

# How to have the conversation: Information sharing with families/whānau/carers



The Royal  
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Best practice psychiatric care involves a collaborative approach between consumers, their carers, other family/whānau<sup>a</sup> members, and clinicians.<sup>1</sup> Carers, who are often family members/whānau/aiga<sup>b</sup> (referred to as 'carers' in this document), play a central role in the care and recovery of individuals who are experiencing a mental health condition.<sup>2</sup> Evidence shows that involving carers in the assessment, diagnosis and treatment of those experiencing a mental health condition can enhance the recovery process.

There should be a transparent understanding between the psychiatrist and the consumer on the nature of information and guidance that will be shared with any nominated carer.<sup>1</sup> Best practice includes the psychiatrist's responsibility to assess the appropriateness of putting information sharing arrangements in place. This resource may assist psychiatrists to come to effective agreements with adult consumers on information sharing. This resource may also assist psychiatrists to work effectively with carers, helping them to establish and maintain working relationships with mental health services and staff.

<sup>a</sup>Whānau' (pronunciation: fa:no) is a Māori word that can be used to describe an extended family group spanning three to four generations. The whānau continues to form the basic unit of Māori society (Rāwiri Taonui)

<sup>b</sup>Aiga - The term Aiga as used in the Samoan sense includes not only the immediate family, father, mother and children, but also the whole union of families of a clan and even those who although not related are yet subject to the family control. (Victoria University).

<sup>c</sup>The term 'chosen family' is used to describe family groups and relationships that are based on choice rather than biology or law. The term is often used in LGBTIQ+ communities.

## Having the discussion

### When to raise information sharing

- ▶ Have a conversation in the early stages of meeting to determine who the consumer's carers/family/whānau/supporters are.<sup>3</sup> Questions may include 'Who are you turning to for support?', 'With whom are you wanting us to engage?', 'Where else are you connected?', and 'Who else are you relying on?'
- ▶ Explain that the consumer can nominate anyone to receive information about their care.<sup>1</sup> The consumer may wish to exclude their next of kin, but instead include a 'chosen family'.<sup>4</sup> Seek to understand what information the consumer is comfortable sharing with who, and how.<sup>5</sup>
- ▶ Seek to obtain agreement on information sharing within the first few meetings.<sup>5</sup>
- ▶ Return to review information regularly.<sup>6</sup>

### How to have the conversation

- ▶ Ensure the consultation environment is relaxed and culturally informed, and that the consumer is prepared to discuss information sharing.<sup>7</sup> It is important to invite as much conversation with the carer/s as possible.
- ▶ Discuss the scope of information sharing, applicable privacy legislation and protocols and how they apply.<sup>1</sup>
- ▶ Record agreed information sharing arrangements within medical records, treatment and recovery plans and if applicable, an advanced statement.<sup>6</sup> Collaborative writing of reports or letters may assist in a mutual understanding.
- ▶ Note that where a consumer refuses to nominate a person with whom information can be shared, this should be respected unless under exceptional circumstances (e.g. allowed for under legislation).<sup>3</sup>
- ▶ Clarify a mutual understanding of the agreement at the end of the discussion and document this.<sup>8</sup>

### Applying the outcomes

- ▶ Respect the agreed information sharing arrangements.<sup>5</sup> There may be some limitations to this outlined in legislation which the psychiatrist should communicate.<sup>3</sup>
- ▶ Communicate the agreed information sharing arrangements transparently with both the consumer and the carer/s.
- ▶ Review any agreement on information sharing regularly to ensure it reflects the consumer's current wishes, particularly where a change in circumstances or carers occurs.<sup>1</sup>
- ▶ Note that if consent is not given, then only general information (as outlined under legislation) can be communicated.<sup>9</sup>

## Where there is no consent to share information

A consumer may be unable or unwilling to consent to the involvement of their carer/s. A consumer can refuse to consent for their personal information to be shared with their carer/s, subject to any exceptions provided for in the relevant legislation, regulation, or duty of care requirements.<sup>3</sup>

### How to have the conversation

- ▶ Enquire further as to the reasons why carer involvement has been refused and try to address the issues; the consumer may be willing to share some types of information and not others, or share information with an alternative carer.<sup>5</sup>
- ▶ Have a welcoming attitude towards the carer/s regardless of the information sharing agreement.
- ▶ Be aware that the consumer may have experienced abuse or other forms of trauma. Enquiries about the nature and history of the consumer's relationships should be undertaken sensitively.<sup>7</sup>
- ▶ Communicate openly with the consumer about what you are required to share and why, so they are aware of the limits of confidentiality.<sup>3</sup>
- ▶ Clarify a mutual understanding of the agreement at the end of the discussion and document this.<sup>8</sup>

### Applying the outcomes when consent is not given

- ▶ Note that only information that is essential for the carer to have should be provided.<sup>6</sup> For example, psychiatrists may not be able to discharge a consumer home to family care without explaining the treatment and methods of contacting necessary health professionals.
- ▶ Support carers by actively listening to their issues and concerns, identifying their needs, providing general information on what they can do as a carer, and encouraging them to access appropriate informal and formal support services.<sup>3, 10</sup>
- ▶ Record agreements made between the consumer, carer and the clinician, including the lack of consent in the consumer's medical record and treatment plan.<sup>3</sup> Where the agreed information sharing instructions change, this should be updated.<sup>3</sup>

## References

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