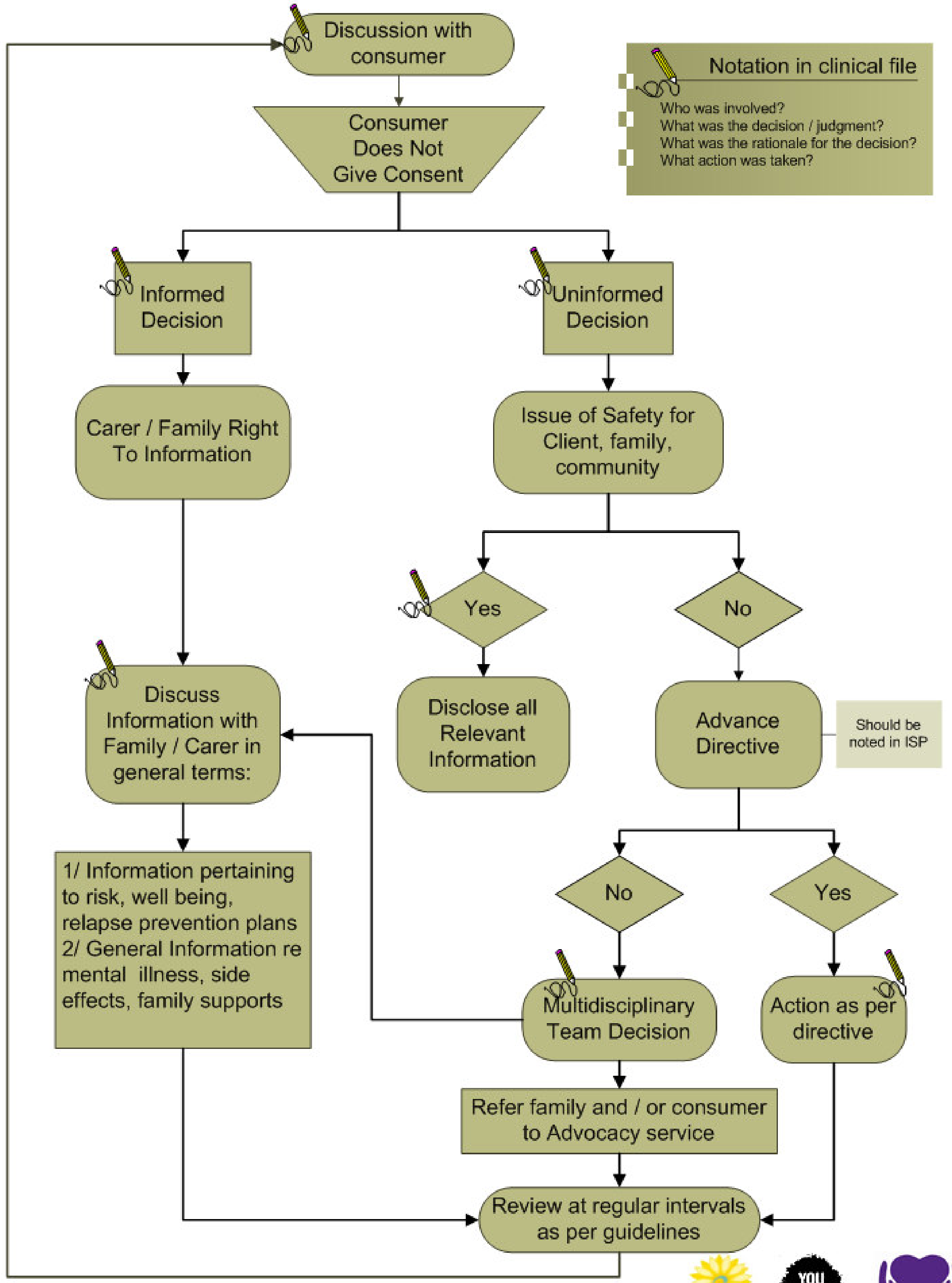
Where consent is given but concerns exist in regards carer role/motivation and/or consumer capacity)



Note: Please see Carer Standards Document for Definition of Carer/ Family Member

Family / Carer Practice Standards Guidelines:

Where the consumer does not consent to information sharing



Note: Please see Standards Document for Definition of Family / Carer Member

6.4 GOOD PRACTICE PROTOCOLS ACCORDING TO SERVICE SETTING

6.4.1 Primary care: General practitioner (GP) practices

The primary focus of these policies and protocols is identification of carers of people with a mental illness. However information obtained from the literature search and the consultations highlighted the clear role that GPs play in the initial identification of all carers, including those who care for a person with a mental illness. Including mental health within a framework of general health, may also be less stigmatising, thus potentially leading to earlier engagement

Waiting rooms provide ideal locations for posters and pamphlets that assist people to self identify and to take responsibility for seeking further information. The information should be presented in the most appropriate format for the target audience. In Indigenous pictorial representations of the information has had some success. In other areas electronic communication may be the best medium.

The following content is suggested for a poster appropriate for display in general practice settings that would:

- Assist people to identify they are a carer;
- Acknowledge they are entitled to recognition and support;
- Provide a simple avenue through the free post or internet option to seek further information and support; and
- Provide opportunities for discussion with the GP practice.

Because these posters are not specific to mental health they avoid the stigma that some people who care for a person with a mental illness can feel.

Posters such as these could also be suitable for use in settings such as Centrelink offices, Emergency Departments, schools, libraries etc. The content could also form the basis for media ads.

EXAMPLE FOR ILLUSTRATIVE PURPOSES ONLY – Taken from the Princess Royal Trust UK.

More targeted posters could also be developed for use in specialist mental health settings

LOGO

Do you provide support or assistance to someone who lives with

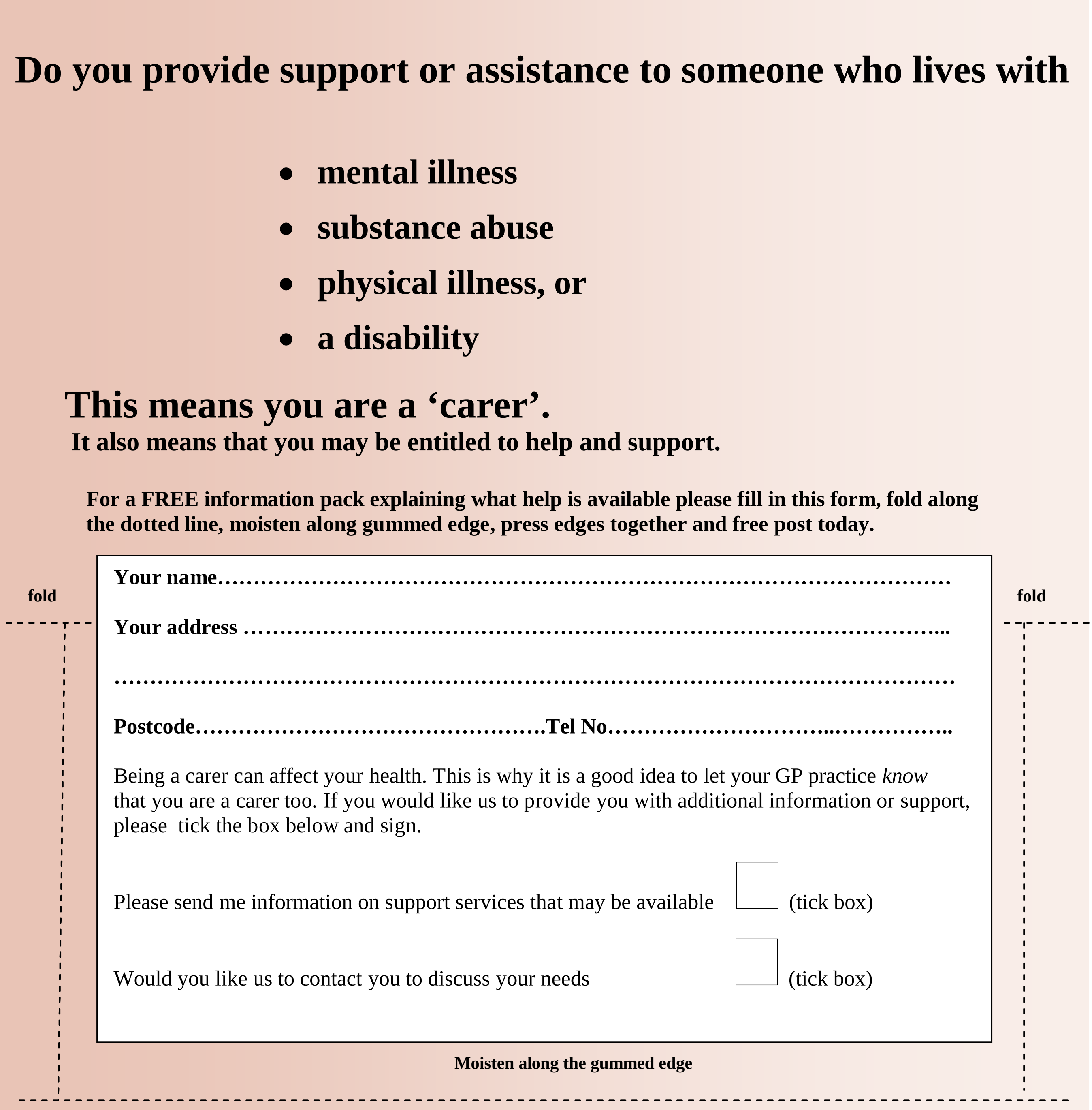
- mental illness
- substance abuse
- physical illness, or
- a disability

This means that you are a 'carer'

It also means that you may be entitled to help and support

FREE Information Packs are available from this service.
Complete the attached form and free post to CARERS AUSTRALIA
Information can also be obtained from

www.carersaustralia.com.au



Do you provide support or assistance to someone who lives with

- mental illness
- substance abuse
- physical illness, or
- a disability

This means you are a ‘carer’.

It also means that you may be entitled to help and support.

For a FREE information pack explaining what help is available please fill in this form, fold along the dotted line, moisten along gummed edge, press edges together and free post today.

fold

fold

Your name……………………………………………………………………………………

Your address …………………………………………………………………………………...

……………………………………………………………………………………………………

Postcode…………………………………………**Tel No**………………………...……………..

Being a carer can affect your health. This is why it is a good idea to let your GP practice *know* that you are a carer too. If you would like us to provide you with additional information or support, please tick the box below and sign.

Please send me information on support services that may be available ☐ (tick box)

Would you like us to contact you to discuss your needs ☐ (tick box)

Moisten along the gummed edge

Tear off forms could be attached to the posters such as illustrated above that would enable requests for additional information or contact to be sent via a free post option to the local office of Carers Australia who are well placed to receive and respond to enquiries. Opportunities also exist for GP practice staff to be specific points of contact for people who identify through this mechanism.

The Fourth National Mental Health Plan, 2009 states:

> *Primary care plays a central role in the treatment and care of those experiencing mental health problems and mental illness. General Practitioners (GPs) are often the first point of entry to the care system. GPs are the route of access to psychologists and other appropriately trained professionals providing services through the* ***Better Outcomes in Mental Health Care*** *and* ***Better Access to Psychiatrists, Psychologists and General Practitioners through the Medicare Benefits Schedule*** *initiatives and the Mental Health Nurse Incentive Program. Their training, attitudes and knowledge of the service system positively influence peoples' experiences of care and treatment outcomes.*

GPs are particularly well placed to identify carers. Families concerned about the early warning signs and symptoms of mental health problems or mental illness are likely to see their GP as the first point of contact for information and assistance with a family member. This provides an ideal opportunity for early intervention and better support for carers.

Minimal modification of the Australian Government Initiatives to include carer identification could provide a significant impetus to identification within the primary care sector.

6.4.1.1 Examples of activities that could be used in general practice include the following.

(i) The Practice Notice board

Each practice could ensure that it displays in its general waiting/reception area at least:

- one prominent poster that:
  - asks adults to identify themselves as a Carer; and
  - offers information on the support available.
- one prominent poster that:
  - asks adult patients who have a young person helping them at home to identify themselves; and
  - offers information on the support available.

Those surgeries with an electronic means of sharing information with patients in waiting areas could run a routine message that assists people to self identify as carers, the support available and who to contact in the practice. Consideration could be given to presentation of this information in pictorial form in Indigenous Medical Centres.

(ii) Carer Registration Vouchers

Each practice could ensure that it has Carer Registration 'Vouchers' available to the general public in its waiting/reception areas. These vouchers could be developed on a national basis and obtained from the Divisions of General Practice at no charge. 'Patients who are carers' reading these vouchers could then be directed to complete a voucher and return it to the receptionist at their GP practice so as to receive a Carers Information Pack. They could also be offered a FREE 'well carer health check' at a time convenient to all parties. The Medicare Benefits Schedule reforms aimed at increasing the uptake in general practice of prevention item numbers due for implementation on 1 May 2010 could be modified to encompass identified carers. The practice could also be responsible for forwarding details for information packs to the appropriate Carers Australia Office.

(iii) Practice Leaflet and New Patient Registration Form

Each practice could ensure that there are relevant questions in Practice Leaflet and New Patient Registration Forms that would lead people to self identify as having a role in caring for someone else, or having someone who provides care to them. The documents should be worded in a manner so as to ensure it attracts the maximum number of 'patients who are carers' as is possible.

This could also be reinforced via the inclusion of a field in the demographic area of the electronic record system for identification of people who are providing care to another person. This will require changes to Zedmed, the clinical software currently used by GPs.

(iv) Consultations and home visits

All consultations provide an opportunity for the GP/Practice Nurse to enquire as to whether or not the person they are seeing as the patient is (as well as being unwell) caring for somebody or being cared for by somebody. Consultations should also be used to establish whether there are children within the family taking an active caring role for a sick or disabled parent or sibling.

(v) Existing records and other known information

Many receptionists, nurses, practice managers and GPs will already be aware of adult and child 'patients who are carers', or patients who have a carer. This information should not be wasted. Each practice could set aside dedicated time when all staff are asked to prepare a list of all patients known to them that are either 'patients who are carers' or patients who have a carer. Those patients identified as 'patients who are carers', could be sent a Carers Registration Voucher inviting them to apply for Carers Information Packs and, a FREE 'well carer health check'. Those patients identified as having a carer should also be sent a Carers Registration Voucher with a covering letter asking them to pass the voucher to their carer. The practice could be responsible for providing the packs or forwarding details for information packs to the local Carers Australia office.

(vi) Medicare Cheques for Doctors and Prescription Folders

Medicare Australia could assist with the identification of carers via the placement of messages on all benefit cheques issued that need to be paid to GPs. These messages could encourage people to speak with their GP if they provide care or support to another person.

This could occur in association with National Carers Week.

Each practice could also ensure that it works on a regular basis with local pharmacies to encourage carers to identify themselves to their GP practice by placing stickers on the folders that are used for repeat prescriptions. Stickers could be developed nationally and obtained free of charge from Divisions of GPs.

This could also coincide with National Carers Week celebrated annually in Australia.

(vii) Influenza vaccination and Screening Programmes

Regular influenza vaccination, mammogram and other routine screening programs could also provide opportunities for identification of carers through a short list of appropriately worded questions.

6.4.1.2 Referral to specialist MH Care

With consumer and carer consent, the referral letter to specialist mental heath care could identify carers and the role they play in caring for the person with a mental illness. This could also include contact details and a request for continued involvement by the mental health service with the identified carers. This would be facilitated by the addition of a ‘carer’ field to referral letter templates in GP electronic data bases.

6.4.1.3 Incentives

The RACGP is currently reviewing practice standards. A submission has been made by the Private Mental Health Consumer Carer Network (Australia) for this review to examine mechanisms to ensure revised standards include the identification and support of carers.

Negotiations could also occur with accreditation bodies to have them consider the allocation of accreditation points to practices that demonstrate they have implemented ‘carer friendly practices’.

These activities could be further supported by planned changes outlined in the Fourth National Mental Health Plan (2009-2014) for partnerships with other government areas of responsibility.

The Peer Support and Mentoring Programs funded by the Australian Government through FaHCSIA already appear to be identifying carers as key to providing comprehensive services for people with mental illness.

6.4.1.4 Suggested national protocols for identification of carers in primary care settings

It is recommended that:

1. **The following protocols to identify carers are discussed with the Royal Australian College of General Practitioners for consideration during the 2010 review of the Standards.**
    - **Provision of general information encouraging self–identification on electronic and paper notice boards including posters and leaflets.**
    - **New Patient Forms to identify carers.**
    - **Utilise normal practice appointment consultations.**
    - **Practice newsletters to feature articles regarding carers.**
    - **Utilise patients' personal health checks to identify if they undertake care for another person.**
    - **Have a named member of staff responsible for maintaining the practice's procedure for identification of carers – a carer specialist or champion.**
2. **Medicare Australia is asked to consider the placement of messages to assist with the identification of carers on benefit cheques issued during Carers Week held annually in Australia.**
3. **Pharmacists are asked to consider the placement of messages to assist with the identification of carers on all folders containing repeat prescriptions during Carers Week held annually in Australia.**

6.4.2 ASSESSMENT SERVICES – PUBLIC and PRIVATE

Initial contact with a specialist mental health service may come about through a variety of mechanisms including:

- Referral from the GP;
- Presentation to an Emergency Department of a local hospital;
- Contact with a mental health crisis team;
- Referral to a private psychiatrist; and
- Police intervention.

All mechanisms provide potential opportunities for identification of carers.

Many Emergency Departments have introduced specific responses to concerns regarding the appropriateness of this environment to manage people who are distressed and agitated, however to date little has been done to use this as an opportunity to identify carers.

It is not unusual for people referred, or being brought to an Emergency Department to be accompanied by family members or friends. This provides an ideal opportunity for identification of carers and initiation of a partnership approach to the care of the person with mental illness.

For other people their first point of contact may be with a specialist mental health crisis team or the police. The contact seeking assistance is generally made by a relative or friend of the person with the mental illness. This also provides an opportunity for identification of carers.

Alternatively, many people are accompanied by family or friends at their first presentation to a private psychiatrist. The family /friends will generally wait in a waiting room during the appointment. The completion of the new patient information form, the initial interview itself and the time spent in the waiting room all provide opportunities for identification of carers. It also provides an opportunity for practice staff to engage with carers and to provide them with a carer information pack. Practices may consider the establishment of 'carer corners', places where coffee and additional resources could be available, including information regarding support groups.

6.4.2.1 Suggested national protocols for identification of carers in assessment settings

It is recommended that the following protocols to identify carers during assessment processes are distributed widely to public and private sectors for feedback regarding the feasibility of introduction on a progressive basis.

- **Generic information encouraging self identification by carers to be provided in waiting areas on electronic and paper notice boards including posters and leaflets.**

- **New patient questionnaire data systems to be expanded to include carer identification by a series of questions phrased in a positive manner designed to encourage consumers to recognise who their carers are and the importance of their ongoing contribution.**

- **Triage processes to ask appropriately worded questions emphasising the positive aspects of family/carer participation in all aspects of care.**

- **Interviewing doctor/nurse to ask appropriately worded questions to determine identification of carers and their level of involvement.**

- **A specific member of staff to be allocated responsibility for maintaining procedures for identification of carers – a carer specialist or champion.**

- **Information packs to be provided for both consumers and carers that include rationale and encouragement for identification of carers.**

- **'Carer corners' be established in waiting rooms.**

6.4.3 FORMAL ADMISSION TO A SERVICE

The paperwork associated with the formal admission of a person with a mental illness to a public or private mental health service also provides an opportunity for identification of carers.

The use of colour coded forms requesting permission from the consumer to identify carers could be sought via a structured set of questions. This form needs to be regularly updated and form an integral part of each admission, or re–admission procedure.

It is important to note that it may not be possible to complete this component immediately upon admission. In fact, it may be desirable to complete the form later once the consumer has had a chance to develop a relationship with staff.

Completion and review of this form should be an ongoing process that is used as the basis of discussion between all parties. The form should highlight the benefits of involvement of a wider range of people in the care and support of the consumer and seek to clarify the level of involvement that the consumer feels comfortable with each person having. These levels may change over time.

Consumers should be encouraged to inform nursing staff if they would like to change any of this information during their admission. This form should remain in the case notes and be up-dated on every admission. An audit process is considered crucial to changing practice over time.

Services should be mandated to provide the following information to carers at the admission stage.

- Welcome message, we are here to help, outline of the processes to be followed, including options for a follow up call from a designated person within the service to answer immediate concerns.
- Confidentiality – explanation of legislative requirements and re–assurance regarding options if the consumer is currently refusing in-depth involvement.
- Information to assist with diagnosis and development of a treatment plan.
- Contact numbers for the hospital and ward.
- Legislative status of the consumer – what this means.
- Rights and responsibilities of carers.
- Complaints process.
- Referral options to appropriate support services to assist them to understand their role.

At this stage the information provided should be specific to the individual needs of the consumer and his/her family or other carers. It should be

practically based with clear guidelines for the ongoing management of the mental health issues.

6.4.3.1 Suggested national protocols for identification of carers during formal admission to a public or private service

It is recommended that the following protocols, to identify carers during formal admission to a specialist mental health service, are distributed widely to public and private sector services for feedback regarding the feasibility of introduction on a progressive basis.

- Generic information encouraging self identification by carers is provided in waiting areas on electronic and paper notice boards including posters and leaflets.
- Colour coded forms inviting consumers to identify carers and nominate the level of involvement be included in all admission procedures. Forms to be completed as soon as practicable and audited on a regular basis.
- In circumstances where a consumer refuses to identify their carer(s), the mental health service will review this status at regular intervals during the episode of care in accordance with Australian and State/Territory jurisdictional and legislative requirements.
- A specific member of staff to be allocated responsibility for maintaining procedures for identification of carers – a carer specialist or champion. This may be a carer consultant/liaison officer/family support worker with the following responsibilities:
  - Staff support and training;
  - Liaison point between staff, consumers and carers, e.g. assistance with completion of admission protocols regarding identification of carers; advocacy for individual carers with staff/services;
  - Information and linkage to alternative options for information and support for carers such as referral to carer support organisations;
  - Provision of carer specific perspectives to staff meetings;
  - Assistance with carer assessments; and
  - Specific point of contact following discharge for carers.
- Ensure accreditation and reporting systems in health and community sectors incorporate the National Standards for Mental Health Services and, in particular, Standard 7 relating to the identification and participation of carers at all areas in service delivery.
- Consumer information packs to include a rationale and encouragement for identification of carers, including the identification of children who are carers.

- **Services to report on the provision of information packs to carers.**
- **Staff to receive ‘carer sensitivity’ and skills development training.**

6.4.4 DISCHARGE PROCESS

Decisions and discussions regarding discharge need to focus on practical issues regarding availability of ongoing care and support, accommodation, future appointments and linkages to other services. This discussion presents a further opportunity to identify carers and to emphasise to consumers the importance of continued support for their recovery.

When undertaking these discussions staff need to be aware that carers may not view themselves as carers, but as partners, parents, sons, daughters etc. It may even be that young children will be taking on the role of carer. If this is the case, special provisions may need to be made including the development of Ulysses Agreements. Ulysses Agreements are a type of Advance Directive developed specifically for use in situations where young children are either cared for, or carers of, a person with a mental illness.

It is important that carers feel fully involved at all stages of care, including the decision to discharge the consumer. This is a process of handing over care and carers are critical partners in this process. Time should be allowed for carers to make choices about:

- Taking on, or continuing to fulfil the role of carer; and
- How much and what type of care they are prepared to provide taking into consideration family and caring commitments, their health, work, education and social activities.

Some people feel they have no choice in this matter even when their personal and physical resources have been exhausted, where they are afraid of the consumer, or where the consumer continues to refuse to acknowledge the role they play. This is an untenable situation for carers who self identify, and the National Standards for Mental Health Services and Carer Recognition Legislation now require services to listen to concerns and refer for support to meet the needs identified.

As part of the discharge process/referral back to a GP, or community service it is also essential that carers have sufficient information to undertake their role following discharge. The Information pack developed as part of this project covers most situations they are likely to encounter. It is also important for them to have information regarding the specific diagnosis, if one has been made, and the medication prescribed, including possible side effects. The name and phone number for a person for them to contact if they are concerned is essential.

6.4.4.1 Suggested national protocols for identification of carers during discharge processes.

It is recommended that the following protocols to identify carers during formal discharge processes from specialist mental health services are distributed

widely to public and private sector services for feedback regarding the feasibility of introduction on a progressive basis.

- **Generic information encouraging self identification by carers is provided in waiting areas on electronic and paper notice boards including posters and leaflets.**
- **Colour coded forms requesting consumers to identify carers and the level of involvement they want them to have be checked for completion.**
- **Ensure carers have personalised information packs including:**
  - **Diagnosis;**
  - **Medication – dosage, purpose and possible side effects;**
  - **This is what you can expect;**
  - **Who to contact to discuss concerns; and**
  - **What supports are available to you locally, eg your GP, Carers Australia, ARAFMI.**
- **Encourage the routine identification of carers, including children, in the development of relapse prevention plans emphasising the benefits of information sharing and support.**
- **A specific member of staff be allocated responsibility for maintaining the Service's procedure for identification of carers and support.**
- **Ensure accreditation and reporting systems incorporate the National Standards for Mental Health Services and in particular Standard 7 relating to the identification and participation of carers at all areas in service delivery.**
- **Discharge letters, with the permission of the consumer and the carer, to identify carers, their willingness to continue in this role and an outline of potential support required.**
- **Services to undertake regular satisfaction surveys regarding their level of engagement with carers.**

6.4.5 ONGOING COMMUNITY AND PRIVATE PSYCHIATRY CONTACT

The majority of mental health services are delivered in a community setting by mental health professionals, GPs, psychologists and psychiatrists in both public and private settings. Each contact potentially provides an opportunity for discussion with consumers at a time when they are not acutely ill to identify who provides support to them and to seek permission for these people to be actively involved in future care.

This discussion needs to involve consumers, carers, case managers and clinicians including private psychiatrists. The majority of people with an ongoing mental illness know they need to have varying levels of support at different stages of their illness. This should be recorded in the notes and updated on a regular basis. This is particularly important when the caring role has been taken on by children.

The development of Relapse Prevention Plans, Advance Directives for Care and Ulysses Agreements are formal processes that could be used to specifically identify carers. It is acknowledged that mental Health Legislation can over–ride these Plans/Directives/Agreements during any future acute episodes of the illness however it is hoped they will have increasing influence on the nature of the care provided.

6.4.5.1 Suggested national protocols for identification of carers in continuing care settings.

It is recommended that the following protocols to identify carers in continuing care specialist mental health settings are distributed widely to public and private sector services for feedback regarding the feasibility of introduction on a progressive basis.

- **Relapse prevention plans to emphasise the benefits of information sharing and support and contain a specific component for identification of carers. Carers also need to give permission for their names and contact numbers to be included in the Plan.**
- **Encourage the identification of carers in the development of Advanced Directives.**
- **Ensure the development of Ulysses Agreements in situations where children are carers.**

6.4.6 CHANGE IN CLINICAL PRACTICE

Change will take time and requires:

- Modification of structures and cultures to support changes in practice;
- Individual and system rewards for making these changes, eg accreditation points for general practices, continuing education points for clinicians, successful surveys for service accreditation; and
- Appointment of adequately remunerated and supported Carer Consultants/Liaison Officers/family support workers in all health services as equal team members to support partnership approaches to service delivery and to act as catalysts for change in practice.

It is recommended that the following good practice checklist to identify carers during all stages of care is distributed widely to public and private sector mental health services and the RACGP for feedback regarding the feasibility of introduction on a progressive basis.

CARER IDENTIFICATION AND ENGAGEMENT A GOOD PRACTICE CHECKLIST FOR STAFF

Choice

Allow carers time to make choices about:

- Taking on the role of carer;
- Whether to continue caring; and
- How much and what type of care, taking into consideration family and caring commitments, health, work education, social activities

Identification

- Throughout the service admission and discharge process and at the earliest opportunity, ensure there are triggers in place to identify carers.
- Be aware that carers may not view themselves as carers but as partners, parents, sons, daughters, etc.

Information

Actively seek permission from consumer to share information with the carer and provide carers with information about the following.

- Discharge plan in writing and verbally.
- Medical condition of consumer.
- What is likely to be involved in caring
- Benefits.
- Financial implications of caring.
- Other sources of help and other organisations, such as ***Carers Australia*** and self help groups.
- Access to interpreters to enable effective understanding and communication.
- Challenging decisions and complaints procedures.

Assessment

- Involve carers in assessments, including those carried out by allied mental health professionals' and community nurses.

Planning for future service delivery

- Ensure carers feel fully involved at all stages of service delivery including the decision to discharge the person and making sure practical arrangements are in place
- View carers as partners, respect and listen to their views – longer term carers are likely to have considerable expertise and skill in how to care for the consumer
- Acknowledge carers' individual needs, consider cultural differences, age, race, disability, health, religious background, sexual orientation, gender assumptions, geography
- Ensure carers have been involved in drawing up, monitoring and reviewing policy and its implementation
- Develop different types of consultation procedures

Support

- Be flexible: provide services that carers want, when they want them
- Ensure practical help is in place prior to discharge
- Offer information on how to care safely: eg administering medications, dealing with difficult behaviour
- Improve co–ordination between health and ***Centrelink*** and other government agencies to ensure carers receive a seamless service
- Refer carers to support groups

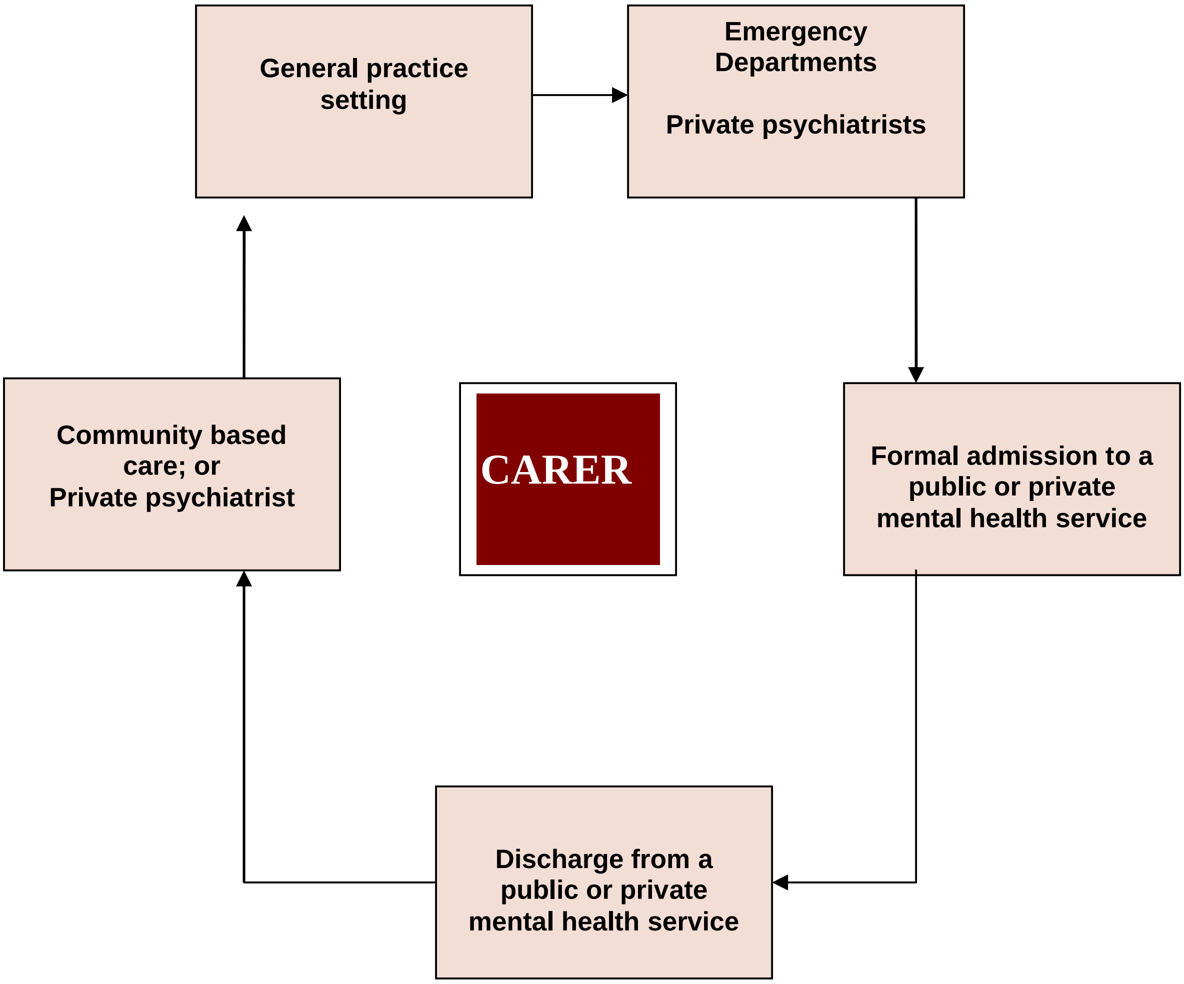
Monitoring

Find out whether carers' outcomes were met by the service delivery process.

Methods of carrying this out could include:

- Carer satisfaction surveys;
- Audits of discharge documentation provided to carers;
- Carer outcome measures; and
- Review policies regularly in consultation with carer consultants, ***Carers Australia, ARAFMI*** etc.

7. THE CIRCLE OF OPPORTUNITY FOR IDENTIFICATION



8. INFORMATION BROCHURE FOR CARERS

This brochure has been developed for national use on the basis of the information obtained during consultation. It includes adaptations and selections of work contained within State, Territory and NGO carer documents, including those produced by Lifeline and beyondblue.

<u>Recommendation</u>

It is recommended that the following section of the report be edited to a 'plain English' format; and be further developed by a graphic designer for transmission by email and to be web based; to enable wide distribution nationally to carers for consideration and feedback. The revised brochure should then be published in hard copy and placed on the DoHA website for national use.

INFORMATION BOOKLET
for Families and other Carers

You have been given this information pack because you live with, or provide support to, someone with a mental illness?

This could mean you:

- Provide emotional support, sometimes for long periods each day; or
- Need to encourage the person you care for to take their medication, and watching for side effects; or
- Provide assistance with bill paying, filling in Medicare claims and other similar tasks; or
- Need to remind the person you care for when they have appointments and make sure they get to them; or
- Help the person you care for to understand what the doctor has said and what the treatment will be; or
- Check to see if there is food in the fridge, and you might make some meals; or
- Help with household chores such as cleaning, grocery shopping, gardening; or
- Make regular phone calls to the person you care for to "check in" on them; or
- Assist the person you care for to be involved in some social activities.

If so, this means you could be described as a 'CARER'. Carers of people with a mental illness are entitled to be recognised, respected and provided with information and support.

'Carer' is a term that is used by services and governments to describe people that provide support to someone with a mental illness that needs help. You may be, and will continue to be, primarily the persons wife, husband, partner, son, daughter, sister, brother, parent, other relative, neighbour or friend. It doesn't matter how many hours per week are spent providing support. Carers may live with the person they are caring for, providing assistance with daily needs, or may visit the person weekly or call regularly. Being a carer involves an investment in time, energy and support.

We know that carers are often 'hidden' looking after a family member or helping a friend or neighbour with day to day tasks and may not see them–selves as a carer. This is particularly true in situations where children may be the carers in the family.

Caring for someone with a mental illness can be a difficult and painful experience. It takes time and can be emotionally draining. Most people have had limited or no previous experience of mental illness and may experience a whole range of feelings. This is often described as 'like being on a roller coaster'.

This can be particularly difficult if the person concerned feels they do not need help, but behaves in ways that causes problems for themselves and possibly for you too.

Some of the reactions commonly experienced by family and friends are:

- Guilt
- Stigma
- Fear
- Frustration/Anger
- Hurt
- Grief

We understand that it may be difficult for you to identify yourself as a carer, particularly in the early stages of an illness because:

- You may be overwhelmed by the situation if you have not had any previous experience with mental illness;
- Mental illness is not always viewed favourably in the community;
- You see it as a duty or family responsibility and would be uncomfortable about accepting help from other people;
- You may be uncomfortable about the involvement of government services or the police;
- You may feel you are a failure if you ask for help;
- You are so busy just coping that you may not be aware there is help available or how it might make a difference; and
- You don't believe anyone could help you

You are not alone in feeling these things and it is important you seek information and support for yourself and other family members.

Carers are our partners in the provision of healthcare. We need to work with you to make sure that your family member or friend receives the best care possible.

ABOUT MENTAL ILLNESS

How do I recognise if someone may have a mental illness?

While symptoms vary, and each person with mental illness is different, all people with mental illness will experience some of the symptoms listed below.

Symptoms on their own, or as isolated events are not necessarily a sign of mental illness, however persistent, multiple or severe symptoms may require a mental health assessment.

Possible symptoms

There are a range of symptoms which may indicate mental illness. These include:

Changes in thinking or perceiving including:

- Anxiety – being overly fearful about things that may never happen
- Depression – sadness and lack of interest in life that lasts for more than a couple of weeks
- Confused or disorganised thinking – sometimes it is difficult to understand
- or make sense of what the person is saying.

Changes in mood including:

- Sadness coming out of nowhere that cannot be explained
- Extreme excitement or happiness
- Mixtures of moods from very happy to very sad
- Pessimism, seeing the world as grey and lifeless
- Feeling hopeless
- Loss of interest in once pleasurable activities
- Thinking or talking about suicide or other forms of self harm

Changes in behaviour including:

- Sitting and doing nothing
- Friendlessness, abnormal self–involvement
- Dropping out of activities, decline in work, academic or athletic performance
- Anger and hostility that is out of character
- Indifference, even in highly important situations
- Inability to express joy
- Inappropriate laughter
- Inability to concentrate or cope with minor problems
- Irrational statements
- Peculiar use of words or language structure
- Excessive fears or suspiciousness
- Drug or alcohol abuse
- Forgetfulness and loss of valuable possessions

- Attempts to escape through frequent changes of address
- Bizarre behaviour (strange posturing)
- Unusual sensitivity to noises, light, clothing

Physical Changes including:

- Being very active or not active at all or a combination of both
- Poor hygiene or personal care
- Unusual eating habits/patterns
- Unexplained weight gain or loss
- Sleeping too much or being unable to sleep

Hallucinations – problems with any of the senses (sight, sound, touch smell and taste). Most often they are auditory hallucinations or voices that the person can hear that are not real to anyone else. They are often very distressing to the person as the voices may say upsetting things and other people deny hearing them.

Delusions – psychotic symptoms of particular types of mental illness, such as schizophrenia. They are firmly held beliefs that are not held by other members of the person's social group. Persons who experience delusions may offer bizarre explanations for experiences or circumstances. For example, they may believe they are being spied upon, followed, poisoned or that they possess great unrecognised talent.

Sometimes, particularly if this is the first time your family member or friend has been unwell, it may not be possible to make a clear diagnosis or to determine what is causing the symptoms. Each person is unique and the symptoms they have will be unique to them. There is no reliable way to predict what the course of an illness may be. Symptoms may change from year to year. Also one person's symptoms may be very different from those of another, although the diagnosis may be the same.

Often symptoms of mental illness run in cycles and may vary in severity. The length of time an episode of mental illness may last also varies. Some people are affected for a few weeks or months, while for others, the illness may last many years or for a lifetime.

In some cases of apparent mental illness, physical illnesses can be found to be the cause. Possible physical illness always needs to be investigated when mental illness is suspected.

Note: *This guide is for informational purposes only. It is not meant to be used as a diagnostic tool. It is very important that you seek a professional evaluation if you have concerns about yourself or another person.*

If you are concerned about a family member or friend you should contact your GP or local mental health service.

SOME COMMON MYTHS

Myth: mental illness is for life

Most people will recover from mental illness, especially with early treatment. Some people may have one episode of illness and recover completely and other people will have episodes of mental illness with times in between when they are well. For a small percentage of people with a more severe illness, episodes of illness will occur regularly and need specialist management and long–term medication. Some people are very disabled by their illness but others with appropriate treatment can lead full and active lives.

Myth: mental illnesses are all the same

There are many types of mental illness with a variety of symptoms for each illness and each individual.

Myth: people who are mentally ill are violent

Having a mental illness does not mean someone will be violent. People receiving treatment for a mental illness are no more violent or dangerous than anyone else. It is much more likely that someone with a mental illness may hurt themselves, or be hurt by someone else.

However, there is a slightly increased possibility someone with a severe mental illness may be violent if they are not receiving treatment, have a previous history of violence, and are abusing alcohol or drugs.

Symptoms of severe illnesses may include frightening hallucinations and delusions as well as paranoia. This means there is a small chance someone who is experiencing them may become violent when they are scared and misinterpret what is happening around them.

Family members and other carers faced with these situations should seek help immediately from their GP, mental health service, or in extreme situations from the police.

If a person is being effectively treated for psychotic illness and is not abusing alcohol or drugs, there is no more risk they will be violent than anyone else.

How do I find out more?

It is important to ask your doctor about any concerns you have about mental illness. You can also call the SANE Helpline on 1800 18 SANE (7263) for confidential information and advice. SANE Australia produces a range of easy–to–read publications and multimedia resources on mental illness.

LEARNING A NEW LANGUAGE

In mental health there are many terms you may not be familiar with. Some of the more common terms you might hear are explained below.

Mental Illness

A disorder of the mind that affects a person's ability to function properly, eg, their thinking, feeling or ability to work or socialize.

Mental Health Service

A specialised service that provides assessment, treatment and support for people experiencing mental illness. Mental health services include both inpatient and community based services and are available on both a public and private basis.

Inpatient Services

When someone is admitted to a psychiatric hospital they may be cared for in either an open or a closed ward. This will be dependent on what is considered the safest option for that person at any point in time.

Consumer

A person receiving treatment from a mental health service.

Carer/Family Carers

Any family member, relative or friend who provides ongoing care and support for a person with a mental illness without payment.

Case Manager/Care Co–ordinator/Key Worker

A mental health worker who may be assigned to help a person being treated

by the mental health service. All people in these positions are required to have training to be able to assist a person by:

- Helping them to identify ways they can develop a treatment plan and work towards recovery from mental illness
- Educating them about mental illness and how they can manage their symptoms
- Linking them to other services and community organisations
- Being a contact person in the mental health service
- Providing support and education to families and carers.

Multidisciplinary Teams/The Mental Health Team

Specialist mental health services provide treatment and support through multidisciplinary teams made up of professionals from various disciplines (e.g. Psychiatrists, Medical Practitioners, Nurses, Social Workers, Psychologists, Occupational Therapists, Aboriginal Health Workers and Aboriginal Mental Health Workers). The team may also include people who work in the non–government sector such as personal mentors and peer support workers. Each of these people have different training and skills. They will work with each other, and with you, to make sure the treatment plan developed for your family member or friend is put into action.

Nurses

Nurses are educated to promote good health, prevent illness, and the care for people when they are ill. They work in a broad range of health settings including in hospitals and GP clinics. Some have received specialist training in mental health. When your family member or friend is in hospital it is the nurses who will provide 24 hour care.

Occupational Therapists

A person specifically trained to assess the practical skills that a person has and to develop programs to support the person to learn new skills in managing day to day living that build their independence.

Psychiatrist

A doctor who has undertaken additional specialised training that qualifies him or her to diagnose and treat mental illnesses. Psychiatrists are able to prescribe medication.

Psychiatric Registrar

A doctor who is currently undertaking specialised training for registration as a Psychiatrist. Registrars are able to prescribe medication.

Psychiatric Medical Officer

A doctor who has experience in the treatment of people who have a mental illness, alcohol or drug abuse but no specialist qualifications. They are able to prescribe medication.

Psychiatric Case Manager

A person appointed to monitor the progress of the treatment and care of a person receiving treatment under a community management or treatment order.

Social Workers

A person specifically trained to work with people to change the way in which they live. This may involve assisting them with their finances or accommodation and helping them to navigate community welfare services that may offer support.

Psychologists

A person who has usually completed a postgraduate degree in psychology. Psychologists are people who have undertaken additional specialist training in the assessment of behaviour and mental functioning, and ways of helping people change how they may think, feel and act towards themselves and other people. Psychologists are not trained in general medicine and are unable to prescribe medication.

Recovery

From the perspective of the person with mental illness, recovery means gaining and retaining hope, understanding of ones abilities and disabilities, engagement in an active life, personal autonomy, social identity, meaning and purpose in life, and a positive sense of self. It is important to remember that recovery is not the same as cure

COMMUNICATING WITH STAFF – a check list

As a carer, you should be provided with information to help you. The following checklist provides prompts that may be beneficial to you in seeking information.

Ask if you can be provided with general verbal and written information about:

- The mental illness and diagnosis.
- What sorts of behaviours you might expect and how to handle them.
- Medication – alternatives, benefits and possible side effects.
- Services that might be available locally for your family member/friend.
- Services that might be available locally to assist you as their carer – government, private and community services.
- Local and national support groups.

In order for you to feel comfortable in talking about your concerns you need to ask if you can have:

- Ongoing opportunities to ask questions and discuss concerns.
- The opportunity to meet with staff on your own.
- Assurances that the information you discuss with staff will be kept confidential.
- Assurances that you are a valued member of the care team.
- Practical and emotional support.
- An assessment of your own needs to help you in your role as a carer.

Have you been given help to understand:

- The rights and responsibilities of people who have a mental illness, you, as their carers, and mental health staff who work in this service.
- Any restrictions on sharing information requested by the person with the mental illness.
- What the treatment plan involves and aims to achieve.
- What a crisis plan might involve. It is a good idea to ask for this in writing.
- What a recovery plan might involve.
- The roles of each staff member involved in care of your family member or friend.

Have you made sure that you have communicated to mental health staff:

- Any information regarding your family member/friend that may be relevant such as changes in behaviour, use of drugs or alcohol.
- Information that that may influence the choice of medication or treatment, such as allergies.
- Information regarding benefits or side effects of medication or treatment previously prescribed.

- Any problems you have in caring for your family member/friend such as them being unwilling to take medication, or to get up in the morning.
- If you need help in solving problems or handling specific situations.

Remember, communication is a two way process.

People with mental illness have the right to refuse to have personal information shared with carers however this does not over–ride your right to present your views and experience to staff and to receive general information about the person you provide care for.

WHAT ARE MY RIGHTS AS A CARER?

Caring for someone is an important and valuable role in the community, which is often a 24 hour job that can be very demanding and may make you feel very alone. A number of pieces of Carer Recognition Legislation, Mental Health Legislation and the National Standards for Mental Health mandate that you receive appropriate support via way of access to accurate and timely information and referral where appropriate.

The mental health team is committed to working in partnership with you and your family member or friend to provide safe, high quality services.

It is important for us to know if we are listening to you and providing the right information and support to help you – so please let us know what you think, because we really do value your opinion.

Carers can expect the mental health team to:

- Introduce themselves and advise you of their role in caring for the person who has been admitted to the service.
- Treat you with dignity and respect
- Explain the level of the information that is able to be shared and the reason for this
- Reply appropriately to any concerns or queries
- Provide you with access to interpreters if you need them
- Keep personal information you give the team about yourself as confidential and respect your privacy
- Inform you of your right to seek further opinions regarding the diagnosis and care of your family member or friend.
- Inform you that you do not always have to be available to your family member or friend, ie you can take time for yourself
- Inform you of your right to make complaints and how you would go about doing this.
- Inform you that there are information and support programs available for carers and where to go to get this information.

In addition, if your family member or friend who is unwell gives permission, you can expect the mental health team to:

- Discuss the available treatment options with you
- Involve you in planning a program of care
- Involve you in planning for discharge and on–going care

Relationships between people with a mental illness and their family or other carers are not always straight forward. They may also change frequently depending on the nature of the illness, or how unwell the person is. There may also be circumstances where the person is too unwell to give, or refuse, permission for the mental health team to involve you because of their disturbed mental state.

If this is the case you can still expect the mental health team to:

- Provide you with an assurance that they will check with your family member or friend on a regular basis, the level of information to be shared; and
- Provide opportunities for you to give the mental health team information you have concerning family relationships and any matters relating to the mental state of your family member or friend to assist with diagnosis and care.

COMPLAINTS PROCESSES

If you feel that something is not right, please **let the mental health team know.** You can do this by asking to speak to a senior member of the staff. You might like to have another family member or friend to help you if this situation arises.

In most cases if you let staff know about any concerns you may have as soon as possible it is generally easy to deal with them.

You may also like to ask the Carer Consultant/Family Worker to help you to speak with, or arrange a meeting with staff.

If you are still concerned, or need more information, it is possible to telephone or meet with people who could assist you. These might include:

Health and Hospitals Complaints Commission
Telephone numbers vary across states and territories

Office of the Public Advocate
Telephone numbers vary across states and territories

Office of the Chief Psychiatrist
Telephone numbers vary across states and territories

Carers Australia
Freecall 1800 242 636

ARAFMI
Telephone numbers vary within states and territories

Mental Illness Fellowship
Head Office in Adelaide – business hours 08 8272 1018

WHAT ABOUT YOU

Supporting someone with a mental illness can be an extremely challenging experience that takes you along unexpected and unknown paths. Trying to make sense of your feelings, the illness, and the whole situation brings many questions with sometimes, it seems, even fewer answers. This is not an unfamiliar experience, many families and other carers often say they feel this way.

It is important to understand that your reactions are normal. They reflect how you feel and shouldn't be questioned or judged by other people who aren't walking in your shoes. Everyone's experience is unique, however it is good to find opportunities to share these feelings as you may be surprised to find how much you have in common with other people who are carers.

When you are the carer of a person with a mental illness you're likely to experience a range of feelings. Sometimes, adjusting to the problems you're facing and understanding your emotional reactions can take its toll. This sometimes means you might become anxious or depressed and need to seek help for yourself.

Maybe you have had thoughts or questions like the ones below. Hopefully the stories from other carers can give you some reassurance and support to help you in your journey.

- **Is what I am feeling a common experience for families and friends?**
- **How will the experience affect the rest of the family and my friends?**
- **I never expected to feel grief and loss.**
- **How on earth am I going to cope?**
- **I feel like I am going to explode...I need help too...**
- **Something or someone's got to change. Maybe its me...**

IS WHAT I AM FEELING A COMMON EXPERIENCE FOR FAMILIES AND FRIENDS?

During the initial stage, when your family member or friend is diagnosed with a mental illness, it's likely that you may feel relief because:

- There is a name for the difficulties you have both been facing
- There is a reason for the behaviour
- Help is available

You may also feel some fear and confusion and wonder:

- Where to from here?
- Is this only the beginning?

These questions are all normal because for most people this is a new experience.

Many family members and other carers say that once the mental illness had been diagnosed, their feelings of love and protection increased. Sometimes, at the same time, you might feel a sense of helplessness because you cant control or fix the situation.

Common feelings at various stages generally include:

- Fear
- Confusion
- Blame
- Guilt
- Uncertainty
- Insecurity

> *"I felt pretty terrible because I hadn't recognized it…so I felt shattered…but I also felt a great relief that now we know what is wrong. I think that it is impossible for anyone who has not had this experience to understand the trauma that mental illness can have on a family. As a mother of a very intelligent and loving son it is very hard to let go of the hopes and dreams that you have for his future.*
>
> *I felt guilty and scared at the same time. I was worried about what this would mean for us, for our family. We are reliant on him to provide for us, and the thought that he would not be able to do this was terrifying. Then I felt even more guilty. He was suffering and there was I thinking about money. How heartless...I was torn between guilt and fear."*

Families and friends of people with a mental illness also describe other feelings such as being overwhelmed by what is required of them. It may seem just too demanding and there may be no relief in sight. The high level of responsibility that can come with caring for, and supporting, another person, particularly if this involves physical, practical and financial support, can be exhausting and may also trigger feelings of resentment, frustration and anger.

"I wouldn't put up with it if I didn't love him."

"I am only hanging in there to help my grandchildren."

It is important to know that these are normal responses to a situation you did not plan. Remember, the situation in which you find yourself is beyond your control. You had no say in it. You didn't ask for this to happen – but nevertheless, here you are.

This does not mean you love or care about your family member or friend any less. However, it is likely that at some stage you might react to all these feelings – and you might not be able to predict when, or how. Again, this is normal response because you are using all your energy and resources to take care of your family member/friend and to take care of yourself.

How will the experience affect the rest of the family and my friends?

Relationships

Living with, or supporting a person with a mental illness not only affects you. It is likely to affect the other relationships within your family and with friends.

Family life may be disrupted. Routines and the sense of 'normality' you once had in your home may gradually change, often without you recognizing it. You may find that the changes you have all gradually made to adjust to living with a person whose behiour has changed have now become the norm.

> *"I rarely see a friend or anything…I don't really invite people over that much because of it."*
>
> *"It has affected my family greatly and still does. Like me, they had no dealings with mental illness and thought their sister was a spoilt brat at first until I gathered all the information I could put my hands on to help me understand more and to convey what I learnt to my children. In one way, it has split the family because they still cannot comprehend mental illness, as they are busy with their own children – my grandchildren."*
>
> *"Whenever we have a family get together I know my family, including myself, are very careful with our choice of words in case my daughter becomes up set and has an outburst. This makes it very unpleasant for everyone."*

Social relationships may also change. The response you get from friends and family members may be surprising or hurtful. This may be because they don't understand mental illness, what it means, or what you may be going through.

> *"Both my husband and my son had difficulty accepting my daughter being diagnosed with mental illness. Now after many years they have become more understanding of mental illness as a whole – not just within our immediate family. We also found it hard that 'friends' of long standing were unable to provide much support to us. In fairness this was probably due in part to their limited knowledge of mental illness and therefore they had their own problems acknowledging what we were dealing with."*

In some situations you may experience financial difficulty as a result of:

- Not being able to continue working full–time
- Ongoing medical expenses
- Helping to meet the financial commitments of your family member/friend.

> *"I just got so much flak from my workmates that I was ready to quit. They don't understand why I sometimes need to take time off at a moment's notice sometimes."*
>
> *"I have been assisting my daughter with money because she can't work and I've been paying whatever she needs to get by."*

Relationships can become one–sided because people with a mental illness are sometimes so focused on their own problems they may have nothing left to share with anyone else.

If your relationship has changed, remember this is mainly due to the person's illness. If that person gets the right treatment, then your relationship has a chance of returning to what it was or you may move to a new stage in your relationship.

Parents

Parents of children who develop a mental illness often feel responsible. They think they might have contributed to this in some way. This can be made worse by parents feeling blamed when they sense underlying questions from friends or other family members about their children's behaviour, their skills as a parent, or the amount of love and support they give to one child.

> *"Other people can be critical of not only the way you are supporting them, but the fact that you are continually supporting them."*

It is important to work out what is being protective and what is reasonable care. Parents often talk about the balancing act they struggle with. Where is the line between reasonable support and becoming over–protective, or when to be there and when to step away.

> *"At the end of the day you have to do what is right for you – but it is really hard."*

Brothers and sisters

Balancing parenting and caring can be even more complicated when there are other children in the family. It's difficult trying to treat all children equally and not focus solely on the child with the illness. Other children may feel resentment when the unwell child is given special treatment.

> *"…our other children, although we didn't realise it at the time, but they told us later that we were kind of putting a lot of pressure on them by not giving them a fair share of our time and by kind of putting expectations on them to be the 'normal' ones...I don't think we knew we were doing it except by saying things like, 'Thank God you're okay."*

Some children may also worry that they too will become unwell – *"Will this happen to me too?"* They may be embarrassed and self–conscious about the situation and withdraw from the family and their brother/sister.

It is very important to discuss the situation openly within the family, educating everyone about the illness and the importance of each person having a role in supporting the person with the illness (and each other) at this time.

Partners

Providing care and support can be particularly draining and tiring for a partner. The mental illness, increased tension, decreased communication and reduced intimacy, may all combine to change the relationship significantly. As a result, over time, the relationship may change and many carers say that they feel a sense of grief and loss that they no longer have the relationship with their partner that they once did.

Many people who care for a partner with a mental illness struggle most at times when the burden of care becomes overwhelming, leaving some to consider leaving the relationship. This in turn may lead you to experience strong feelings of guilt for considering abandoning her/his partner in their time of need.

It is important you try to relieve the burden by looking for other avenues of support and by giving yourself some time out. This not only provides a time to relax but also to step back and review the relationship and the situation. Individual and/or couple counseling may also help provide support, reassurance and strategies to cope with difficulties.

Friends

Friends who take on a caring role may struggle to find the right balance in their relationship and they may worry about over–stepping the mark. There can be a fine line between being intrusive and being supportive. It can sometimes be difficult to maintain the friendship and, at the same time, encourage the person to seek treatment. It can also be difficult when only one person in the friendship group is aware of the problem and can't share it with others.

While you may feel privileged that your friend has confided in you, it can become difficult if she/he becomes totally dependent on you. It is important to try to maintain open discussion and encourage the person with the illness to develop other supports and strategies from friends, family and/or support groups.

Finding the right balance

One of the big challenges for family and other carers is the issue of accommodating the person's illness, her/his behaviour and needs, and the impact this has on family life. Sometimes, because you adapt so much to the changes in your life, you begin to see the situation almost as a new kind of normal.

With changes at home, your behaviour may alter and your quality of life may be affected because you are trying to make life easier for the person with the illness.

Many carers describe this as *'walking on egg shells'*. Remember, you also have needs and at some point, you may have to put those needs first.

Many carers say it's important to access professional help to assist them in their caring role and to provide practical strategies and reassurance.

> *"The only way I could get the balance right was with the direction of a psychologist who helped me learn what I needed to know, and when and how to respond to different situations."*

I NEVER EXPECTED TO FEEL GRIEF AND LOSS

Many carers have also described experiencing what is referred to as 'anticipatory grief'. This refers to a feeling of loss and sadness at 'what might have been' – the fear that someone may never reach his/her full potential, fulfill hopes and dreams or that the relationship may never return to what it was.

> *"There's this awful grief that goes on. It's not like when someone dies and the grief is there for a year or so and then it's finished. This type of grief goes on and on. You think this time it will be all right, but then you fall in a hole again. It is continual and that's what wears me down."*
>
> *"I clearly recall the shock of recognition I had when, some months after my son had been diagnosed, a mental health professional asked how I was handling my grief. "Grief? Me? But he's alive?" And then, "Yes. Of course that's what it is." It was almost a relief. Finally I could identify the awful, heavy feeling that had dragged along with me as each day I continued putting one foot in front of the other. Finally I could begin to talk about my engulfing sadness that my beautiful boy had already lost almost a year of his youth to this awful, awful illness that I found so hard to understand. I grieved that his friends had moved on from him – they didn't understand either and at 20 they didn't have a second to waste as they hurtled on into their own futures. I grieved at not having been able to prevent this dreadful illness, at not being smart enough, and at somehow being responsible for his pain…".*
>
> *"But my grief, my sense of loss, was also for me, for my innocence, for the loss of my perfect family. After years of sharing my son's triumphs, joys and aspirations with my own circle of family, friends and acquaintances, I could no longer do this. And I was angry that this should have happened to me, who'd tried so hard to do it all the right way."*
>
> *"It helped me to talk about my feelings; it helped me to read books on grief and loss, and the various stages one goes through. It's true, much of it is not the same, but there are similarities and I knew instinctively that, whatever the course of my son's illness, we would never be able to go back to those earlier, simpler days. And there was grief in that too …"*
>
> *"Small achievements, like getting out of bed for the day, were the victories we would learn to celebrate. I still feel sad and empty when I look at her childhood photos. When she was paranoid and argumentative*

> *I would wish it all away and resent the ugliness of mental illness. When she died I felt relief that the madness was over but absolutely devastated that we had lost her for eternity. I still want her back.”*

HOW ON EARTH AM I GOING TO COPE?

For many people who find themselves in a caring role, fear, concern and worry are always present, even when they’re not with the person for whom they care. They may wake up thinking about the person and even when they are busy doing other things, the person is always in the back of their mind. They wonder how he/she is. They hope he/she is okay and safe.

> *“Anger was only upsetting me and our whole family atmosphere was affected. Tension was created, I found it hard to continue through my day and I had no positive results from my outbursts. I had to realise that my anger was only affecting me and not working so I stopped being angry and found other methods of expressing my opinion.”*
>
> *…I had to take a good look into myself and try to analyse my reactions and behaviour and understand what impact I had on other people. An interesting development occurred when I investigated alternative options of dealing with people and life. I discovered that I had stumbled onto an opportunity for personal growth. It is the irony of life, the harder the challenge the more you learn.*

I FEEL LIKE I AM GOING TO EXPLODE...I NEED HELP TOO

> *“Caring for someone with a serious mental health condition can be socially and emotionally isolating. It is difficult to navigate these seas without incurring some personal problems along the way. I developed two sides to me – the public “I am coping/I’ve got it together” face and the private secret face that only I knew. I felt I had to keep things together on the surface because people were depending on me to help my sister and my brother as well as dealing with my own family’s needs. I was being torn in several directions and eventually I thought I was going to explode.”*

One way of taking care of yourself is to recognize when you need more help and seek support. Monitor what you’re thinking and how you are feeling. Are you experiencing more than the usual number of headaches, tightness in your muscles, lack of sleep or poor concentration?

Remember that you are merely human and have needs of your own. Continually putting them off, or not allowing time for yourself, will only make you resentful, irritable and could eventually make you unwell.

- Allow time each week to do something you enjoy, something to make you feel relaxed, refreshed and that life is good.

- Eat regularly and well. Poor sleep and diet will only add to your overall stress levels.

- Exercise as much as possible – even a short brisk walk will help.
- Plan to take regular time out and/or holidays – and take them.
- Put in clear boundaries with the person you care for. Be clear about what you can, and cannot do – and stick to it.
- Ensure there is at least one supportive person with whom you can talk confidentially. It is really easy to lose your perspective and sense of humour if you feel isolated.
- Remember that your GP can be a source of help. Take a friend with you if you think you may not be able to tell the doctor how you are feeling.
- Knowing about the mental illness you are dealing with will help you to understand it and act appropriately, even if the person you care for doesn't want to know.
- Joining a carers group may help relieve isolation, stress, loss of humour and loneliness as well as helping you to understand different types of illness.
- Seek advice from the team involved with providing care if you can – if not a Carer Consultant/Family Liaison Worker can help get answers for you.
- If you feel you should be receiving services that you're not getting, don't be too proud or too afraid to complain – don't just cope all by yourself.

SOMETHING OR SOMEONE'S GOT TO CHANGE. MAYBE IT'S ME.

So much of your role as a carer is about supporting the person with the mental illness. You helped them to see a GP, and to find and start treatment. You monitor their medication. Your thoughts, conversations, lifestyle, worries, lack of sleep, frustrations, efforts and energy have been mainly directed towards the person you care for. What support is there for you? What support is right for you?

> *I am convinced that the transition from purposeful coping to recovery came about when I faced my fear of losing my brother and understood that this journey was about sharing the load with others. Reaching out for help from mental health organisations, support agencies and professionals, really made a difference at times.*
>
> *I have learned that I CAN make a difference in certain areas of his recovery but there are times when I have also had to accept that I have NOT been helpful in my attempts at caring. Ultimately I had to really understand that my brother was his own person, an adult who had the right to make his own decisions, that stepping back and letting him exercise his rights was essential.*
>
> *My family and I have learned that it is important to become informed about dealing with mental illness – learn strategies that work eg how to support someone financially without creating dependency, how to*

> *recognise signs of early breakdown to intervene sooner, how to cope with dual diagnosis – drug/ alcohol dependency.*
>
> *Learning to say "no" helped me cope and helped me look after my own health. There came a time when I decided that I would only allow a certain amount of my time to be used up by my son and I learnt not to feel guilty when I was doing something for myself that I enjoyed. It was sometimes very hard not to feel guilty when my son had been home on his own in a bad way, but I decided I just needed to live a life too.*

Privacy

Some people like to maintain their privacy and keep to themselves when dealing with mental illness. However it is important that this does not prevent you from seeking support for yourself.

If you are struggling to support a person, don't think you are betraying a confidence because you talk to someone in order to get support for yourself. There is only so much you can do for other people if you're not physically and mentally well yourself.

Informal support networks

Some people say they prefer to rely on family and friends for support. They know you and they know the situation. This is fine however there may be times when you may need to have your opinions and actions challenged if you are going to move forward. You may need an independent sounding board – someone with whom you can be truly honest, rather than censoring some of your thoughts, particularly if you are feeling resentful, or thinking about leaving a relationship.

Counselling

Some carers find individual counseling helpful because it gives you time to off load everything in an uninterrupted way. This could be a constructive and safe place to voice all your worries, fears grievances and frustrations.

It can also be a way of learning some new ways of thinking about old situations and developing some new skills.

Support Groups

When it comes to support groups, there is a range of options and it's not one size fits all.

Talking to people who are in a similar situation may be helpful in gaining support. There are support groups just for carers. You could attend the group for as long as it meets your needs and find it helpful. The advantage is that people will know what you're going through because they have been there and you wont have to keep on explaining what is happening. Even if you don't attend for long, you may meet some people whom you can continue to see outside the group.

> *"I don't know if I have coped very well, there have been many times when I just didn't... After about 13 years into my daughter's illness, and*

> *with other health issues and business worries, I saw a 'Carer's Group' advertised. I went along and now don't know how I managed without the warmth, friendship, understanding and total support of this group, which has been invaluable. I believe this has helped immensely and has made a big difference not only to me, but the rest of the family. Personal counseling provided a confidential means of talking freely of my concerns and at the time helping me with strategies to deal with issues and challenges."*

There is a range of support groups but not all groups will suit everyone. It's important to find a group with a structure in which you feel comfortable. Some carers say the most important thing to look for in the group is a positive, forward–looking attitude and perspective.

What will work for you

You will probably need some time to think about what you might find helpful. You could get some help in deciding by discussing the options with your GP. Some people find support groups helpful because they hear how other people manage – whereas others find this overwhelming. Rather than participating in a group you may prefer to talk to one person on an ongoing basis – so individual counseling may best for you. Some people find comfort in spiritual support and counseling.

Remember, not every option works for everyone, so you need to choose what works best for you.

ANSWERS TO SOME COMMON QUESTIONS

For many years mental illness was not discussed openly in the community because of fear, ignorance or stigma. Most people can easily recognize when someone has a physical illnesses or disability and is happy to seek treatment from a GP or a specialist. This is not often the case with mental illness, particularly when it develops during the teenage years. We have all heard comments such as:

> *" He was moody and irritable, but we thought it was just being a teenager" " I just thought I was so stressed I could not think straight" "I know I drink too much, but it blocks out all the bad thoughts I am having"*

It is common for people not to discuss what may be symptoms of mental illness with family or friends. Negative views, or stigma about mental illness, are often due to lack of information or experience, misunderstandings, or cultural beliefs.

Some people from different cultures or Indigenous people feel okay about accessing normal services however some may need to be referred to specialized services where their specific language and/or cultural needs are able to be given particular attention.

What if I am worried that my relative or friend is becoming unwell?

It is important to encourage the person to seek help. Talking with someone about the situation is also important for you. If the person is being treated by a mental health service then speak with their Case Worker.

If the person is being treated by their local GP then this may be a good place to start.

Advice, information and assistance can also be obtained from the State/Territory Mental Health Service. Other options for help include Private Psychiatrists and community organisations *(see Contact Details section on page …..)*.

What information will services need to know?

Asking questions is how services find out what is happening and how they might be able to help. Being prepared for these questions will help you feel less anxious and enable the services to assess the situation better. Some questions that you may be asked include:

- Is the person talking about hurting themselves or other people?
- Has the person already been diagnosed with a mental illness?
- If yes, which one? Who diagnosed the illness? When?
- Are they currently under the care of a Doctor or other services?
- Is the person willing to accept help?
- Does the person have any medical conditions?
- Is the person on any medication? If so what?

- Does the person misuse substances? (alcohol, illegal drugs, inhalants)
- What is happening that is worrying you and for how long has it been happening?
- What has prompted you to seek help now?

What can I do if the person refuses help?

Sometimes people don't feel they need help or refuse to accept help. Everyone is an individual and there may be many reasons for refusing help such as:

- What will people think?
- I live in a small town – everyone will know
- Men are strong, they don't get sick
- I am too anxious to talk to anyone
- I am not unwell

In other cases denial that anything is wrong may be one of the characteristics of the illness.

This can be a difficult situation for families and friends who are concerned about the person. In circumstances where the person is very unwell and refusing to acknowledge this, the Mental Health Act can be used to get help for the person even if they do not agree. Talk with your GP or your local MHS for information and advice about getting help for your relative or friend under the Act.

What do I do if I'm concerned someone needs help urgently?

If the person is talking or behaving in a way that suggests they are going to hurt themselves or another person, help needs to be obtained urgently. If you feel:

- Afraid for the person you care for
- Afraid for yourself or another person
- Helpless or despairing
- That you cannot keep on caring
- That you do not know what to do

Don't be afraid to contact someone and ask for help, even if you are not sure if it's the right person. If they cannot help they should be able to tell you who can.

Before you call:

- Take a few deep breaths
- Stay as calm as possible
- Stay safe
- Decide who might be the best person to contact

When you call:

- Say who you are and what is wrong
- Say what is needed
- Trust what they say to you
- Say if there is any reason why you cannot do what they say

Your local mental health service can provide you with information, advice and assistance in most cases.

However, if you feel that you, or anyone else is in real danger, dial 000 and ask for the Police. The police are authorised under legislation to take a person to hospital to have a psychiatric assessment.

What happens after the person has been assessed?

This depends on individual circumstances and how unwell the person is. Sometimes the person may need to be admitted to hospital, sometimes the person can get treatment and support in the community from the mental health service, private mental health practitioners, other community services or their GP.

In some situations you may notice that the person you care for has become more upset or anxious after their assessment or appointment. They may have been talking about issues they find difficult, or their relationship with you. Listen quietly and calmly to what they have to say without becoming defensive.

Sometimes people just want to talk about their concerns. They are not necessarily looking for answers. Make it clear they have your full attention and you are listening properly. You might like to save any suggestions for a later conversation.

If your conversation becomes difficult or the person you are talking to gets angry, stay calm, be firm, fair and consistent, admit if you are wrong and don’t lose control.

Often just spending time with the person lets them know you care and can help you understand what they are going through.

What will happen when my friend or family member is admitted voluntarily to hospital?

When your family member/friend first comes into the hospital a doctor will examine them and decide whether they need treatment and if so, whether this should happen in hospital or in the community. If the doctor thinks they would benefit from treatment from the service, they will also make sure that they agree to admission and that they know what that means for them. They will be given a consent form to sign, which they should only complete if they understand and agree to the admission and the treatment offered.

What if my friend or family member wants to stop their treatment?

Voluntary patients have the right to stop treatment whenever they wish, this includes leaving the hospital or deciding to stop attending community mental health services and they have the right to refuse any treatment offered to them. However, if they do decide they would like to leave the hospital or stop attending appointments at a community mental health service they should talk to someone from their treating team to discuss their plans.

Can my family member/friend who is a voluntary patient be made an involuntary patient?

Yes. If your family member/friend changes their mind about staying in hospital and wants to leave against all the advice of the treatment team then a doctor will examine the person again. If the doctor feels that your family member/friend are so unwell that there are risks to the health and safety of themselves or other people then they have the power to keep them in hospital for their own good. This means they become an involuntary patient.

What will happen when my family member or friend is admitted involuntarily to hospital?

When your friend or family member first comes into the hospital for admission, a doctor will examine them to determine whether they need to stay in the inpatient unit. In some situations where the person with the mental illness is very unwell or may feel like hurting themselves, or another person, it may be necessary for a short period of time for the doctor to make a decision that this person MUST be admitted to hospital. This is called an involuntary admission. The legislation that enables this to occur is called the Mental Health Act.

In this situation the person with the mental illness will, within a short period of time be examined by a second doctor. If the second doctor agrees with the first doctor then the involuntary admission will continue for a further time.

If this situation occurs the doctor will also have to decide how much information he or she is able to discuss with you. Once the person with the mental illness is feeling better they will be able to decide how much information they want to share with you.

It is important during this period that staff listen to your concerns and explain as much as they are legally allowed to do.

Legal orders are only allowed to be used in cases where a person does not understand how unwell they are and refuses to have any treatment, or in cases where because of their illness they may pose a risk to themselves or another person. The order usually stays in place until the person is well again. However during this time the person with the mental illness, or you, as the person who cares for them may challenge the legal order if you think it is unfair.

If either the first or second doctor decides that they don’t need to be admitted as an involuntary patient, they may consider admitting them as a voluntary patient or consider involuntary or voluntary treatment in the community.

Can my friend or family member who is an involuntary patient leave the hospital?

While they are being detained as an involuntary patient your friend or family member cannot leave the inpatient unit unless their doctor says they can. If they are given leave it will be for a specific purpose and they must comply with the conditions of their leave.

If they do leave the hospital without permission, a police officer or someone else authorised by their doctor may pick them up and take them back.

If they want to leave the hospital to see someone, or attend an appointment, they can ask their doctor for permission. If the doctor thinks that the leave is for a good reason and will be good for them then they may be given permission. The doctor may cancel your friend or family members leave if they believe that they are likely to come to harm, harm someone else or become more unwell, or if they have not done what they agreed to while on leave.

What does this public or private mental health service do?

The service assesses and helps people with mental illness. Our goal is to provide you and your loved one with a service that is based on each person's individual needs. We have experienced staff who have expertise in helping people with all types of mental illness as well as helping parents, carers and other family members. Our aim is to help people with a mental illness to get well quickly and to return to live in the community as soon as possible.

There is a lot of paperwork that needs to be completed when a person with a mental illness is admitted to a public or private mental health service. This is also a time when you can tell staff about your relationship with the person and what you do to support them.

Part of this process may involve asking the person you care for, for permission for the staff to talk with you about your experience of living with them, or supporting them. Sometimes the person you care for may be so unwell that they say that they do not want staff to talk with you. Whilst staff have to respect their wishes at that time it is important for you to understand that the staff will keep discussing this matter with the person as they become well as their feelings about this issue are likely to change as time goes by.

Staff recognise how important carers are in the ongoing support of a person with a mental illness. They will therefore be working with the person to encourage them to include you in their care and planning for their discharge.

You will also be given information about the Carer Consultant/Family Support Worker who will contact you within the next couple of days. You may also make contact with this person at any stage to obtain extra information to help you to understand what is happening.

Being discharged from the hospital/clinic

The person you care for may only be in hospital for a short period until their illness has been stabilised. They may be referred to a less intensive level of service such as a community service or private psychiatrist.

Discharge planning will start from the moment your friend or family member starts receiving treatment from the mental health service. The treating team will also involve you in these discussions wherever possible and appropriate.

When your friend or family member leaves the hospital they will have a discharge plan that contains arrangements for:

- The level of on–going care necessary
- Who will be available to provide this care?
- Where the person will live?
- Who will be responsible for medication?
- Provision of information and support to everyone involved
- Development of a relapse prevention plan

It is important that you feel fully involved at all stages of care, including the decision to discharge the person. This is a process of handing over care and carers are critical partners in this process. Ideally, time should be allowed for you to make choices about:

- Taking on, or continuing to fulfil the role of carer
- How much and what type of care you are prepared to provide taking into consideration your other family commitments, work, health education and social activities.

Some people feel they have no choice in this matter even when their personal and physical resources have been exhausted, where they are afraid of the person with the illness, or where that person will not allow you to have enough information to provide proper care. This is an extremely difficult situation for carers who want to help. Services must listen to your concerns and provide you with information regarding people and services that can help you.

What is a Community Management /Treatment Order and when are they made?

Community Management/Treatment Orders are made where a person is unwilling or unable to follow a treatment plan on a voluntary basis but can be treated involuntarily in the community rather than admitted to a hospital. If your friend or family member is on a Community Management/Treatment Order they can live in a hostel, at home with you or independently, but they have to follow a treatment plan that is developed for them.

The treatment plan will include things like:

- Who is responsible for your friend or family member’s treatment
- Where the treatment or care is to take place e.g. home
- How often the person treating or caring for your friend or family member must visit them or vice versa
- Medication and/or other treatments your friend or family member will need to receive under the order.

The mental health team will work with your family member/friend during the period of this Order to help them develop insight, understanding and knowledge of the mental illness and its management. You, as their carer should also have input at this time.

Dealing with difficult behaviour

Much of the care of people with a mental illness takes place in the community with brief visits to hospital only if essential. It is therefore possible that you may, from time to time, need to deal with some difficult behaviour. This will depend on the nature of the illness and will vary from person to person. There is a lot of misunderstanding about mental illness but generally people find it uncomfortable to be with people who might be behaving strangely or are withdrawn and unhappy. Often when someone becomes distressed they seem to be like a different person. Some of you may become angry about what appears to be laziness or disinterest. Most people do not realize that some mental illnesses and medications can make people unable to motivate themselves or to see how they affect other people.

Those people with severe illnesses who experience hallucinations or delusions may not be able to understand how their illness affects them; the voices they hear and beliefs they have are real to them, and therefore they think their actions are entirely appropriate. You may find that at first you try to prove to them that their beliefs are wrong, but it is a pointless exercise. It may be more helpful to explore their feelings and plan how to cope with them, or to distract their attention. Sometimes when a person is recovering they may remember what was going on inside their head, but often they cannot.

Medication may make people drowsy and unable to think quickly and clearly; some medication can affect sleep or make people more anxious. You are often in the best position to notice if behaviour is worsening, or if medication is having an adverse affect. If the person also uses alcohol or drugs it may prevent medication working effectively.

Dealing with unusual thoughts or behaviour

Unusual thoughts or behaviour often cause problems for families, friends and carers. The problems that can arise include:

- Disordered thinking and speech which may indicate paranoia and delusions
- Social withdrawal
- Loss of motivation

- Depression, attempts at self harm or suicide
- Aggression (usually verbal)
- Risky behaviour (see below)

Some suggestions for managing these situations:

- Respond calmly and with tolerance
- Communicate clearly, simply and without undue emotion
- Be patient, give time and space to let coping begin again
- Be realistic in your expectations
- Be clear and consistent in what you say and do
- Avoid letting their pessimism influence your thinking and feelings
- Take action in small steps

Disordered thinking and speech

It is important to avoid going along with or humouring the person you care for by agreeing with their perceptions or beliefs. You can say that you do not see or hear the things they do, and that 'delusions' are part of their illness – which you can help via distraction, talking about how they feel, encouraging them to ignore voices etc.

Try to avoid:

- Confronting or laughing at their expressed thoughts
- Undermining them by telling them they are 'stupid' or 'mental'
- Ignoring them by remaining silent

Risky behaviour

Aggressive or risky behaviour is often a response to a feeling of losing control. It will help you if you can try to:

- Understand the person's response: although the response may be extreme, real problems have usually triggered it.

- Recognise the triggers: what are the situations that make them fear losing control? Learn to recognize the early warning signs.

- Have realistic expectations of what the person you care for can achieve, and give plenty of encouragement. Try to avoid criticism or nagging. However let your personal knowledge of what works guide you.

- Give them space and time. The person you are caring for needs to regain control and learn to cope again. If there is no risk to the person or other people, you could leave the room or go out for awhile until the emotional temperature has cooled.

- Provide reassurance. The person you care for needs to know that you support them fully as they regain control over the situation and cope again.

- If the person you care for is saying that they want to die, or to kill themselves, it may help to encourage them to talk about why they feel like this. They may be afraid of being alone, of being unwell forever or they may be overwhelmed by feelings of paranoia or guilt. It can also help to let them know that you understand why they may feel so desperate but that you will help them get through it. Discussing such feelings rarely makes them worse. It will help if you can keep calm and discuss how you can support them during this time. Try to give them hope that it will pass.

Know whom you should contact and how to do this if you have real fears for your safety.

If the behaviour of the person you are caring for is causing you concern, speak to the mental health team involved, they should be able to help you with this.

WHO CAN HELP YOU

Information regarding diagnosis, treatment and medication

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) has developed a number of guidelines to assist you to gain a deeper understanding of specific diagnoses. These are available in printed form or from their web site www.ranzcp.org.

CARER ORGANISATIONS

Carer Advisory and Counselling Service

This organization can refer you to services and tailored information and resources to support you in your role. They can also provide you with a Carer Support Kit containing general information about issues such as looking after yourself, managing health care and medications, loss and grief and an Emergency Care Kit.

Call Freecall 1800 242 636

Commonwealth Respite and Carelink Centres

Provide assistance to carers to access respite or to take a break and provides information about community and aged care services. They can provide information and advice about respite options and help with organizing planned or emergency respite.

Visit www.commcarelink.health.gov.au or call **Freecall 1800 052 222**. For after hours emergency respite call **Freecall 1800 059 059**

The Association of Relatives and Friends of the Mentally Ill (ARAFMI).

ARAFMI's aims are to:

- Ensure state and federal governments recognise the role, contribution and needs of carers.
- Advocate for policy changes and improve services to address carer needs.
- Support carer involvement in the planning, delivery and evaluation of services for people with mental illness and their carers.
- Facilitate communication between carers and government.
- Establish partnerships between carers and service providers.
- Encourage research on best practice in carer support.

Carer issues are identified and worked on through monthly Carers Network meetings and specific working groups. Carer issues and policy positions are taken to State and Federal government officers and Ministers via:

- Regular meetings with the Mental Health Branch;
  - Letters, submissions, deputations;
  - Liaison and representation on government committees.

On a local level carer representatives are often asked to:

- Sit on interview panels for staff selection of mental health services staff;
- Represent carers at mental health service quality meetings;
- Represent carers at mental health service strategy workshops;
- Advise mental health services on carer issues and perspectives.

ARAFMI NSW Information and Support Line	➔	**Ph: or regional:**	**(02) 9332 0700 1800 655 198**
ARAFMI QLD 24 hour support line	➔	**Ph: or regional:**	**(07) 3254 1881 1800 351 881**
ARAFMI TAS	➔	**Ph:**	**(03) 6228 7448**
Mental Health Carers NT formerly NT ARAFMI	➔	**Ph:**	**(08) 8948 1051**
ARAFMI WA	➔	**Ph: or rural:**	**(08) 9427 7100 1800 811 747**

There are a number of other organisations available for support. Many have a website with generally a lot of information which you might find helpful. Others have support telephone services.

Carers Australia (National) For family carer support and counselling you can contact your state or territory Carers Association on the same telephone number	→	**Ph:** 1800 242 636 **Website:** www.carers.australia.com.au
SANE	→	**Ph:** 1800 187 263 **Website:** www.sane.org
Beyondblue: ***the national depression initiative***	→	**Ph:** 1300 224 636 **Website:** www.beyondblue.org.au
Mental Illness Fellowship Australia	→	**Ph:** (08) 8272 1018 **Website:** www.mifa.org.au
Multi Cultural Mental Health Australia	→	**Ph:** (02) 9840 3333 **Website:** www.mmha.org.au
Orygen Youth Health	→	**PH:** (03) 9342 2800 **Website:** www.oyh.org.au
Headspace – Kids Help Line A 24–hour telephone and online counselling service for 5 to 25 year olds in Australia.	→	**Ph:** 1800 551 800 **Website:** www.headspace.org.au
CounsellingOnline Free alcohol and drug counselling online 24–hours–a–day, 7– days–a–week	→	**Ph:** 1800 888 236 (Counselling) **Website:** www.counsellingonline.org.au
Alzheimers Australia **National Dementia helpline**	→	**Ph:** 1800 100 500 **Interpreter:** 131 450 **Website:** www.alzheimers.org.au
Alcoholics anonymous List of telephone contacts	→	**Website:** www.aa.org.au
Grow List of state groups	→	**Website:** www.grow.net.au
Anglicare List of state contacts	→	**Website:** www.anglicare.org.au
Centacare List of state contacts	→	**Website:** www.centrecare.com.au
Relationships Australia List of state contacts	→	**Website:** www.relationships.com.au
YWCA List of state contacts	→	**Website:** www.ywca.org.au

Where to go for help

- **Your general practitioner.**

- **Your community health centre.**

- **Your community mental health centre.**

For immediate counselling assistance, contact

Lifeline on 13 11 14

24 hour confidential telephone counselling to anyone within Australia

For information on services, check the Community Help and Welfare Services and 24–hour emergency numbers in your local telephone directory.

IT IS SUGGESTED THAT THIS BECOMES AN INSERT WITHIN THIS BOOKLET

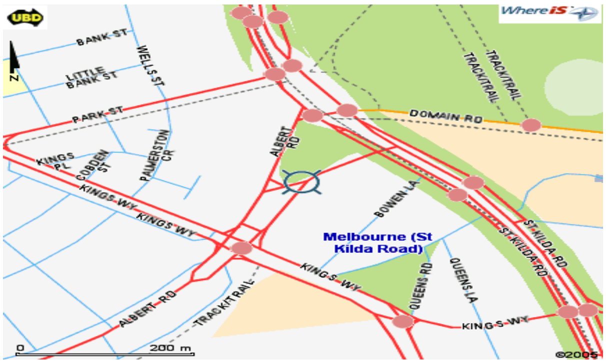
Location of the Service

INSERT NAME AND ADDRESS OF THE SERVICE
Ph:
Email:

The service is located between ……. and ……., close to ……….. and has good access to public transport.

INSERT SECTION FROM STREET DIRECTORY

eg



Trams

INSERT INFORMATION

***Trains*The closest train station IS……..**

Buses

INSERT INFORMATION

VISITING HOURS:

Carers, family and friends may visit outside of program hours, from …am to….. pm weekdays and 9 am – 8:30 pm over the weekend. Whilst we appreciate the importance of retaining close contact with families and friends, it is also important that the person you care for participates in all therapeutic activities appropriate to the stage of their illness. We understand that some families may live some distance from the hospital and therefore will need a degree of flexibility in visiting times.

APPENDIX A: Project Reference Group

Ms Rosemary Warmington	Chief Executive Officer, Carers Australia SA
Dr Maria Tomasic	Psychiatrist
Ms June Mattner	Director of Clinical Services, Ramsay Health Care (SA) Mental health Services
Dr Sharon Lawn	Public sector service provider
Mr Anthony Fowke AM	National carer representative, MHCA Board
Ms Pat Sutton	Carer
Ms Ann Smith	Consumer
Ms Robyn Milthorpe	Australian Government Department of Health and Ageing
Ms Helen Schenscher	Public sector service provider (resigned 11 May, 2010)
Ms Janne McMahon OAM	Project Manager on behalf of the Network
Ms Judy Hardy	Project Officer

APPENDIX B: Proposed National Standards for Mental Health Services

Standard 7. Carers

The MHS recognises, respects, values and supports the importance of carers to the wellbeing, treatment, and recovery of people with a mental illness.

Criteria

7.1 The MHS has clear policies and service delivery protocols to enable staff to effectively identify carers as soon as possible in all episodes of care, and this is recorded and prominently displayed within the consumer’s health record.

7.2 The MHS implements and maintains ongoing engagement with carers as partners in the delivery of care as soon as possible in all episodes of care.

7.3 In circumstances where a consumer refuses to nominate their carer(s), the MHS reviews this status at regular intervals during the episode of care in accordance with Commonwealth and state / territory jurisdictional and legislative requirements.

7.4 The MHS provides carers with a written statement, together with a verbal explanation of their rights and responsibilities in a way that is understandable to them as soon as possible after engaging with the MHS.

7.5 The MHS considers the needs of carers in relation to Aboriginal and Torres Strait Islander (ATSI) persons, culturally and linguistically diverse (CALD) persons, religious / spiritual beliefs, gender, sexual orientation, physical and intellectual disability, age profile and socio–economic status.

7.6 The MHS considers the special needs of children and aged persons as carers and makes appropriate arrangements for their support.

7.7 The MHS has documented policies and procedures for clinical practice in accordance with Commonwealth, state / territory privacy legislation and guidelines that address the issue of sharing confidential information with carers.

7.8 The MHS ensures information regarding identified carers is accurately recorded in the consumer’s health record and reviewed on a regular basis.

7.9 The MHS provides carers with non–personal information about the consumer’s mental health condition, treatment, ongoing care and if applicable, rehabilitation.

7.10 The MHS actively seeks information from carers in relation to the consumer’s condition during assessment, treatment and ongoing care and records that information in the consumer’s health record.

7.11 The MHS actively encourages routine identification of carers in the development of relapse prevention plans.

7.12 The MHS engages carers in discharge planning involving crisis management and continuing care prior to discharge from all episodes of care.

7.13 The MHS provides information about and facilitates access to services that maximise the wellbeing of carers.

7.14 The MHS actively seeks participation of carers in the policy development, planning, delivery and evaluation of services to optimise outcomes for consumers.

7.15 The MHS provides ongoing training and support to carers who participate in representational and advocacy roles.

7.16 The MHS provides training to staff to develop skills and competencies for working with carers.

7.17 The MHS has documented policies and procedures for working with carers.

APPENDIX C: Focus Groups and consultations

CONSULTATIONS AND TELECONFERENCES	PARTICIPANTS	TOTAL
Melbourne Date: 17th February, 2010 Chair: Ms Janne McMahon Facilitator: Ms. Judy Hardy	4 public sector carer consultants 1 private sector carer consultant 4 carers 2 public sector service providers 1 private sector service provider 7 NGO representatives (Peninsular Carers; Victorian Mental Health Carers Network; Grow; The Haven Foundation) 3 consumers)	22
Adelaide Date: 22nd February, 2010 Chair: Ms. Janne McMahon Facilitator: Ms Judy Hardy	7 carers public sector 4 carers private sector 1 consumer 1 public sector service provider 1 private sector service provider 1 NGO representative (Mental Illness Fellowship of Australia)	15
Brisbane Date: 1 March, 2010 Chair: Ms Janne McMahon Facilitator: Ms Judy Hardy	3 carers public sector 3 carers private sector 2 public sector carer consultants 1 public sector consumer consultant 1 public sector consumer 1 private sector consumer 1 public sector service provider 3 private sector service providers 1 NGO representative (Carers Qld)	16
Launceston Date: 5 May, 2010 Chair and Facilitator: Ms Judy Hardy	4 Public sector service providers 2 NGO representatives (Carers Tasmania) 2 carers public sector 1 carer private sector	9
Brisbane Date: 2 March, 2010 Chair: Ms Janne McMahon Facilitator: Ms. Judy Hardy	5 public sector service providers – Queensland Health	5
Brisbane Date: 1 March, 2010 & 2 March General Practice	1 General Practitioner 1 Member Division of General Practice	2
Teleconference: NSW, ACT Date: 6th April, 2010 Chair: Ms Janne McMahon Facilitator: Ms Judy Hardy	2 carers public sector 3 private sector service providers 1 NGO Representative (ARAFMI)	6
Teleconference: NT, TAS, WA Date: 8th April, 2010 Chair: Ms Janne McMahon Facilitator: Ms Judy Hardy	4 carers public sector 3 public sector service providers 1 private sector service provider 3 NGO Representatives (AARAFMI, Carer Respite Centre)	11
Teleconference: NMHCCF, National Register Date: 8th April, 2010 Chair: Ms Janne McMahon Facilitator: Ms Judy Hardy	3 carers public sector	3
Consultation: Austin Health Date: 17 February 2010 Chair: Ms Janne McMahon	1 Assoc. Prof. Richard Newton, Medical Director, Mental Health Clinical Service Unit North East Area Mental Health Service, Austin Health, 2 Dr. Raju Lakshmana, Clinical Director, North East Area Mental Health Service, Austin Health Director of ECT, Mental Health Clinical Service Unit, Austin Health 3 Rod Marsh, Senior Clinical Nurse, North East Area Mental Health Service, Austin Health	3
Key people consultations: Dr. Margaret Leggatt Dr Robert Menz Mr. Peter Gianfransco Dr. Aaron Groves Nick Goddard	Internationally renowned carer representative Senior Medical Advisor, Medicare Australia Director, MIND, Northern United Kingdom Director of Mental Health, Queensland State-wide & Mental Health Services, Tasmania	5
	Total participants	97

APPENDIX D: Advance Directive for Treatment – Courtesy of

HYSON GREEN
CALVARY PRIVATE HOSPITAL

ADVANCED DIRECTIVE

An advanced directive is an expression of the patient's preferences of future mental health care and treatment. The directive is usually written when the patient is well and referred to when the patient is experiencing a relapse in their mental health. Thus the patient is preemptively able to communicate their preferences for care.

This advanced directive should be filled out in collaboration with a clinician and is a summary of an agreement between the patient, psychiatrist, hospital and any other concerned mental health professional.

It should ideally be adhered to as much as possible with the understanding that clinical needs will at all times override any preferences expressed in this document.

The Advanced Directive contains information on the following:

- Signatories to the document
- The treating team
- Significant others to be contacted
- Those ***not*** to be contacted
- Early warning signs and symptoms and action plans
- Preferred methods of transport to the facility
- Preferred treatment facility
- Preferred inpatient interventions
- Preferred medication at each stage of relapse
- Preferred treating psychiatrist/mental health professional/CATT etc
- Preference to ***not*** be treated by psychiatrist/mental health professional etc

Signatories to this document:

NAME	POSITION	CONTACT NUMBER
	Patient	
	Community Psychiatrist	
	Admitting Psychiatrist	
	GP	
	Community Mental Health Team	
	Partner	
	Parent	
	Friend	

Preferred Treating Team:

NAME	POSITION	CONTACT NUMBER
	Patient	
	Community Psychiatrist	
	Admitting Psychiatrist	
	GP	
	Community Mental Health Team	

Significant others to be contacted:

NAME	PHONE	RELATIONSHIP	SPECIAL TASKS	WHEN NOTIFIED

Who NOT to contact/visit:

NAME	RELATIONSHIP

Relapse Prevention Plan:

EARLY WARNING SIGNS	ACTION PLAN
MILD	
MODERATE	
SEVERE	

Preferred transport to hospital:

TYPE OF TRANSPORT	REASON
1	
2	
3	
4	

Preferred treatment facility:

FACILITY	REASON
MILD:	
MODERATE:	
SEVERE:	

Inpatient interventions:

INTERVENTION	REASON

Other interventions:

INTERVENTION	REASON

Preferred Medication:

MEDICATION	REASON

Medications *NOT* to be administered:

MEDICATION	REASON

Preference to NOT be treated by Mental Health Professional:

PROFESSIONAL	REASON

NAME:____

SIGNATURE:____

DATE:____

APPENDIX E: Ulysses Agreements – Courtesy Calgary Mental Health Services, Canada

The Ulysses Agreement

The Ulysses Agreement is a non-legal document that serves as a proactive plan. It is named after the Greek mythological hero, Ulysses, who asked his crew to tie him to the mast of the ship so he could resist the call of the Sirens. It might also be referred to as a Care, Treatment and Personal Management Plan. It allows for a parent with a mental illness to prepare some information for sharing and to make some decisions in advance of going through a period of incapacitation due to their mental illness. The plan can outline provisions for themselves, their family and the care of their children.

There are several considerations in developing this kind of plan:

- *It is not a legal document.* As an informal plan, it depends on good faith and cannot be enforced through the courts. For example, if the parent states in the agreement that he or she does not wish to change it without a defined process, it is legally open to be changed by the parent at any time. Laws about child protection, custody and confidentiality supersede the agreement. Service providers should consult with their supervisors regarding their own ability to enter into advance plans.

- *It typically takes a long time to develop a plan that will actually work in a crisis.* The effectiveness of the plan corresponds to the strength of the family's support network. If this network is not strong enough, early efforts to develop a plan may still be helpful but the plan itself may not work out as hoped. For example, a preferred caregiver may not be endorsed by child welfare authorities (if they are involved with the family). However, it is likely that the relationship between the person named by the parent and possibly the child will be respectfully considered by those who work with the family.

- *The parent must be well enough to make a good, safe plan.* Some parents, especially people living in smaller communities, may be too isolated to be able to enlist others to give sufficient support. The nature of some mental illnesses (paranoia, for example) may interfere with the parent's ability to trust others even in developing a plan. Also, parents may not be aware of past histories of friends and acquaintances that would preclude them from being good caregivers for their children.

- *Children can have an active role in the plan, as developmentally appropriate.* For example, a child may be the first person to notice symptoms in their parent, and should have the means to seek help for themselves and their parent. An adolescent may have strong views about issues such as alternative care, which should be respected as far as possible.

Basic Model of the Ulysses Agreement

A basic model of an advance plan for the care of children in the event of mental illness relapse should include the elements listed below.

1. **Dates, Names, and Contact info:** List the people named in the agreement and their phone numbers. List the people to be informed about the agreement. The date is important because this agreement should be reviewed frequently as the information may change quickly.

2. **Purpose:** The purpose of this agreement is to provide a clear set of guidelines for actions to be taken by members of the support system if the parent exhibits symptoms of the illness which interfere with the parent's ability to provide good care for the child.

3. **Symptoms:** List the symptoms that the parent making the agreement would like others to notice and respond to, and describe the most helpful way to respond. Often it is the children who first notice a worsening of symptoms in the parent and they need to know how to get help quickly.

4. **Communication:** Record how the writer would like to deal with the issue of confidentiality, and attach signed consents if desired. Even with consent, no more information than is necessary for the implementation of the Agreement should be shared. The action plan can describe who the writer would like contacted, the order of response, as well as instructions about treatments or medications that have been helpful in the past.

5. **Plan of Action:** Record the parent's wishes for support services.

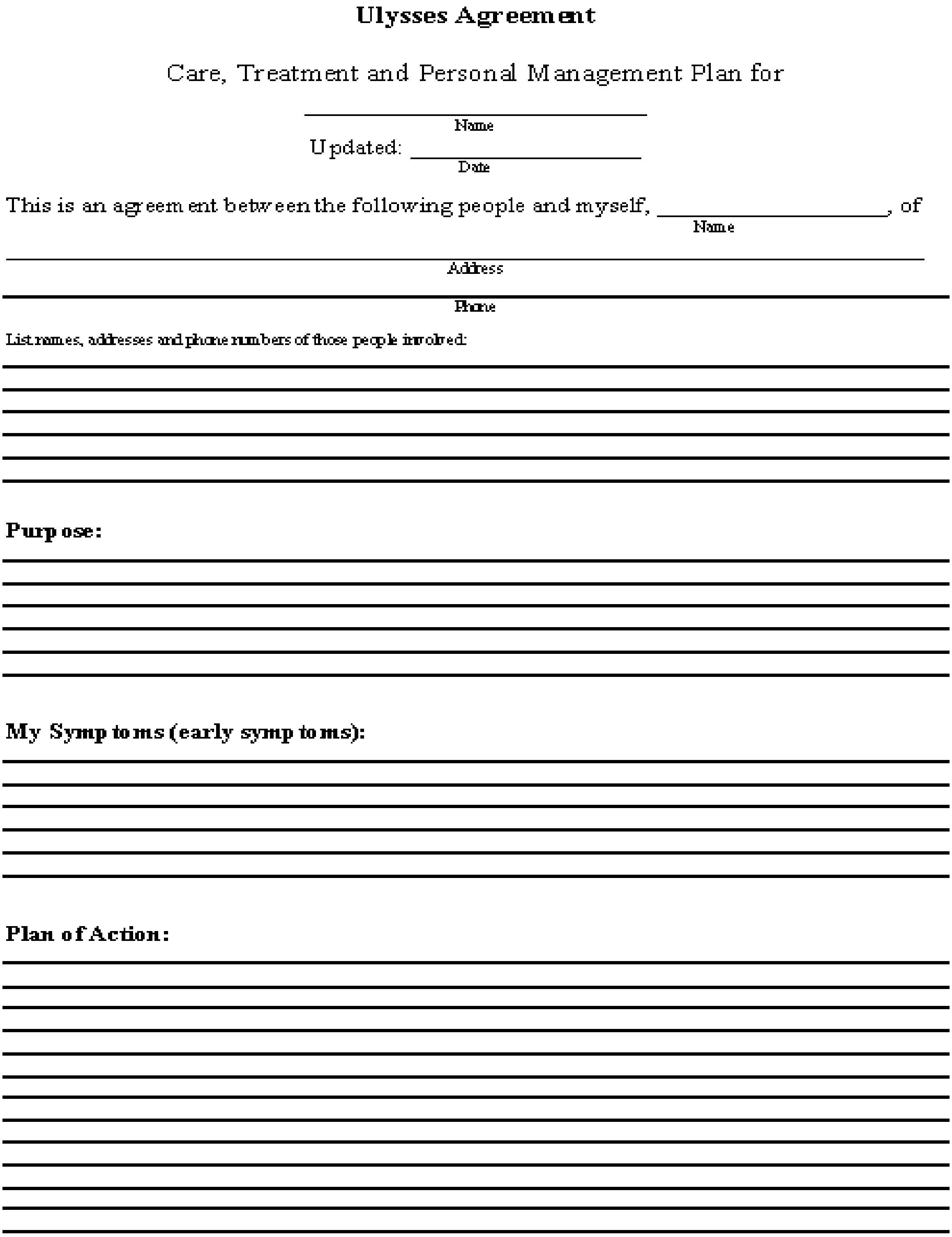
6. **Child Care Information:** Record the parent's wishes regarding the care of their child(ren), including any information about allergies, special needs, favourite foods or toys, daily routines, and so on.

7. **Involvement of the Children:** Children can be a valuable resource to include in the agreement, where possible. They are often well aware of their parent's symptoms and, depending on their age, could be the first to get the Agreement plan into action when necessary. Involving children appropriately can increase their sense of security as well as their compliance with the Agreement.

8. **Cancellation:** Describe the manner in which the Agreement can be cancelled. The purpose of the Agreement is so that it cannot be easily cancelled when the parent is actually ill, so it is wise to set up a process of cancellation that requires a period of time and a set of steps (note: this may pose a problem for some professionals who are unable to enter an agreement that does not allow for cancellation within a shorter specified time. It should be noted that this is an informal rather then a legally binding document, based on the good intentions to prevail, and wording to that effect may be included).

9. **Periodic Review:** Describe the manner in which the Agreement will be reviewed (at least annually is recommended, as well as after each time the Agreement is put into action). At the review, a copy of the Agreement should be given to everyone named in it, and each person should be clear about his or her role. A meeting can be helpful to introduce the people in the support network to each other and to allow everyone to express their care, concern and support for the family.

SAMPLE 1: Blank Ulysses Agreement and Addendum.



Ulysses Agreement

Care, Treatment and Personal Management Plan for

Name

Updated:

Date

This is an agreement between the following people and myself, , of

Name

Address

Phone

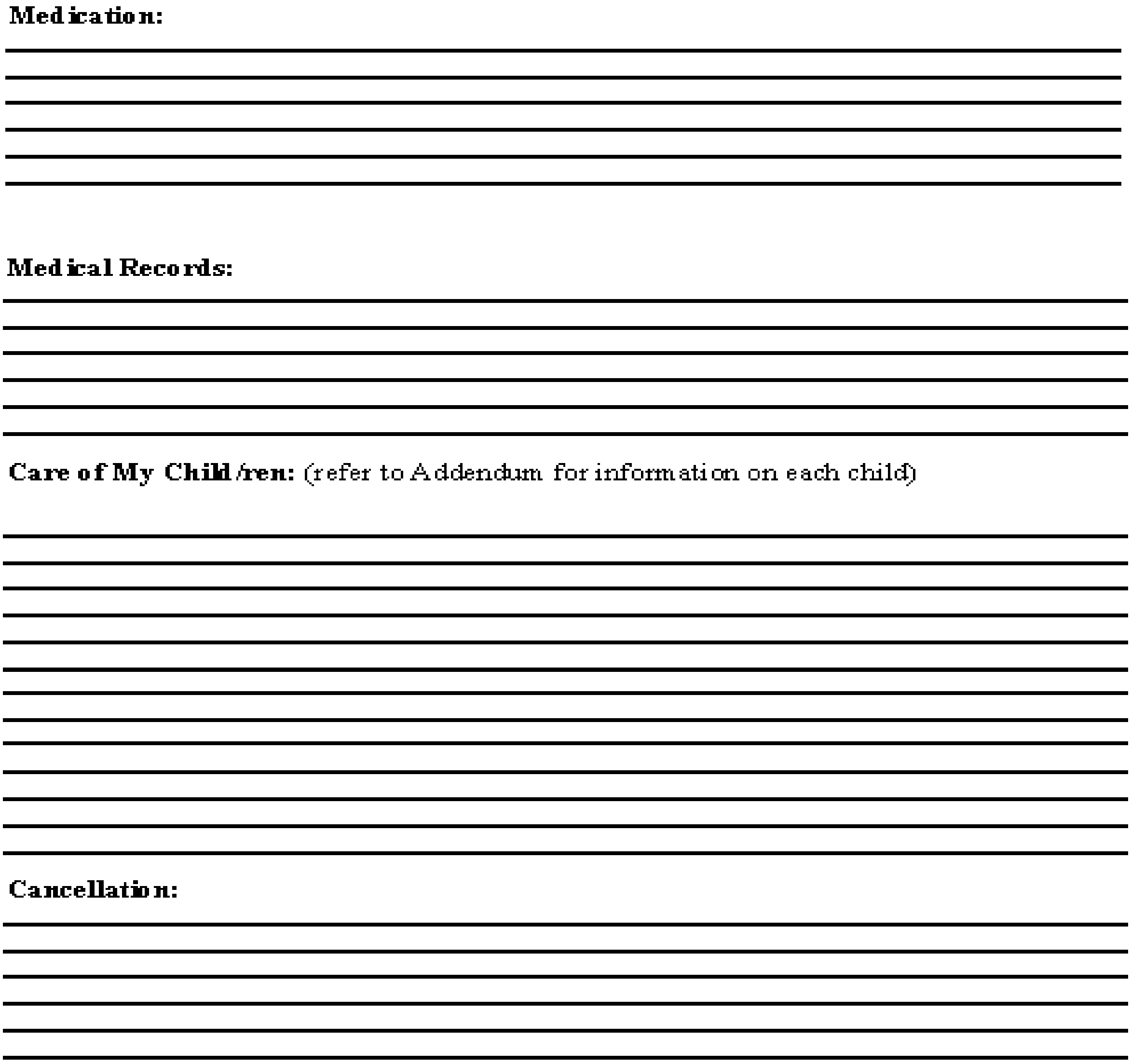
List names, addresses and phone numbers of those people involved:

Purpose:

My Symptoms (early symptoms):

Plan of Action:

SAMPLE 1: Blank Ulysses Agreement and Addendum (continued)



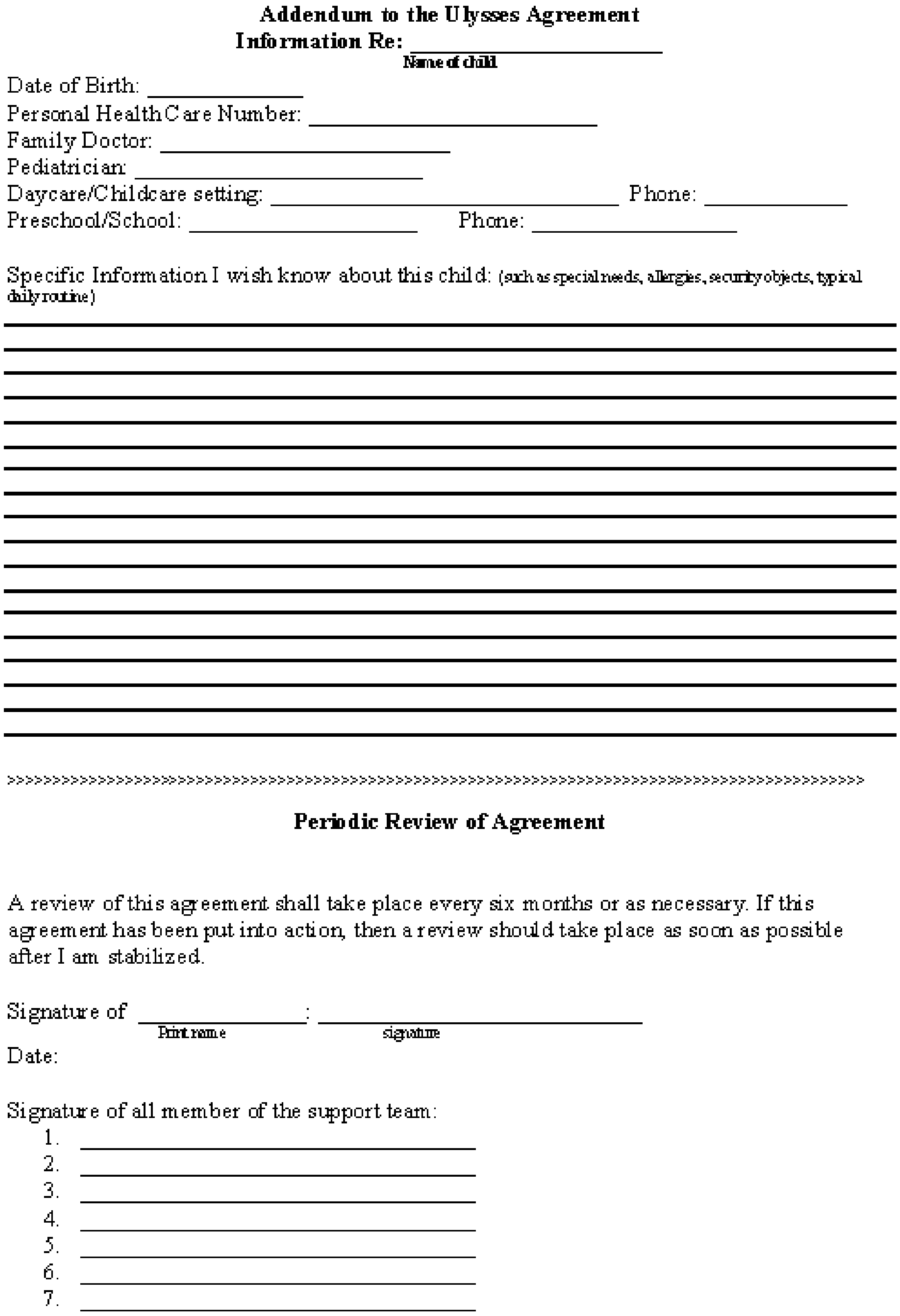
Medication:

Medical Records:

Care of My Child/ren: (refer to Addendum for information on each child)

Cancellation:

SAMPLE 1: Blank Ulysses Agreement Addendum



Addendum to the Ulysses Agreement

Information Re: ______________________
Name of child

Date of Birth: ____________
Personal Health Care Number: ______________________
Family Doctor: ______________________
Pediatrician: ______________________
Daycare/Childcare setting: ___________________________ Phone: ___________
Preschool/School: __________________ Phone: ________________

Specific Information I wish know about this child: (such as special needs, allergies, security objects, typical daily routine)

>>

Periodic Review of Agreement

A review of this agreement shall take place every six months or as necessary. If this agreement has been put into action, then a review should take place as soon as possible after I am stabilized.

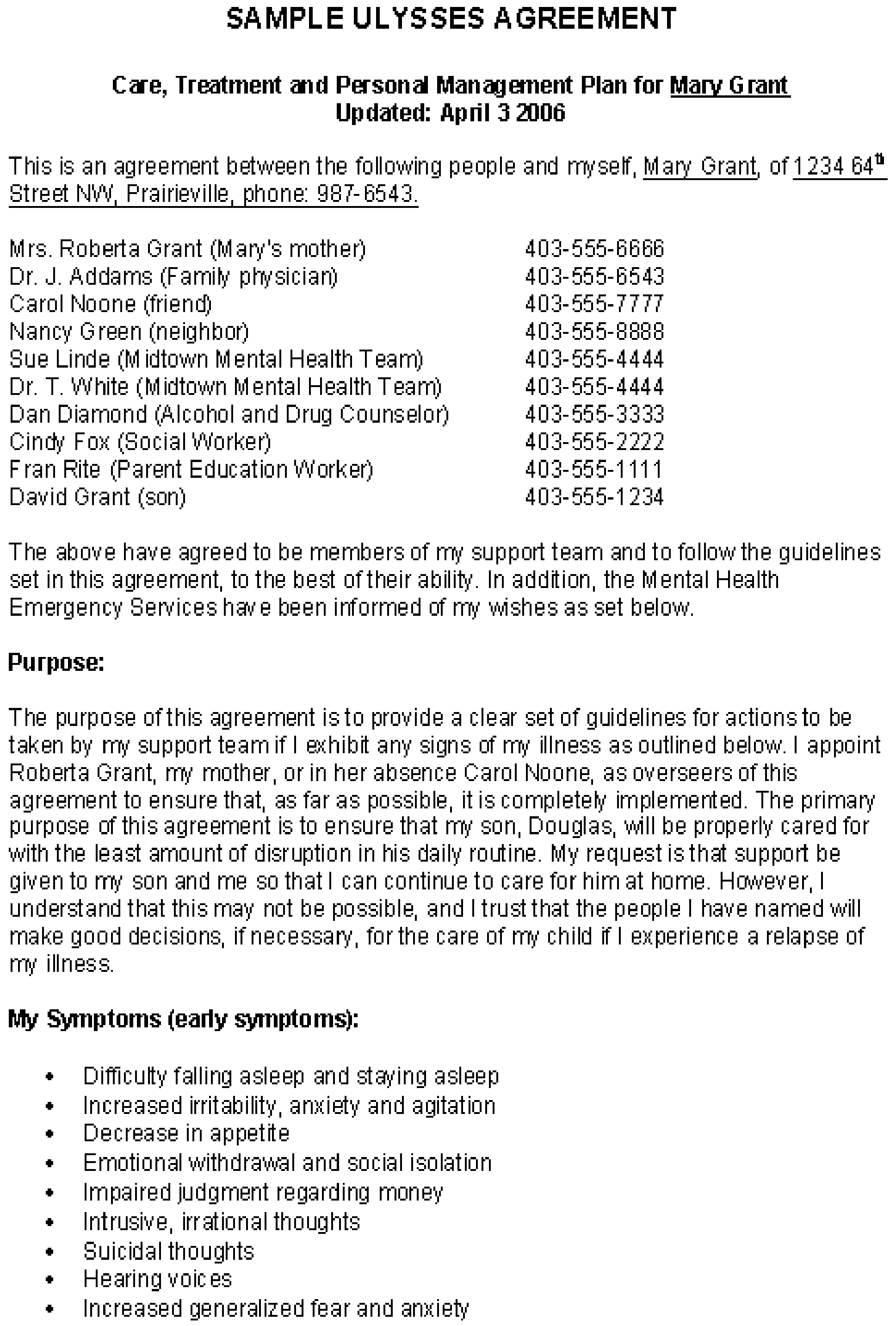
Signature of _____________: __________________________
Print name signature
Date:

Signature of all member of the support team:

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________
6. ______________________________
7. ______________________________

SAMPLE 2: Completed Ulysses Agreement

The following is an example of a Ulysses Agreement that is constructed using the basic model. The Agreement was prepared with an actual family and used with success, but the names have been changed to protect confidentiality.



SAMPLE ULYSSES AGREEMENT

Care, Treatment and Personal Management Plan for Mary Grant
Updated: April 3 2006

This is an agreement between the following people and myself, Mary Grant, of 1234 64th Street NW, Prairieville, phone: 987-6543.

Mrs. Roberta Grant (Mary's mother)	403-555-6666
Dr. J. Addams (Family physician)	403-555-6543
Carol Noone (friend)	403-555-7777
Nancy Green (neighbor)	403-555-8888
Sue Linde (Midtown Mental Health Team)	403-555-4444
Dr. T. White (Midtown Mental Health Team)	403-555-4444
Dan Diamond (Alcohol and Drug Counselor)	403-555-3333
Cindy Fox (Social Worker)	403-555-2222
Fran Rite (Parent Education Worker)	403-555-1111
David Grant (son)	403-555-1234

The above have agreed to be members of my support team and to follow the guidelines set in this agreement, to the best of their ability. In addition, the Mental Health Emergency Services have been informed of my wishes as set below.

Purpose:

The purpose of this agreement is to provide a clear set of guidelines for actions to be taken by my support team if I exhibit any signs of my illness as outlined below. I appoint Roberta Grant, my mother, or in her absence Carol Noone, as overseers of this agreement to ensure that, as far as possible, it is completely implemented. The primary purpose of this agreement is to ensure that my son, Douglas, will be properly cared for with the least amount of disruption in his daily routine. My request is that support be given to my son and me so that I can continue to care for him at home. However, I understand that this may not be possible, and I trust that the people I have named will make good decisions, if necessary, for the care of my child if I experience a relapse of my illness.

My Symptoms (early symptoms):

- Difficulty falling asleep and staying asleep
- Increased irritability, anxiety and agitation
- Decrease in appetite
- Emotional withdrawal and social isolation
- Impaired judgment regarding money
- Intrusive, irrational thoughts
- Suicidal thoughts
- Hearing voices
- Increased generalized fear and anxiety

SAMPLE 2: Completed Ulysses Agreement (continued)

Plan of Action

Upon onset of the symptoms of my illness as detailed above, the following actions should be taken by my support team:

- There should be open communication between the members of my support team. Any one of my support team shall speak to me first about their concerns and then contact the Mental Health Team Case Manager.

- The following actions should then be taken:

  1. My mental health case manager, team doctor, myself, and any other members of my support team that I wish to be present, should meet for an assessment of my mental status. Adjustments in medication and a care plan should be established

  2. The team will provide increased support through more frequent contact and by advocating for additional needed services, such as homemaking

  3. The mental health case manager will contact the social worker to enlist her support and services. Specifically these supports would be a homemaker, increased child care and possible placement of my son if necessary

  4. The area counselor at the school should be informed of my difficulties so as to be responsive to possible difficulties my son may exhibit at school

  5. The mental health case manager will contact the friends I have listed to enlist their support

  6. If I am abusing substances the mental health team may contact my Alcohol & Drug counselor and elicit his support

  7. If I am unable to care for my son with the additional support, every effort should be made for my son to be able to remain at home under the care of one of my friends or relatives listed above

  8. Attached to this agreement is information important to my child's care

  9. Only after all efforts have been made to meet the above plans have been exhausted, will the case manager contact the Ministry of Child and Family Services to arrange respite care

  10. If after review and actions as outlined in #1 and #2 have not been effective in stabilizing me then I will give consent to admission to the Venture program. Arrangements for the care of my son are outlined below

  11. Hospitalization should be considered as a last resort

Medication:

As long as I remain stable, medications will continue to be dispensed to me on a monthly basis. Should I exhibit any symptoms of illness, this schedule will be reviewed.

Medical Records:

I authorize my case manager or doctor to discuss my mental status and current functioning or any other medical information required for decision making with any members of my support team, or any person responsible for my care.

SAMPLE 2: Completed Ulysses Agreement (continued)

Care for My Child:

In regard to my son Douglas, I would like the following to take place:

1. If I am not able to care for my son at home, or if I am admitted to Venture or the hospital, I request that Douglas be placed in the care of my mother, Roberta Grant. My mother will need to apply for compensation for the cost of caring for Douglas, and the financial compensation is contingent upon current legislation and policy. I request that Douglas' daily routine be maintained as closely as possible. This includes attending daycare on a regular basis. Please see the attached addendum for information about Douglas' routine and allergies

2. If my mother is unavailable immediately, I request that the Ministry make every attempt to place Douglas in her care as soon as possible. In the interim, Carol Noone or Nancy Green should be contacted regarding their ability to care for Douglas on an emergency short-term basis

3. If I have been admitted to the Venture program or to hospital, I agree not to have contact with Douglas for the first week of admission

Cancellation:

As a result of my illness I might attempt to cancel this agreement. I only wish to cancel this agreement in the following way:

1. I will inform my case manager or doctor at the Mental Health Team that I want to revoke this agreement

2. My own team psychiatrist will assess me. The purpose of this assessment is to ensure that I am not showing symptoms of my illness. I would like another member of my support team to be present. The psychiatrist may consult with another doctor

3. The case manager and I will inform members of my support team of this revocation in writing

I expect this cancellation to take approximately two months. Until this process is complete, I want this agreement to remain in place.

Addendum to the Ulysses Agreement
Information re: Douglas Grant

Born: ________________________ Personal Health Number: _____________________

Family Doctor: ____

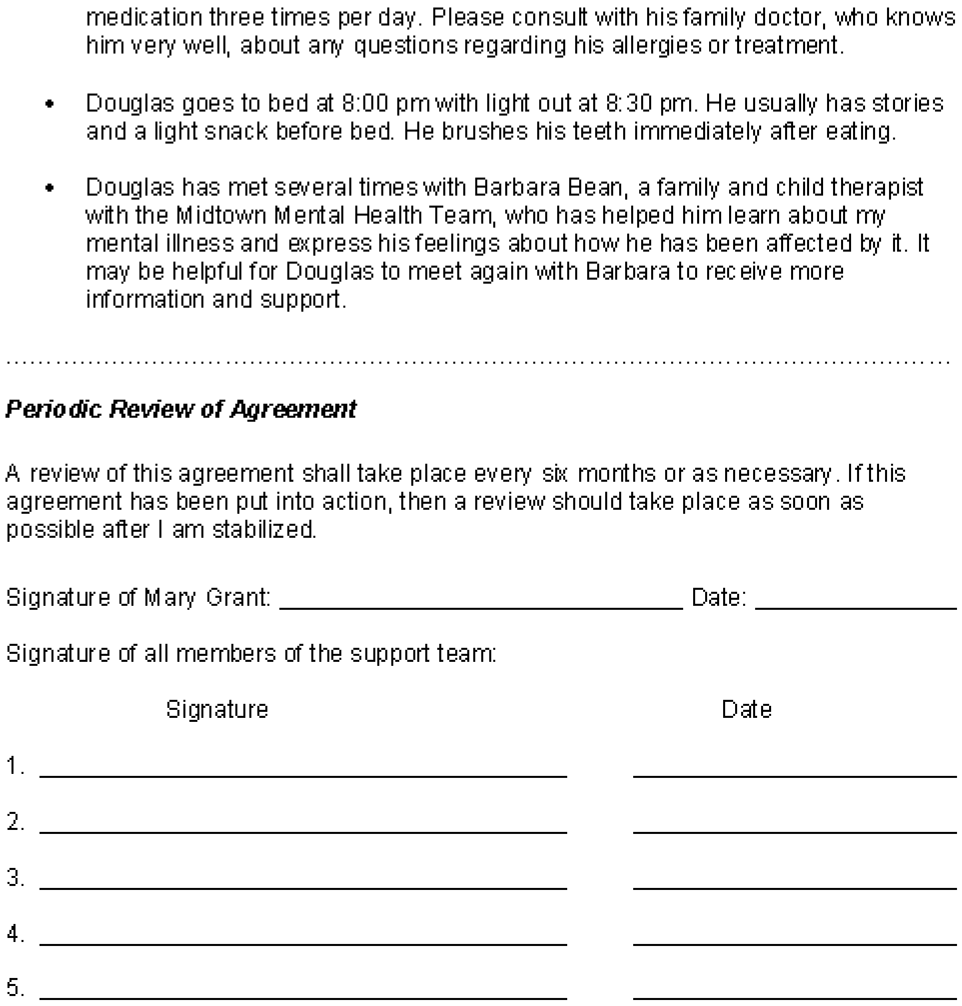
School: ______________________________ 9:00 am to 3:00 pm. Phone: ___________

After school care: ____

Contact person: ______________________________ Telephone: ___________________

- Douglas is severely allergic to nut products. He is also allergic to dust, feathers, perfume and many other irritants. Caregivers must have an epi pen needle at all times. Douglas carries an inhaler for emergencies and uses *Ventalin* preventative

SAMPLE 2: Completed Ulysses Agreement (continued)



medication three times per day. Please consult with his family doctor, who knows him very well, about any questions regarding his allergies or treatment.

- Douglas goes to bed at 8:00 pm with light out at 8:30 pm. He usually has stories and a light snack before bed. He brushes his teeth immediately after eating.
- Douglas has met several times with Barbara Bean, a family and child therapist with the Midtown Mental Health Team, who has helped him learn about my mental illness and express his feelings about how he has been affected by it. It may be helpful for Douglas to meet again with Barbara to receive more information and support.

……

Periodic Review of Agreement

A review of this agreement shall take place every six months or as necessary. If this agreement has been put into action, then a review should take place as soon as possible after I am stabilized.

Signature of Mary Grant: ______________________________ Date: _______________

Signature of all members of the support team:

	Signature	Date
1.	______________________________	____________________
2.	______________________________	____________________
3.	______________________________	____________________
4.	______________________________	____________________
5.	______________________________	____________________

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