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Working with Families and Carers

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# Applicability

This procedure applies to:

* All NT Health employees

# Procedure statement

This procedure provides instructions that support the Mental Health and Related Services Act.

Families and carers are to 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.

# Procedure details

## Purpose of the guideline

To provide NTMHS with a framework in which to:

* Develop clinical practice standards;
* Consider issues relevant to working with families and carers, including guidance on identification of a person’s primary carer;
* Establish expectations of NTMHS clinicians in working with families and carers;
* Clarify legislative and confidentiality provisions.

## 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 has been demonstrated in the literature.

## Policy context

The National Mental Health Strategy has, from its inception, included initiatives aimed at improving support for and engagement with families and carers. These have covered development of carer plans in conjunction with individual consumer care plans, emphasised 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.

'Partnership' is a key concept in the development of policy to empower consumers of mental health services and their families and/or carers at both State/Territory and Federal levels. It is expected that health professionals will adopt a partnership approach in providing mental health care and services. People with a mental illness and their families and/or carers have the right to expect this approach.

## Scope

These guidelines concern the involvement of family and carers in the individual treatment and care of patients/clients. NTMHS are expected to develop their own procedures and clinical practices that address issues raised in these guidelines and reflect the broader policy requirements.

Children of a parent with a mental illness who have a caring role must also be recognised 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 patient/client. 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, patients/clients, families and carers should occur regularly.
* Clinicians require a sound understanding of the confidentiality provisions of the Act (Part 12) that defines what information can be conveyed to families and other carers and under what circumstances.
* Consideration should also be given to the cultural and language needs of families and carers.

## Issues associated with identification of a Primary Carer

There are a number of important issues to consider in the process of identifying a ‘primary carer’ for the purposes of the Act. These are summarised as follows:

* Carers have an important role to play generally however specific identification of a primary carer is crucial in circumstances where their role is likely to be ongoing over an extended period of time such as when they are caring for a person with a long term mental illness.
* The ideal process for identification of the primary carer is by the patient/client. These discussions together with the degree of involvement should be negotiated, documented and regularly reviewed at times when the patient/client is well.
* Some patient/clients will from, time to time, because of the nature of their illness, refuse to identify or to involve carers.
* Patient/client refusal to identify a carer does not lesson the burden on carers. It may in some cases increase the burden of care.
* Patient/client refusal to identify carers should not prevent clinical staff 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.
* Carer identification is not a one-off process. Service providers need policies, training, support, regular monitoring and legislative backing to enable them to develop the skills to build the process of identification (and participation) into every day practice.
* Patient/clients with long-term mental illness should be encouraged to develop Advanced Directives regarding identification and involvement of carers. This should occur when they are well.

## Implications for NTMHS and staff

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

Prior to a patient/clients discharge from either an ATF or ATA, carers should be fully involved in discharge planning and the process of implementing continuing care. The plan put in place by the clinician’s should be based on an assessment of the family or carer’s ability and willingness to provide care.

Families have consistently expressed the need to be listened to. Feedback from clinical consultations and meetings is a critical component of the relationship between clinicians and carers.

It is important to work 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 patient/clients, families and carers in:

* The development of a crisis plan with a clearly identified clinical service response;
* The development of a Discharge Plan;
* 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. NTMHS staff should be familiar with NTMHS Policies in regard to case management, individual care planning and discharge planning arrangements.

The role of families and carers in the treatment relationship should be raised with the client as early as possible. The extent to which families and carers have their wishes taken into account will depend on the client. Where family members/carers are to be involved, including dependent children, NTMHS 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 client refuses any involvement for family/carers, or only permits limited involvement, this subject should be periodically re-visited to see if the client 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 client 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 family member or carer who is involved in providing ongoing care or support to the client must be taken into account unless the clients objects and the APP considers this objection reasonable under the circumstances.

Giving identified patient/client information to families and carers is governed by the confidentiality provisions of the Act in **s91**, which is discussed more fully later in this guideline. Subject to the requirements of **s91**, where nominated family members or carers and other service providers have an agreed role, they should be provided with a copy of any care, treatment or discharge plans.

## Documentation and information provision

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

* Discussions with the patient/client 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 patient/clients treatment and care;
* When information recorded is not directly observed, the source that provided the information should be recorded;
* Carer packs of information – similar to those given to patient/clients should be provided to a client’s primary carer and/or family. Admission protocols contained in NTMHS Policies require that a note be made in the clinical record that this information has been given;
* Permission to provide information about the client is to be asked at the time of admission. If refused, the question should be re-asked at a later date;

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 91** of the Act is the principal law regulating disclosure of information by mental health clinicians. The NT *Information Act* supplements **s91** by broadly regulating the collection and use of health related information.

**Section 91** of the Act also details circumstances when information about a client of an ATF or ATA may be disclosed without their consent.

**Section 91(2)(e)** allows information to be disclosed to family, primary carers and representatives if the information is relevant to the ongoing care, treatment or rehabilitation of the person and disclosure is considered to be in the persons best interests.

**Section 91(2)(d)** allows disclosure where information is required in the course of proceedings relating to guardianship of the person to whom the information relates.

**Section 91(2)(h)** allows disclosure of information when it is required to prevent or lessen a serious or imminent threat to the life or health of the person, another person or the general community.

For the full list of provisions regarding disclosure of information, refer to **s91** of the Act.

Clinicians should routinely seek client 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 **s88**, **89** and **91** of the Act. Were consent is not given for disclosure, the carer must be informed of his/her right to apply to the Tribunal for a review of this decision.

The *NT Carers Recognition Act* formally acknowledges and recognise the role of carers as an essential part of the NT community.

The Act defines the legal status of a carer and requires organisations to think about carers when making decisions about service planning and delivery.

Where carers are affected by non-consent, their needs should be addressed sensitively. Non- consent should be reviewed on a regular basis.

The *NT Carers Recognition Act* formally acknowledges and recognise the role of carers as an essential part of the NT community.

The Act defines the legal status of a carer and requires organisations to think about carers when making decisions about service planning and delivery.

# Procedural roles and responsibilities

The following roles and responsibilities are set out for this procedure.

|  | **Method** | **Responsibility** |
| --- | --- | --- |
| **Implementation** | Document will be accessible to staff via the MHARS Act intranet page and the PGC. | Health Policy Guidelines Program |
| **Review** | Document will be reviewed within a period of 4 years. | Senior Policy Officer Mental Health Central Office |
| **Evaluation** | Document will be informally evaluated at time of review. | Senior Policy Officer Mental Health Central Office |

# Appendices

## Appendix A: Background Information

Working with a client’s family and/or carer/s is integral to the provision of high quality specialist mental health care. Increasing evidence demonstrates that the involving families and carers improves the wellbeing and outcomes of both consumers and their family and carers. Evidence also indicates that there is a need to optimize genuine carer involvement in treatment and care, including participation in service planning and delivery through existing service, policy and planning structures.

Research also indicates that clinical practice needs to be more sophisticated in the assessment of the role of family and 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. A partnership should be established between clinicians and carers based on respect and recognition of the perspective of families and carers and their needs for information, education, skill development and support.

The process of identifying a person’s carer is also a process that requires further procedural attention and practice rigor. The term ‘carer’ includes those who, while not related to the consumer by biology or marriage, are nevertheless actively involved in their care. This may include intimate friends, housemates and professional carers. The term ‘primary carer’ is defined in s7A of the Act as:

*“someone providing care and support to the person because of his or her sense of responsibility as a relative of, or someone close to, the person…if the person does not have anyone providing [this] care and support…someone most closely involved in the treatment or care of, or support to, the person.*

*For this section, a relative of the person includes anyone related to the person through a relationship that arises through common ancestry, adoption, marriage, de facto relationship or any customary law or tradition (including Aboriginal customary law or tradition)”.*

This CEO Direction is issued to provide guidance to clinicians working with families and carers.

## Appendix B: Disclaimer

These guidelines are not intended to represent a comprehensive analysis of the law and should not replace the exercise of professional judgment 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.

# Document history

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