

PARTICIPATION OF CARERS AND FAMILIES

Guiding principles

- Active carer participation in decision-making leads to better treatment and care outcomes.
- Care and support provided by family members and others often enables a person to remain well.
- Families, carers and support persons of persons with mental illness are strong advocates and have the patient's best interests at the forefront.
- Carers and family members often have information about the person for whom they are caring or supporting, including their past medication and treatment history, emotional and other support needs when they are unwell, the person's financial management and housing arrangements, lifestyle preferences and support systems. This information is extremely important to incorporate in developing care, support, and treatment plans for the person.
- People providing such care and support also have their distinct needs. Mental health providers must support them to build their capacity as informal carers and to improve their quality of life.
- It is important to recognise that a carer could be a family member or a close friend of the patient they are supporting.

Definitions

Child	A person who has not attained the age of 18 years
Parent of a child	A person having, for the child, all of the responsibilities which, by law, a parent has in relation to his or her children AND if there is not person who falls into this category, someone who generally acts as a parent, has acted for some time, and is recognised by the child as a parental figure.
Carer	A person providing care and support to the person
Family members	A member of the person's biological or extended family
Guardian	A person named as a guardian in a guardianship order or as an enduring guardian in an instrument of appointment (<i>Guardianship and Administration Act 1995</i>)
Support person	A person who provides the patient with ongoing care or support
Friend	A person who knows the patient but is not a family member or a carer
Advocate	A person who advocates for the patient
Representative of the patient	A representative may be: <ul style="list-style-type: none"> • the patient's guardian OR • the patient's legal representative OR • if the patient is a child and raises no objection, a parent of the patient OR • Any other person nominated by the patient to represent his or her interests
Legal representatives	A legal practitioner who has been appointed as a legal representative by the person

Overarching Practice Guidance

Recognise	<p>The importance and value of the role played by carers and families as partners in the provision of treatment and care to the extent that is appropriate and consistent with the wishes of the patient and his or her representatives and support persons.</p> <p>The appointment of any enduring guardianships or other advance expressions of the patient's wishes about the involvement of support persons and representatives in decision-making processes.</p> <p>Permissions assigned to carers and others, for example, as an enduring guardian and other agreements or advance expressions of the patient's wishes for them to be involved in decision-making processes.</p>
Engage	<p>Involve, engage and encourage carers to be active participants in decision-making about a person's care, unless this is contrary to the person's wishes or not otherwise consistent with the patient's health or safety or the health or safety of others.</p>
Respect	<p>The wishes of persons receiving services, and the wishes of their families and support persons, to the maximum extent consistent with the health and safety of those persons and the safety of others.</p>
Reinforce obligations of carers	<p>Respect the patient's wishes about matters such as whether information about the patient should or should not be disclosed to the support person or representative.</p> <p>Advise staff, if and when they cease to be a patient's support person or representative, or if there has been a change to their contact details.</p> <p>Be polite, respect boundaries, and follow reasonable instructions given by staff about behaviour and conduct within mental health service facilities.</p>

Specific Service Delivery principles that must guide practice.

Practice areas	Practice points
<p>Representation</p> <p>Carers are encouraged to be nominated by a patient to represent the patient's interests under and for the purposes of the Act</p>	<p>Patients and prospective patients should be:</p> <ul style="list-style-type: none"> • Asked the names and contact details of any family members, support persons or representatives involved or potentially involved in their future care. • Asked for details of any appointed enduring guardians or other advance expressions of their wishes, about the involvement of support persons and/or representatives in their care. • Advised of the ability to nominate a person to represent their interests under and for the purposes of the Act, and about legal representation or advocacy services available within Tasmania. • Provided with a reasonable opportunity and supported to contact such legal representation and/or advocacy services should this be requested by them and/or by a support person or representative of the patient, and at other times as may be considered necessary and/or appropriate.
<p>Receipt of information by carers</p>	<p>Families, carers and support persons:</p> <ul style="list-style-type: none"> • Must be given information in a language or form that they understand, through the assistance of an interpreter or alternative or supplementary communication system, if necessary. • Should not be used to provide interpreter services. Rather, only independent and qualified interpreters should be used.

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<p>Sharing of information Confidential or personal information should only be shared where this has been consented to by the patient</p>	<ul style="list-style-type: none"> • Encourage families, carers and support persons to share information about the patient which is necessary for the ongoing treatment and care of the patient. • Share with families, carers and support persons information about the patient's wishes about the involvement of support persons and representatives in decision-making processes. • The provision of confidential or sensitive information to support persons and representatives should be gauged as early as possible in the assessment and treatment process. This information should be prominently recorded in the patient's clinical notes. • Any changes to the patient's wishes about the provision of information to his or her support persons or representatives should be recorded in the patient's clinical notes as and when necessary. • Information may also be given to families, carers and support persons if the person making the disclosure reasonably believes it to be necessary so as to prevent or lessen a serious threat to the life, health or safety of the patient or other person, or to lessen or prevent a serious threat to public health or safety.
<p>Assessment and treatment To participate in assessment, treatment planning and clinical care decisions.</p>	<ul style="list-style-type: none"> • Seek to include families, carers and support persons and representatives of patients and prospective patients in decision-making processes affecting individual patients unless there is any objection from the patient to this occurring. • Particular consideration should be given to including – or excluding – families, carers and support persons in decisions about whether or not a person has decision-making capacity. While the presence of a support person or representative may assist some prospective or potential patients to exercise decision-making capacity about assessment or treatment decisions, there are other occasions when the presence of a support person or representative or of a particular support person or representative may compromise the person's ability to make a free and informed choice.
<p>Involuntary treatment</p>	<ul style="list-style-type: none"> • Consult families, carers and support persons in the development of treatment plans that are prepared for involuntary patients unless there is a clear clinical reason not to. • Encourage carers to correspond privately with an involuntary patient for whom the person is a representative or support person. • A carer may apply for leave of an involuntary patient from an approved hospital for personal reasons, in relevant circumstances.
<p>Participation in the Mental Health Tribunal</p>	<ul style="list-style-type: none"> • Families, carers and support persons can institute or intervene in Tribunal proceedings concerning a patient for which the person is a representative. • If the family, carers or support persons is a party to Tribunal proceedings, they can attend the hearings held in those proceedings and either appear personally or be represented by an Australian legal practitioner, advocate, or another person.

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Forensic patients	<ul style="list-style-type: none"> • A family member or carer may apply for leave of a forensic patient from a secure mental health unit for personal reasons, in relevant circumstances. • A representative can object to a police officer visiting a forensic patient in a secure mental health unit and /or be present during a police visit if this is requested by a forensic patient in a secure mental health unit. • Families, carers and support persons have the right to ask a person for proof of their identity, who is purporting to exercise, discharge or perform a responsibility as a custodian or escort.
Notifications	<ul style="list-style-type: none"> • Families, carers and support persons must be notified of certain patient admissions, transfers and discharges subject to the patient's views about the notification being given and to the desirability of the notification being made with regard to the patient's health or safety or the safety of other persons and/or any Tribunal direction for the notification to be given. • Families, carers and support persons must also be notified of certain patient leaves of absence and unlawful absences from approved facilities subject to the patient's views about the notification being given.
Concerns and complaints	<ul style="list-style-type: none"> • A family member or carer can make a complaint, concerning a patient, to an Official Visitor or ask the Principal Official Visitor to visit premises in or from which a patient is being provided with services under the Act.
Parents of child patients	<ul style="list-style-type: none"> • Parents of child patients who are required to be given a notice or other documentation under the Act additionally have the right to receive a copy of any notice or document that is given to the child, at the same time, subject to any objection from the child to this occurring.
Supporting carers	<ul style="list-style-type: none"> • Ask about how they are feeling. • Communicate clearly in an honest, open and understanding way. • Include support persons and representatives as valued members of the care team and respect their significant role. • Provide information to support persons and representatives about support and respite services that are available, and if necessary, refer them to services for support in their caring role.
Children who are carers of their unwell parents	<ul style="list-style-type: none"> • Reassure children of parents with a mental illness that they are not alone, that they did not cause their parent's mental illness, and that their parents can recover. • Encourage the child or young person who is supporting their parent to utilise other family members or informal supports where possible to prevent carer fatigue. • Give information about the general nature of their parent's illness and encouraged them to ask for help about how to write a plan for what they should do if their parent becomes unwell. <p>For many young carers the caring role can require the assumption of adult responsibilities and interfere with schooling and sporting and social activities. This impact should be considered in any decision to refer a young carer to support services.</p>

Practice areas	Practice points
Services supporting carers	<p>A range of services which may be of assistance to families, carers and support persons are available at health.tas.gov.au/mental-health</p> <p>Additional support and resources can also be found at:</p> <ul style="list-style-type: none"> • Mental Health Families & Friends Tasmania (mhfamiliesfriendstas.org.au) • Mental Health Lived Experience Tasmania (mhlet.org.au) • Advocacy Tasmania (advocacytasmania.org.au) • My Health Care Rights Poster A4 (safetyandquality.gov.au)

Guidance for approved facilities and persons in charge

- Ensure policies and protocols are aligned with this guideline.
- Provide education and training programs that support provisions in this guideline.
- Ensure appropriate documentation is maintained.
- Ensure referral information and supporting resources for families and carers are available.