

Working together with families and carers

Chief Psychiatrist's Guideline

Key message

Families and carers should be recognised, respected and supported as partners in providing care to the consumer. **Families and carers** should be engaged as early as possible in the episode of treatment and care.

Introduction

Working with the families and carers of consumers is integral to the provision of high quality specialist mental health care. Research indicates that clinical practice has focused on consumers, with carers viewed as secondary. Increasing evidence demonstrates that well-being and outcome for both consumers and carers are improved by involving families and carers. As we begin to understand the contribution that carers make in the process of recovery and relapse prevention there is a need to optimize genuine carer involvement in treatment and care. This includes participation in service planning and delivery at many levels through relevant area mental health service (AMHS) structures.

Clinical practice needs to be more sophisticated in the assessment of the role of family and others as carers and in their engagement in treatment and care so that it places appropriate value on the vital role that carers play in the recovery process. It establishes a partnership between clinicians and carers based on respect and recognition of carers perspectives and needs for information, education, skill development and support.

The term 'carer' includes those who, while not related to the client by biology or marriage, are nevertheless actively involved in their care. This may include intimates, friends, housemates and professional carers. The term 'primary carer' is defined in the *Mental Health Act 1986* as any person who is primarily responsible for providing support or care to a person other than wholly or substantially on a commercial basis.

The Chief Psychiatrist has a statutory responsibility for the medical care and welfare of those receiving treatment for a mental illness. The issuing of clinical practice guidelines is consistent with this responsibility.

Disclaimer

These guidelines are not intended to represent a comprehensive analysis of the law and should not replace the exercise of professional judgement on a case-by-case basis. Nothing in these guidelines should replace the seeking of appropriate legal advice by services where this is considered appropriate.

Purpose of the guideline

To provide AMHS with a framework in which to:

- develop clinical practice standards
- consider issues relevant to working with families and carers
- establish expectations of mental health service clinicians in working with families and carers
- clarify legislative and confidentiality provisions.

AMHS are expected to develop their own procedures and clinical practices that address issues raised in these guidelines and reflect the broader policy requirements.

Rationale

The rationale for working with families and carers is five-fold:

1. **Assessment.** This includes assessment of the relationship with family and carers. Families and carers often have knowledge that is essential information for clinicians in their assessment.
2. **Treatment.** Working together with families and carers promotes understanding of the goals of treatment and care and enhances a mutually supportive relationship.
3. **Meeting the needs of families and carers.** Families and carers value the support clinicians can provide through sharing information and through providing training in the most effective management techniques that will ensure the best outcome for their relative.
4. **Research evidence.** Family studies repeatedly confirm that working with families and carers bring benefits to consumers and to families.
5. **Cost-effectiveness** of working with families has been demonstrated in the literature (see references section).

Policy context

The third National Mental Health Plan (2003-2008) includes directions to improve support for families and carers. These cover: development of carer plans in conjunction with individual consumer care plans; emphasises regular review of the needs of carers; the range of supports necessary for carers such as respite and help for children of a parent with a mental illness; and provision of information to enhance carer involvement.

New Directions for Mental Health Services, The Next Five Years (2002), represents the Victorian Government's priorities for mental health services and encompasses as a core goal the strengthening of services for carers and the development of systems for carer involvement in policy and planning. The need to understand and acknowledge the carer's contributions is clearly articulated.

Caring Together: An action plan for carer involvement in Victorian public mental health services, August 2004, further articulates strategies for improving carer involvement.

Scope

These guidelines concern the involvement of family and carers in the individual treatment and care of consumers. AMHS are expected to develop procedures to collect information about carers' needs, including those of ethnic subgroups and devise intervention strategies to enhance carer involvement accordingly.

Children of a parent with a mental illness who have a caring role must be recognized as having special needs and be appropriately supported.

Key service principles

- Families and carers should be recognised, respected and supported as partners in providing care to the consumer. Roles and responsibilities of clinicians and of carers should be clearly defined.
- Families and carers should be engaged as early as possible in the episode of treatment and care. Clear and open communication and the sharing of information between clinicians, consumers, families and carers needs to occur regularly.
- Clinicians require a sound understanding of the confidentiality provisions of the *Mental Health Act* which defines what information can be conveyed to families and other carers and under what circumstances.
- Services should ensure that the cultural and language needs of families and carers are considered.

Implications for mental health services and staff

Staff must have the skills and competencies to enable them to work with families and carers. AMHS need to foster an inclusive approach and establish clinical practice standards. Staff training in working sensitively with families and carers is pivotal to their effective engagement.

Prior to a consumer's discharge from either hospital or a community-based public mental health service, carers should be fully involved in discharge planning and implementing continuing care. The clinician's opinion should be based on an assessment of the family or carer's ability and willingness to provide care.

Families have expressed the need to be listened to. Feedback from clinical consultations and meetings is a critical component of the relationship between clinicians and carers. Families and carers need timely information (which often needs to be repeated) about mental illness, its likely course and outcomes.

Working with families and carers in a way that promotes their strengths (whilst acknowledging their difficulties) empowers them to be more effective and resourceful.

Underpinning principles of treatment and care will include the involvement of the consumer, families and carers in the development of:

- a crisis plan with a clearly identified clinical service response
- discharge planning
- assistance with the psychological and social as well as the clinical needs of the consumer (*this means working collaboratively with relevant agencies involved in providing care to the consumer*)

- recognition of the high incidence of co-morbid conditions including substance use and physical illness.
- emotional support from clinicians and from family and carer support networks.
- clinicians need to make clinical judgments as to whether or not sensitive information given by a third party needs to be conveyed to the consumer.

Treatment plans

Families and carers can play an important role in supporting people with mental illness. The role can often be difficult and the effect of the consumer's illness on the family can be significant. Families and carers will often have views and preferences that they would like the treating team to take into account when developing a treatment plan. AMHS staff should be familiar with the new provisions relating to treatment plans in section 19A of the *Mental Health Act 1986*.

The role of families and carers in the treatment relationship should be raised with the consumer as early as possible. The extent to which families and carers have their wishes taken into account will depend on the consumer. Where family members/carers are to be involved, including dependent children, the AMHS should ensure an assessment is made of their needs, including cultural and language needs, that these are taken into account, and that the assessment is updated at critical points.

If the consumer refuses any involvement for family/carers, or only permits limited involvement, this subject should be periodically re-visited to see if the consumer has changed their mind or to encourage greater involvement.

Regardless of whether their wishes are taken into account, families and carers who are involved in providing ongoing care or support to a consumer will require information about mental illness, how to respond to disturbing behaviours, how to access practical assistance and general assistance in dealing with the illness.

The wishes of any guardian, family member or primary carer who is involved in providing ongoing care or support to the consumer must be taken into account unless the consumer objects. Giving identified consumer information to families and carers is governed by the confidentiality provisions of the Act in section 120A which is discussed more fully later in this guideline. Subject to the requirements of section 120A, where nominated family members or carers and other service providers have an agreed role, they should be provided with a copy of the plan.

Documentation

Services should have clearly documented policies and procedures for working with families and carers. Discussions and contacts with families or carers should be clearly documented in the clinical record. Documentation should demonstrate:

- discussions with the consumer to obtain consent for providing information to families and carers about their treatment and care
- contacts with families and carers for the purposes of involvement in treatment and care plans
- reasons for non-involvement of the family in a consumer's treatment and care

- when information recorded is not directly observed, the source that provided the information should be recorded
- clinicians need to ensure that information provided in confidence and documented is protected according to locally established procedures as documentation may be subject to release under Freedom of Information legislation.

Relevant legislation

Section 120A of the *Mental Health Act* is the principal law regulating disclosure of information by clinicians. The Health Records Act 2001 supplements section 120A by regulating the collection and use of health information.

Section 120A of the *Mental Health Act 1986* also details circumstances when information about consumers of approved mental health services may be disclosed without their consent.

- Section 120A(3)(ca) allows information to be disclosed to family, primary carers and guardians if the information is reasonably required for ongoing care and the person who receives the information will be involved in providing the care.
- Section 120A(3)(e) allows disclosure of information when it is required for further treatment.

For the full list of exceptions, refer to Section 120A of the *Mental Health Act*.

Clinicians must routinely seek a consumer's consent before providing information about their condition and treatment to carers. Where consent is not given, information can only be disclosed in situations covered under section 120A of the *Mental Health Act*. Where carers are affected by non-consent, their needs should be addressed sensitively. Non-consent should be reviewed on a regular basis.

For further information regarding this guideline contact:

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About Chief Psychiatrist's Guidelines

The information provided in this guideline is intended as general information and not as legal advice. If mental health staff have queries about individual cases or their obligations under the *Mental Health Act 1986*, service providers should obtain independent legal advice.

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