

Communicating with Carers and Families

Information sharing for better outcomes



Delivering a Healthy WA





Information booklet and practice guide for mental health clinicians

The guide has been developed in partnership between the School of Psychiatry and Clinical Neuroscience, UWA; the Mental Health Division; the Office of the Chief Psychiatrist and Carers WA



Introduction

Carers and families provide essential care and support for consumers with mental health problems. 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.

Current clinical practice should reflect the contribution provided by carers. This includes optimising the engagement of carers during service planning and delivery at multiple levels throughout mental health service organisations. Such engagement between clinicians and carers must comply with the Western Australian Carers Charter mandated by the *Carers Recognition Act 2004*, which requires that carers' different perspectives and need for information, skill development and support, be respected and recognised.

The term 'Carer' under the *Carers Recognition Act 2004* refers to a person nominated by the consumer to provide care or assistance without payment apart from a pension, benefit or allowance to the consumer because of the latter's frailty, disability, chronic illness, or mental illness. A carer can be any consumer-nominated friend, intimate, or housemate who provides essential ongoing care and support for that consumer. The issuing of this practice guide is consistent with the Chief Psychiatrist's statutory responsibility for the medical care and welfare of all involuntary patients, as well as for the monitoring of standards of psychiatric care provided throughout the state. This guide provides a general framework to guide good practice regarding issues of privacy, confidentiality and the sharing of information.



Key message

Effective communication with carers is vital in the delivery of high quality mental health care. Carers must be recognised, respected, valued and supported for the essential service they provide. Where consumers refuse to consent to the sharing of information, general information about mental illness can still be given to carers without breaching confidentiality. Collaboration with carers should be sought as early as possible in any episode of treatment and care.

Disclaimer

This guide is intended as general information and not as legal advice. This guide should not replace judicious professional judgement on each individual case. Whenever services consider it appropriate, legal advice should be sought and take precedence over this guide.

Purpose of the Guide

The purpose of this guide is to provide a framework from which to:

- Develop procedural standards for clinical practice;
- Consider ways to overcome difficulties associated with working with carers;
- Establish consistency of expectations and practice among mental health service clinicians working with carers;
- Clarify the legal and ethical provisions for confidentiality.

It is recommended that all mental health services across the public and private sectors develop policies and procedures for clinical practice that address the issues raised in this guide.

This guide aims to increase the knowledge and ability of staff to communicate effectively with carers and families regarding issues of confidentiality.



Key service principles

- Carers and families must be recognised, valued and supported in their care-giving role;
- Clearly defined roles and responsibilities for clinicians and carers should be disseminated and understood by all;
- Carers and families should be consulted and engaged as soon as possible in any episode of care;
- Clinicians, consumers, carers and families need to communicate effectively and share information to ensure quality care;
- Clinicians must have a sound knowledge of what information may be given to carers and families under different circumstances by referring to the relevant sections of Mental Health legislation;
- Services should ensure that the language and cultural needs of carers are considered;
- Consumers' right to decide not to involve carers should also be recognised and respected.

Rationale

Research evidence consistently supports the benefits of working with carers and families. Such benefits include:

1. Assessment

- Knowledge provided by carers and family members can facilitate making a diagnosis or assessment (e.g., a family history of schizophrenia).

2. Service delivery

- Mental health consumers are not always able to advocate competently for themselves, particularly in times of health crisis. Hence the carer's perspective provides a critical, second source of information regarding the consumer's health;



- Carers and families often have an historical as well as intimate knowledge of the consumer's health, behaviour and well-being that is not otherwise available to the treating clinicians. Such knowledge allows for regular feedback on changes in behaviour and the effects of a particular medication or treatment.

3. Treatment outcomes

- Sharing information regarding the goals of treatment and care, including issues such as knowledge of side-effects of medication, educates carers and family members as to what is needed for optimal ongoing daily care;
- Regular discussions between mental health clinicians and carers can ensure practical problems relating to day to day care are promptly identified and addressed. Problem solving skills can be taught and practiced to ensure effective care strategies.

4. Relapse admissions

- Effective liaison between mental health clinicians and carers will improve and maintain the quality of care provided for the consumer at home to ensure maximum opportunity to wellness and reduce relapse rate.

5. Cost effectiveness

- Evidence from research demonstrates that carers and families are a vital resource in mental health services with their engagement in service delivery providing a highly cost effective method of improving treatment outcomes.

6. Carer support

- International and Australian research evidence demonstrates significant, adverse impact of caring on the health and wellbeing of carers and families. Timely and appropriate information and support can assist in reducing the adverse impact of caring.



Implications for mental health services and staff

Clinical practice standards, which promote an inclusive approach need to be established by all mental health services across the public and private sectors. Such an approach should promote carers' strengths, acknowledge their difficulties, and help empower them in a practical sense to be capable and resourceful. Practice standards should particularly focus on enabling clinicians to work sensitively with carers and families to build effective engagement.

It is vital that, with the permission of the consumer, carers are-

- consulted and informed as early as possible;
- given timely, regularly up-dated information about mental illness, its likely course, treatment options and outcomes; and
- given feedback regarding clinical consultations and meetings.

The clinician's assessment of the family or carer's ability to be involved will determine optimal, ongoing engagement.

The consumer, carer and family should be involved as much as possible in the development and regular updating of:

- a treatment and care plan;
- a crisis plan;
- a carer list of contacts for access to support services.

Treatment plans

The views and preferences of the carer and family should be taken into consideration in the development of the treatment plan. In relation to patients on Community Treatment Orders, all clinicians should ensure they are familiar with the provisions relating to treatment plans in section 68 of the Western Australia *Mental Health Act 1996*.



Carers or nominated support persons who have an agreed role in delivery of service or care are required under section 157 of the *Mental Health Act 1996* to be given an explanation regarding the rights and entitlements of the consumer.

When carers and family members are to be involved clinicians should ensure their needs (including cultural and language needs) are assessed at critical points, taken into account and addressed where possible.

If a consumer refuses or limits the involvement of the carer or family, the issue should be sensitively explored to identify the limits of the refusal.


Irrespective of whether or not the consumer allows the wishes of the carer to be taken into account, the carer will still require:

- general information about mental illness;
- advice on problem solving, accessing practical help, responding to and coping with behaviours manifested by mental illness;
- general support including information about carer support.

The role of the carer and family providing support for the consumer is a difficult one. The negative effect of the illness on the carer and the associated reduction in their quality of life is significant. It is important for clinicians to recognise and address the reciprocal effect of the consumer and carer/family relationship by informing and supporting the carer in addition to the consumer.

Procedure and Documentation

Clear policy and procedural guides are required in all mental health services to enable staff to effectively implement and maintain carer engagement in accord with the *Western Australian Carers Recognition Act 2004* and Carers Charter.

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- It is recommended that a consistent, structured approach be followed in regard to communicating with consumers and carers on issues of confidentiality;
 - Service documents should be used to record consumer permission to verbally communicate information to the carer, up to date carer contact details, and the level of carer engagement for which the consumer has given permission;
 - Contact and discussions with carers and families should be clearly documented in clinical records.

It is recommended that regular communication with carers is maintained from intake throughout all stages of service delivery:

Intake

- Carer contact details;
- Carer contacted, informed and given carer support information.

Treatment plans

- Consumer's permission requested to involve carer in treatment plans;
- The extent of carer involvement when only partial permission is given;
- Any necessary follow-up.

Carer crisis plan

- Indications suggesting consumer's deterioration in health or impending crisis;
- Suggested action the carer can take to arrest deterioration;
- Procedure and emergency contact details for carer in times of crisis.

Referral, discharge and community treatment plans


- Provision for maintaining carer contact;
- Regular update and review of information by treating clinicians.



The Ethics of Confidentiality

Professional ethics govern the communication with and engagement of carers during service delivery. The codes of ethics and guides to professional practice that relate to the notion of confidentiality are summarised as follows:

- The promise of confidentiality is a commitment that the patient's information will not be transmitted to a third party without the consumer's express permission.
- The promise of confidentiality permits voluntary suspension of privacy when a person consults a doctor or other healthcare clinician on the understanding that his or her privacy will be maintained. The promise of confidentiality allows a person to reveal information about themselves, mind and body, in order that they can be assisted.
- This promise is founded on the notion of respect for persons generally, respect for the right and capacity for self-determination, and as such is a principle that must be adhered to for its own sake. But this maintenance of privacy is also a requirement for a health system to function successfully in a community. People must be able to trust that health clinicians will keep their confidences secret so that they can effectively seek help. Hence, the goal of privacy is to optimise health outcomes for individuals in a community.
- However, confidentiality is not absolute. Although a consumer may voluntarily allow confidential information to be provided, the community, in the form of the state, may also mandate that a consumer surrender the right to confidentiality if the community or individuals within the community are understood to be endangered.
- The modern environment of healthcare provision is far more complex than the paradigm of a consultation between a single consumer and a single healthcare clinician. In this context, it may be entirely appropriate for many members of



a health care team to have access to sufficient information about a consumer to facilitate that person's optimal care.

- In this context it may also be appropriate for others who are neither members of the healthcare team nor clinicians, such as family and carers, to have access to certain information about the consumer to help them make decisions in the best interests of the consumer, and indeed, themselves. In such cases it may be appropriate for the clinicians to provide family and carers with necessary information

Policy Context

The third National Mental Health Plan 2003-2008 states that carers and families are to be provided with improved support. Such support includes:

- providing carers with information to promote their involvement in care;
- developing a carer plan in conjunction with each consumer treatment plan;
- regular review of each carer's needs;
- ensuring a range of support services and resources are provided and accessible for carers, including respite and assistance for children who have a parent with a mental illness.

Legislation

The disclosure of information by clinicians about consumers of mental health services is governed by section 206 of the MHA. Clinicians must routinely seek a consumer's permission before providing information about the consumer's condition and treatment to a carer. However, even when consumer permission is not given, carers are to be given sufficient knowledge to enable them to provide effective care. (See section 206 of the *Mental Health Act 1996* for the full list of circumstances in which mental health clinicians may breach confidentiality).



The Western Australia *Carers Recognition Act 2004* requires service providers to comply with the Western Australian Carers Charter, which states:

- Carers must be treated with respect and dignity;
- The role of carers must be recognised by including carers in the assessment, planning, delivery and review of services that impact on them and the role of carers;
- The views and needs of carers must be taken into account along with the views, needs and best interests of people receiving care when decisions are made that impact on carers and the role of carers;
- Complaints made by carers in relation to services that impact on them and the role of carers must be given due attention and consideration.

The decision by a consumer not to permit or limit confidential information should be regularly reviewed. Carers are also to be given the opportunity to discuss and help in resolving difficulties involved in caring. Providing carers with general information about mental illness, and practical and emotional support does not breach confidentiality.



Carer communication checklist¹

ENLIST carers to build effective collaboration

Engage: Carers are given general verbal and written information about:

- The mental illness and diagnosis
- What behaviour to expect and how to deal with it
- Medication - alternatives, possible side effects and benefits
- Planning to cope with care, signs of risk, crisis, and recovery
- Other supports and information available for the carer

Needs: Carers are cared for:

- Ongoing opportunities to ask questions, give feedback, and discuss concerns
- The opportunity to see a clinician on their own
- The right to confidentiality in communications with a clinician
- Positive feedback as a valued member of the care team
- Available local services - both inpatient and community
- Local and national support groups

Listen: Carers are encouraged to communicate:

- Any history of the consumer relevant to the mental health illness and diagnosis
- Personal characteristics of the consumer that may influence the choice of medication or treatment
- Effects of medication or treatment on the consumer

¹ This checklist is aligned with that provided for carers' use in the carers support information



Inform: Carers are given help in understanding:

- The rights and responsibilities of consumers, carers, and mental health clinicians
- Any restrictions on sharing information requested by the consumer
- The aims of, and what is involved in, the consumer's treatment plan
- The roles of each clinicians involved in care of the consumer

Support: Carers are given advice:

- Problems they have in caring for the consumer and when they need help in practical problem solving
- If they would like training in cognitive behavioural therapy
- If they would like family therapy sessions
- Confidence to express their opinion and concerns
- Practical and emotional support
- An assessment of their own needs and written care plan when required

Trust:

Trust is essential in good care. Trust must be developed between clinicians and carers. The different problems faced by each need to be understood before mutual respect and helpful collaboration can grow.



Acknowledgement

Dr Hugh Cook's comprehensive 1996 Western Australian guide on *Confidentiality in mental health settings*, Professor C. D'Arcy Holman's *Review of the Mental Health Act 1996*, and the Chief Psychiatrist of Victoria Associate Professor Amgad Tanaghow's guide *Working together with carers and families*, are gratefully acknowledged for their contribution to this guide.

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The Carers Recognition Act 2004

The Western Australian Carers Charter

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The information in this Guide will be reviewed periodically and amended as required.



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Produced by Office of the Chief Psychiatrist
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