Family and carers principle

1. What do **the Act** and relevant guidance say?

Families, carers and supporters (including children) of a person receiving mental health and wellbeing services are to be supported in their role in decisions about the person's assessment, treatment and recovery (s 20).

This principle recognises the importance and centrality of the role of families, carers and supporters in a person's assessment, treatment and recovery (Explanatory Memorandum to the Mental Health and Wellbeing Bill 2022 (Vic), p 21).

Carers, families, supporters and kin (including children) play a vital role in supporting a person's recovery and decision making in mental health and wellbeing services. The Act recognises this by outlining specific provisions that require services to involve and consult with carers at various stages of assessment, treatment, and recovery.

The Chief Psychiatrist's guideline: Working together with families and carers (Department of Health and Human Services 2018c) emphasises the importance of acknowledging care relationships and ensuring carers have access to information, support, and skills to fulfill their role. Compliance and continuous improvement in line with the Chief Psychiatrist's guideline will support proper consideration of the family and carers principle.¹⁴

Balancing the involvement of carers, families, supporters and kin with a person's right to autonomy and privacy can be complex. The Act sets out principles and requirements for information sharing, ensuring that decisions about disclosure are made carefully, particularly where there is a risk of family violence or other serious harm, or where sharing information could pose a risk to the health or safety of any person or unreasonably impact on the privacy of other people.

Different terms are used throughout this section, including 'carers, families, supporters and kin', 'families, carers and supporters', and 'carers, guardians and parents of consumers aged under 16 years'. See our note on language for further discussion.

¹⁴ We acknowledge that at the time of publication, the *Working together with families and carers guideline* has not yet been updated to reflect the *Mental Health and Wellbeing Act 2022*. However, the practice guidance it contains remains relevant, and can be read together with relevant sections of the Mental Health and Wellbeing Act handbook (e.g. information sharing, and families, carers and supporters).



2. How do **human rights** relate to this principle?

Generally, when the family and carers principle is applied to a decision being made or function being exercised under the Act, the right of 'protection of families and children' in section 17 of the Charter will be relevant and will also need to be given proper consideration. Summarised, section 17 of the Charter recognises that families are entitled to be protected and that every child has the right to such protection as is in the child's best interests.

Other relevant rights under the Charter include the right not to have a person's privacy, family, home or correspondence arbitrarily interfered with (section 13(1)) and cultural rights particularly in relation to the maintenance of kinship ties (section 19(2)(c)).

In Victoria, being a parent or a carer is also considered a protected attribute under the *Equal Opportunity Act* 2010 (Vic). Mental health and wellbeing services must not unlawfully discriminate against parents and carers when providing a service, because of their status.

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Related mental health and wellbeing principles include:	Related decision making principles include:
Supported decision making Dignity and autonomy Cultural safety Wellbeing of dependents	Care and transition to less restrictive support Autonomy Consequences of compulsory assessment and treatment and restrictive interventions

3. How might a **consumer** experience this principle?

When my family, carers, supporters or kin are recognised and supported in their roles:

- I am asked who supports me and who I want involved in my care. My choices are respected, documented and reviewed regularly.
- I receive clear explanations about privacy, confidentiality, and what information can or cannot be shared.
- The people I choose to involve are welcomed, informed, and supported to assist me in my recovery.
- With my agreement, the service works in ways that help to maintain and strengthen relationships with the people who are important in my life.
- If I decide not to involve someone, my choice is respected (unless there is a legal or safety reason not to).
- I am supported to understand and make decisions about who receives information about me, and how to change those decisions over time.
- My role as a parent or carer is acknowledged and supported (see wellbeing of dependents principle).
- The people I rely on are supported in their caring role, including access to carer peer support, carer consultants, and local or state carer services to support their wellbeing.



4. What may this principle mean for **carers**, **families** and supporters?

When I am recognised and supported in my role:

- I am acknowledged as someone who plays an important role in the person's life, and my insights are respected and considered in decisions about their care - where appropriate and with their consent.
- I am supported in ways that help maintain, strengthen, or restore a respectful, supportive relationship with the person, in line with their wishes.
- I am provided with clear, timely information (with consent or to the extent allowed without consumer consent) that helps me understand the person's treatment and how I can support their recovery.
- I am supported to maintain my own wellbeing and mental health, including through access to carer peer support, carer consultants, and relevant local and statewide resources.
- I am helped to navigate the service system and understand my rights and responsibilities as a carer, including around privacy and information sharing.
- When safety concerns arise, I am treated with sensitivity and care, and the person's and my own safety are prioritised in how information is shared or withheld.

5. How do **treating teams** put this principle into practice?

This section gives an overview of requirements and good practice suggestions for putting the families and carers principle into practice. As noted earlier in this guidance, the dignity and autonomy and supported decision making principles underpin all other principles and must always be considered.

Explore the key topics covered in this section:

- Identify and welcome carers, families and supporters
- Identify and support consumer preferences about family and carer involvement
- Proactively involve carers, families, supporters and kin
- · Share information
- Identify and respond to family violence and other risks
- Learn from the lived and living experiences of carers, families, supporters and kin
- · Actively support family and carer wellbeing





Identify and welcome carers, families and supporters

Requirements include:

- Consistently and inclusively identify carers, families, supporters and kin (including young carers).
- Regularly review and update family, carer and supporter details and involvement preferences at key points in care (such as admission, discharge, transfers of care). Make sure any changes are clearly recorded and accessible. Note, the accuracy of information principle (s 726) requires reasonable steps to be taken to ensure information about a person receiving mental health and wellbeing services is accurate, relevant and up to date.
- Acknowledge and welcome diverse family structures including extended family, kin, community Elders, and family of choice. Use posters, signage, lanyards, etc. to welcome all families. Greet visitors warmly and ask who they are.
- Share accessible information, tailored to the diverse needs of the community you work with, about:
 - rights, responsibilities and supports (for example, sharing <u>Tandem rights resources</u>, general information about consumer healthcare rights)
 - service-specific resources about how your service works with carers, families, supporters and kin such as videos, posters or brochures.
- Take all reasonable steps to find out whether a person has an advance statement of preferences that outlines who they would like involved in their care. See supported decision making principle.
- Take all reasonable steps to find out whether a
 person has a nominated support person. For example,
 ask the consumer and any known family, carer or
 support person, check the clinical file, explore if the
 nomination is still current. See supported decision
 making principle.

Good practices may include:

- Undertake projects to increase the proportion of consumers accessing the service with an identified carer or support person.
- Ensure consumers, carers and families receive information and support about how to appoint a nominated support person and the benefits of doing so.

Identify and support consumer preferences about family and carer involvement

Requirements include:

- Explore how the consumer would like their carer, family, supporter or kin involved in their care and treatment. Discuss the benefits of families, carers and supporters receiving information that will help them to support the consumer, and what kinds of information the consumer agrees to or prefers not to share. Revisit these discussions regularly.
- Explain information sharing, privacy and confidentiality policies in plain language to consumers, families, carers and supporters. For example, share Tandem's resources about <u>information sharing with families</u>, carers and supporters.

Good practice may include:

 Identify a clear plan with the consumer, carer, family and supporters about who the consumer would like to be involved as a primary contact. If possible, within health information systems, this may include more than one contact if that is in line with the consumer's preferences.

Proactively involve carers, families, supporters and kin

Requirements include:

After exploring consumer preferences and seeking their agreement as outlined above:

- Involve carers, families, supporters and kin in the consumer's care. This includes inviting family members and carers to be involved in discussions about treatment, care, and discharge planning, for example, case management meetings, family meetings, care planning meetings, family-based interventions and welcoming ongoing dialogue.
- Where there are differences in opinion between a consumer and a carer, uphold the consumer's preferences as far as possible, while respecting and supporting the carer's role. For example, by hearing their views and concerns, providing the information they need to provide care and connecting them with supports. See also dignity of risk principle.
- III Use appropriate supports (including interpreters) to communicate with carers, families and supporters. See dignity and autonomy principle.



Good practices may include:

- Create opportunities, early and often during a
 person's care and treatment, to capture and use carer,
 family and supporters' insights into the consumer's
 strengths, history, preferences, communication styles,
 early warning signs, how to support the consumer's
 autonomy and decision making, and protective
 factors. Record these insights in care and crisis
 support plans.
- Ensure care plans also reflect carer feedback about their ability to provide care, and any limits.
- Give clear orientation and welcome information to carers and families - for example, about the service environment and key contacts. For bed-based services, clearly share information about visiting hours and ways to maintain contact with the consumer.
- Reduce barriers to carer and family engagement for example, offer flexible visiting or out of hours contact arrangements, make reasonable efforts to offer flexible meeting times or approaches to accommodate carer/family responsibilities such as work or caring for dependents, recognise diverse family structures and support connection to rural or remote carers and families.
- Maintain and support relationships between consumers and their carer, family, supporters or kin as part of quality treatment and care planning.
 For example, arrange access to family-friendly spaces for visits.

Share information

Requirements include:

- Ell Give carers, guardians, parents of consumers aged under 16 and nominated support persons copies of compulsory orders and relevant statements of rights at points required by the Act (for example, when a temporary treatment order is made, varied, revoked or expires, when a psychiatrist makes a treatment decision, applies for a treatment order, gives a second psychiatric opinion, when a restrictive intervention is used). See the families, carers and supporters page of the Mental Health and Wellbeing Act 2022 Handbook for a full list of these points.
- El Consult and inform carers, guardians, parents of consumers aged under 16 and nominated support persons of key decisions (see link in the above dot point).
- Share information and resources to help carers, families and supporters understand their rights for example, Tandem's information kit for families, carers and supporters.

- Share general information for example, about how the person is feeling or visiting hours - if doing so is not against the consumer's views and preferences (s 730(2)(f)).
- Share information that a family member, carer or supporter of a compulsory patient reasonably needs to help them provide care or prepare for their caring role. For example, information about the person's mental health condition, early warning signs, strategies for responding to concerns, safety planning, support options and practical assistance. The consumer's preferences about information sharing including any expressed in an advance statement of preferences must be considered before sharing such information (s 730(2)(g)).
- Explain to carers, families and supporters that, even if the consumer does not wish information to be disclosed to them, carers and families can still share their concerns and any information they would like the service to know (for example, strategies that have worked well in supporting the consumer and their family), and this will be considered. Explain to families and carers that information they share may be shared with the consumer unless there is a reason to protect that information for example, where disclosures could negatively affect the care relationship or cause personal risk. If indicated, enable private opportunities for carers to share and discuss concerns. Be mindful of the possibility of family violence, child protection or child custody disputes in considering this information.
- Do not share information even if permitted or required by the Act and even with the consent of the person whose information it is: if you have a reasonable belief that doing so would pose a risk of family violence or other serious harm to a person (s 31).
- Do not share a person's health information (even with consent) if you have a reasonable belief that disclosing the information could: pose a risk to the life or health of any person, unreasonably impact on privacy, be unlawful or inconsistent with another legal requirement, prejudice law enforcement activity or damage national security (s 723).



Identify and respond to family violence and other risks

Requirements include:

 Separately, ask consumers, carers, families and supporters sensitively how they experience key relationships, including what works well and any concerns - for example, trauma, abuse, child custody or child protection issues, or family violence. Follow any steps required by the MARAM framework (Family Safety Victoria, 2018).

Learn from the lived and living experiences of carers, families, supporters and kin

See lived experience principle.

Actively support family and carer wellbeing

Requirements include:

- Ell Give reasonable assistance to an IMHA mental health advocate (s 49), who, with the consumer's consent, is advocating for the rights of a family member, carer or supporter as they relate to the consumer's treatment, care, support or recovery.
- Support carers, families, supporters and kin in their caring role. For example:
 - Proactively check in with families, carers, supporters and kin about their wellbeing throughout their engagement with the service, not just at crisis points.
 - Ensure that family, carer, and supporter wellbeing and support needs are actively considered and addressed in care planning, including discharge planning.
 - Refer carers to confidential support so they can address their own wellbeing needs.
- Proactively identify young carers. Provide information about and connect young carers with age-appropriate supports, such as peer support groups, counselling and school-based supports. For example, <u>Satellite</u> <u>Foundation</u> or <u>Little Dreamers</u>. Ensure their wellbeing is actively considered in all care planning.

Good practices may include:

 Actively acknowledge the interconnectedness of carer and supporter wellbeing and consumer recovery.
 This includes taking steps to maintain and strengthen supportive and respectful relationships where safe and appropriate.

- Refer to practical supports such as respite, flexible visiting arrangements, transport assistance, help to navigate multiple services/service systems, and carer support services. For example, Mental Health and Wellbeing Connects, Tandem's Support and Referral Line phone 1800 314 325, peer support groups, Carer Gateway, Carer Support Fund, Psychiatric Illness and Disability Donations Trust Fund (PIIDDTF).
- Link carers, families and supporters into targeted support for complex or high-stress caring contexts, such as when there is relational conflict or a history of trauma in the family or support network.
- Offer practical guidance on self-care and managing stress while supporting a loved one. For example, sleeping enough, eating well, moving your body, connecting with people, meditating, journalling, listening to music, or doing enjoyable activities.
- Support carers, families, supporters and kin to connect with the family carer lived experience workforce at your service, including carer peer support.

Tips for talking about family and carer involvement

- Ask open ended questions. For example: Who usually supports you/who are important people in your life/who takes an interest in your wellbeing?
- Avoid making assumptions about a person's family structure
- Talk with consumers about the benefits of involving support people and the kinds of information a consumer is willing to share, even if there are things they do not wish to share
- Be alert to the possibility of family violence or safety risks to consumers, carers, families and children
- Recognise that carers, families, supporters and kin, including young carers, hold valuable knowledge about what works and doesn't work for the consumer as well as the family
- Check in regularly with carers, families, supporters and kin about their own wellbeing and support needs.



6. How might services reflect on practice?

- How and when do we ask whether a consumer has someone who supports them, and how they would like them to be involved?
- How do we recognise the diversity of people's support networks (for example, extended families, Elders, families of choice)?
- How do we make sure carers, families, supporters and kin have the information and supports they need, including for their own wellbeing?
- Where the consumer and their supporters have different views, how do we support the consumer's views and preferences while supporting the role and wellbeing of the carer, family or supporter?
- How do we support our family carer lived experience workforce and embed them into the service?

7. **Scenario:** identifying family and carers and clarifying information sharing¹⁵

What happened?

21-year-old Sarah came into the emergency department and had not yet been admitted. Sarah had been using drugs that are impacting her mental health and wellbeing. Sarah lives in a share house with friends and one of her flatmates brought her to hospital. Sarah's clinical file indicated she did not have an identified carer, advance statement of preferences or nominated support person. Sarah is already known to the service, and her last admission was 18 months ago. Drug use was indicated in Sarah's previous admission, and she was discharged after a short stay and then linked in with a SHARC peer support group.

The service needed to understand her preferences and choices. While respecting her privacy, some information was required for safe care. The flatmate had exams and was unable to stay. The service identified Sarah needed immediate admission and care.

What actions did the service take?

Nursing staff asked Sarah if there is someone who usually supports her, noting that Sarah can choose what information the service shares with them. This assurance from the staff gave Sarah confidence to share that her preferred carer/family member was her older brother, Adam, who has supported her through a similar experience in the past. Sarah's in-patient stay lasted a few weeks, and Adam visited every day.

Adam wanted to understand more about her diagnosis, treatment and discharge plan so he could be better prepared to support her following discharge. This raised questions about confidentiality, prompting staff to explore with Sarah what information she felt comfortable sharing. Sarah expressed that she was anxious about Adam knowing about her drug use or diagnosis. However, she agreed with the treating team providing Adam with a fact sheet about the medication she has been prescribed, discharge plan, general education about supporting someone after a hospital stay and agreeing he could be informed about when her follow-up appointments were scheduled.

One of the senior staff members met with Adam to explain privacy and confidentiality and how best to support Sarah in the current circumstances. Adam was also referred to the service's family/carer peer support worker. The staff member documented that information was shared in accordance with Sarah's preferences, and offered carer education sessions separate from the clinical information.

¹⁵ Note: The scenarios in this guidance are adapted from real examples. These simple scenarios focus on the application of one principle and are intended to show that applying the principles is not always complicated. Scenarios that address the principles in more complex situations and ways are available in implementation resources on the Commission's website.



Reflections from Commission lived and living experience staff

Respecting Sarah's autonomy about what to share built trust in the service and the therapeutic relationship with the treating team. Working with Sarah to identify her preferred carer, helped to support Sarah's recovery in community. The service has also respected and navigated Adam's request for information in a way that respected Sarah's preferences, and can re-visit with Sarah over time whether she is willing to share more information.

The service respected Sarah's privacy and did not share any clinical information other than what Sarah agreed to. This shows families and carers can be supported without undermining a person's privacy and decisions about what can be shared. Staff validated Adam's concerns but kept Sarah's preferences central to decision making.

Which other principles were engaged?

Mental health and wellbeing principles: dignity and autonomy, supported decision making

How would you approach this situation?

What might you do differently?



8. Where can I find more information?

Guidance

Department of Families, Fairness and Housing (2018) Recognising and supporting Victoria's carers: Victorian carer strategy 2018-2022 https://www.dffh.vic.gov.au/ publications/recognising-and-supporting-victoriascarers-victorian-carer-strategy-2018-22

Department of Health and Human Services (2018c) Working together with families and carers: Chief Psychiatrist's guideline https://www.health.vic.gov.au/chief-psychiatrist/working-together-with-families-and-carers

Department of Health (2025b) Implementing
<a href="Implemen

Mind Australia (2016) - <u>A practical guide for working with carers of people with mental illness</u> https://www.mindaustralia.org.au/sites/default/files/2023-07/A_practical_guide_for_working_with_people_with_a_mental_illness.pdf

Resources

Department of Health <u>Mental Health and Wellbeing</u> <u>Act 2022 Handbook: Families, carers and supporters</u> https://www.health.vic.gov.au/mental-health-and-wellbeing-act-handbook/supported-decision-making/families-carers-supporters

Nexus <u>Three Step Carer Identification</u>, <u>Conversation and Options tool</u> https://www.svhm.org.au/ArticleDocuments/2140/ ThreeStepCarerConversationSupport.pdf.aspx?embed=y

Nexus <u>Carers can ask</u> booklet https://www.svhm.org. au/our-services/departments-and-services/n/nexus/ carers-can-ask

Tandem's <u>Information and resources for family, carers and supporters</u> including:

- Information Sharing with families, carers and supporters https://tandemcarers.org.au/Common/Uploaded%20 files/Your-Rights/250228%20Tandem%20info%20 sheet%202.pdf
- Tandem support and referral line 1800 314 325

