Facilitating advance care planning in older people with mental illness

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Advance care planning (ACP) involves an ongoing discussion about a person's preferences for future healthcare, reflecting their individual values and wishes. Despite the demonstrated need and potential benefits, ACP is often overlooked in older people with mental illness. This article provides practical guidance for GPs to support ACP, including collaboration with carers and mental health services.

KEY POINTS

- Advance care planning (ACP) is rarely discussed with older people with mental illness, despite its recognised importance and benefits.
- Barriers include misconceptions about ACP, concerns about decision-making capacity and cognition, inadequate guidance on processes and lack of training.
- GPs are ideally positioned to facilitate ACP discussions with people with mental illness because of trusted relationships and continuity of care.
- A collaborative team-based approach, including patients, family or carers, mental health clinicians and other healthcare professionals, can facilitate ACP for people with mental illness and complex care needs.
- Clear, accessible documentation, supported decision-making and multidisciplinary collaboration help optimise ACP and improve patient outcomes.

Advance care planning (ACP) is an iterative process of discussing a person's preferences for future healthcare, aligned with their individual wishes and values.[1] It helps ensure that care remains person-centred, particularly if individuals lose capacity to make or communicate decisions themselves towards the end of life. An advance care directive (ACD) is a legally binding written document that records a person's specific preferences for future healthcare.[2]

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Psychiatric advance directives (PADs) differ from ACDs in that they are legal documents communicating an individual's preference for future mental health treatment if they lose decision-making capacity (e.g. during an episode of mental illness).[3] Not all jurisdictions in Australia have legislation for PADs, which also involve complex ethical and practical considerations.[3-6] This article focuses on ACP.

It is important to distinguish between ACP and voluntary assisted dying (VAD), as the terms are often misunderstood and conflated, including by some older people with mental illness.[7,8] VAD, also known as physician-assisted suicide and medical assistance in dying, refers to a legislated process whereby a person with decision-making capacity who meets strict eligibility criteria (e.g. terminal illness) can access medication to end their life.[9,10] Requests for VAD cannot be included in an ACD in Australia.[11] This is because ACDs come into effect when a person loses capacity, whereas access to VAD requires decision-making capacity to be retained throughout the process.[11]

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TABLE 1. BARRIERS TO ADVANCE CARE PLANNING IN PEOPLE WITH MENTAL ILLNESS

Stakeholder group	Barriers to ACP
Older people with mental illness[8]	• Not knowing what ACP is • Not knowing it involves their choice • Feeling underestimated by clinicians • Perceptions that their GP is too busy • Thinking it is not the right time as they are not dying • Misconceptions about the cost of ACP
Carers of older people with mental illness[8]	• Dying and death are too confronting and complex • No one has raised ACP • Perceiving GPs to be too busy or lacking the skills (to help a person with mental illness) • Thinking ACP is only needed if someone is dying • Considering ACP is inappropriate for someone who is cognitively impaired
Mental health clinicians[25]	• ACP is too complex • Fear of causing harm (distress, exacerbating mental illness, damage to therapeutic relationship) • Incorporating families and culture • Systemic barriers such as ageism and discrimination against people with mental illness • Capacity and legal issues, especially if there are symptoms of mental illness and cognitive impairment • Uncertainty about the timing of ACP in relation to state of illness • Lack of knowledge and training • ACP is not embedded in practice or prioritised

Abbreviation: ACP = advance care planning.

Although ACP is widely endorsed, people with mental illness are often overlooked in its implementation.[12-14] This is especially concerning given the higher burden of medical comorbidity and premature mortality in this population, as well as poorer end-of-life outcomes, such as suboptimal symptom management, reduced access to palliative care, experiences of stigma and poor co-ordination of healthcare services.[15-21]

This article provides a practical guide for GPs to support their involvement in ACP with older patients with mental illness. Although the Royal Australian College of General Practitioners (RACGP) has useful practice tools and a position statement on ACP, these provide general information and are not tailored to the specific needs of people with mental illness.[22-24] This article addresses the unique challenges of engaging in ACP in the context of ongoing symptoms of mental illness, cognitive impairment and concerns about decision-making capacity. It also proposes greater collaboration between primary care and mental health services to overcome barriers and support practical implementation of ACP in people with mental illness. The discussion draws on recent qualitative research with older consumers (age 55 years and older) of mental health services, their carers and clinicians to inform how ACP can be effectively facilitated in general practice.[8,25]

Challenges to ACP in people with mental illness

Older people with mental illness and their carers have expressed interest in ACP, recognise its benefits and want to be involved.[8,14,26] Barriers to ACP exist across all healthcare settings, including clinician uncertainty about whose role it is, concerns about cognition and decision-making capacity, uncertainty about when to initiate discussions, limited time, and gaps in clinicians' knowledge and skills.[27] However, additional challenges may further limit engagement in ACP among people with mental illness.[28-30] Qualitative research involving older people with mental illness, their carers and mental health clinicians in Australia has identified specific challenges (Table 1).[8,25] Notably, some people with mental illness and carers perceive GPs to be too busy for ACP or lacking the skills to adapt conversations when symptoms of mental illness are present, and have indicated a preference for undertaking ACP with mental health clinicians.[8] Meanwhile, mental health clinicians may not view ACP as part of their role, and report that it is not embedded in practice or prioritised.[25]

The RACGP recommends that GPs incorporate ACP into routine patient care, particularly for older patients (aged 75 years and older).[24] The accompanying clinical and practice management guidance highlights the importance of considering capacity and mood when discussing ACP and ACDs.[24] There are several high-quality resources to support GPs, such as the *Advance Care Planning Improvement toolkit* tailored to each state and territory, resources for ACP with residents of aged care facilities and people with dementia (https://www.advancecareplanning.org.au/professional-resources) and conversation guides.[31,32] However, there are currently no dedicated resources to guide GPs in conducting ACP specifically in people with mental illness. Until recently, there were also no freely available, evidence-based resources to support mental health clinicians, consumers and carers in this area.[33]

Turning barriers to ACP into solutions

Themes regarding barriers and facilitators of ACP identified from our qualitative studies with consumers, carers and mental health clinicians informed strategies to support ACP in older people with serious mental illness, including psychosis (Table 2), and the development of targeted resources to support implementation.[8,25,33,34] Given the limited knowledge and identified

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TABLE 2. EVIDENCE-INFORMED STRATEGIES TO ENABLE ADVANCE CARE PLANNING IN PEOPLE WITH MENTAL ILLNESS

Identified need	Strategy	Resource
Education for patients and carers	• Information about ACP • Dispelling myths about ACP • The optimum timing of ACP	Bespoke take home summaries for patients and carers in four languages.[33] Available at: https://capacityaustralia.org.au/acp-resources/
Education for clinicians	• Information on ACP, including addressing concerns about fear of causing harm • Capacity and legal issues; supported decision-making • Cultural considerations in ACP • How and where to seek support with complexity – drawing on the multidisciplinary team (e.g. timing of ACP discussions)	Bespoke take home summary for clinicians to accompany education sessions on ACP[47] Available at: https://capacityaustralia.org.au/acp-resources/
Clinician skills training	• Training films demonstrating aspects of ACP in older people with mental illness and cognitive impairment • How to involve carers • Role play and opportunities to practice and refine ACP discussion skills • Making it feasible – a series of short iterative discussions over time	YouTube films. Available at: https://capacityaustralia.org.au/acp-resources/
Improving access to ACP	• Practical training on where and how to document ACP in the medical record • Broad sharing of ACP with the patient and family, GP, specialists, hospital medical record, My Health Record	Education sessions for clinicians demonstrating processes for documentation and sharing ACP[34]
Systems change	• Leadership support for ACP becoming embedded in practice • Embedding ACP in care plans, ward rounds, case reviews • Appoint champions • Audit ACP documentation and feedback to teams • Routine documentation of ACP in medical records	

Abbreviation: ACP = advance care planning.

misconceptions about ACP and mental illness, education was recognised as essential for consumers, carers and clinicians alike.[8] As no evidence-based resources specific to the needs of people with mental illness were identified, we developed some and made these freely available via the Capacity Australia website https://capacityaustralia.org.au/acp-resources.[33] These one-page summaries, which address the specific needs of older people with mental illness and their carers, may also assist GPs in initiating ACP conversations.

Given the identified challenges, clinician uncertainty regarding roles and patient and carer preferences, an adapted stepped-care approach is appropriate.[35] This enables GPs, practice nurses and mental health clinicians to work together to facilitate ACP, particularly in more complex cases. Practical tips for ACP with people with mental illness are outlined in Box 1, and suggested conversation starters for primary care are provided in Box 2.[32]

Assessing decision-making capacity

Assessing decision-making capacity for ACP in people with mental illness has been identified as challenging for mental health clinicians and is also likely to be challenging for GPs.[25,36] Under common law in Australia, all adults are presumed to have decision-making capacity.[37] However, capacity may fluctuate or be affected by symptoms of mental illness, emotional distress and cognitive impairment.[38-40] Importantly, a diagnosis of a mental illness or cognitive disorder does not equate to a loss of capacity, and people with mental illness and disability have equal recognition before the law (Article 12, Convention on the Rights of Persons with Disabilities).[41] Similarly, age-based assumptions about capacity must be avoided and challenged.[38]

Capacity is decision-specific. Compared with ACP more generally, there is a higher threshold for completing an ACD, which is a legally binding, witnessed document that must be respected by healthcare professionals.[2] An enduring guardian, family member or person responsible cannot complete an ACD on behalf of another person.[2] In contrast, ACP reflects an iterative process of discussion, ideally involving the person and often their family or carers, and is not legally binding. It may involve supported decision-making. ACP can also be completed by a substitute decision-maker, taking into account the person's wishes and preferences, even if the person lacks capacity. To assess a patient's capacity to engage in ACP or complete an ACD, GPs need to:

- provide clear information about ACP/ACD (noting many people with mental illness are unfamiliar with these concepts)[8]
- assess whether the patient understands the nature, content and implications of ACP/ACD (personalised to their health condition and likely end-of-life decisions)

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1. PRACTICAL TIPS FOR GPS FACILITATING ADVANCE CARE PLANNING

Approach

- Be collaborative
- Check understanding; listen before explaining
- Explain; do not assume knowledge of terms and avoid jargon
- Ask questions sensitively: be sensitive to stigma associated with discussing future care in the context of mental illness
- Provide reassurance and encouragement as you go through the process
- Pace ACP conversations to the patient's needs, current cognition and mental state
- Allow time for reflection
- Invite patients to bring a trusted carer, friend or family member to discussions about ACP

Checking understanding

- Echo the patient's words to check you've understood their wishes
- Make it personal – use your knowledge of their health comorbidities to start discussions about particular wishes and preferences for end-of-life care
- Ask the patient to summarise what the plan means to them
- Reinforce knowledge about ACP by providing resources and encouraging questions at future visits
- Be flexible with the content
- Reassure patients that it is OK if they do not wish to complete a part of their plan
- Keep it relaxed and unpressured. If time is running out suggest further appointments to continue the discussion

Make it count

- Encourage patients to share copies of ACP/ACD with family, allied healthcare providers and mental health clinicians (with consent)
- Suggest sharing their ACP/ACD documents with the Local Health District for upload to their electronic medical record
- Facilitate uploading ACP/ACD to their My Health Record
- Revisit and revise ACP as needed

Abbreviations: ACD = advance care directive; ACP = advance care planning.

- assess whether the patient can weigh up the pros and cons of creating an ACP/ACD (including the implications of their choices), and
- assess the patient's ability to communicate a choice.[2,37]

Capacity assessments should be documented and can be revisited as needed.[42]

Supported decision-making

GPs can employ several strategies to optimise decision-making capacity, including for people with mental illness. Supported decision-making involves enabling individuals to make their own decisions with appropriate assistance and to participate meaningfully in the process.[43] This includes understanding the person's values and preferences, identifying their specific support needs (e.g. use of an interpreter, involvement of a nominated carer or family member, use of hearing aids, preferred communication methods – visual, verbal or written formats) and optimising their ability to participate in the process. Supported decision-making differs from substitute decision-making, where another person makes decisions on behalf of the individual in line with what they would have wanted if they had capacity to make decisions.[43]

Choosing the right time to discuss ACP is crucial.[25] Mental state may fluctuate, for example during periods of relapse of psychosis or depression, periods of stress (psychosocial or medical) or worsening cognitive symptoms (e.g. delirium or poorer cognition late in the day in some people with dementia). GPs may liaise with psychiatrists, mental health clinicians or aged care teams to determine optimal timing of ACP, as recommended in mental health settings.[25] Practice nurses and residential aged care staff may assist with documenting the 'values' component of ACP.[44] GPs can then discuss medical conditions and treatment options, address patient questions and witness completed documents.[44] Information should be presented clearly and in plain language. ACP discussions can occur over multiple sessions to reduce burden, reinforce key information, check understanding and assess consistency of preferences over time, which is an important aspect of capacity assessment.[2,37]

GPs should encourage involvement of family members or nominated carers to support decision-making.[8] Carers of people with mental illness have expressed an interest in being involved and recognise the benefits of ACP, including respecting the patient's preferences, providing reassurance and relieving the burden of decision-making at end of life.[8] They have also highlighted their potential roles as patient advocates, cultural brokers and sources of important contextual information, including knowledge of the person's history and experiences (e.g. trauma), which are important for sensitive engagement.[8] More generally, ACP should recognise the significance of culture on identity, practices and decision-making for individuals and their family.[45]

2. SUGGESTED QUESTIONS TO ENGAGE PEOPLE WITH MENTAL ILLNESS IN ADVANCE CARE PLANNING

- Remember when you had XXX illness and you were really unwell? It was difficult for the hospital team and your family to know what kind of care you wanted. Advance care planning involves setting out your preferences for care ahead of time, so clinicians can respect your wishes if you cannot voice them. Would you like to talk about this?
- Have you thought about what kind of care you might want if you got very unwell?
- Is there any kind of care you do not want?
- Have you ever heard of an advanced care directive? What do you think it means? Would you like to learn more?
- How do you feel about filling out the form with me?
- Do you think it would help you?
- Would you prefer your friend or a trusted family member to come in with you to discuss it together?
- Would you like an interpreter or a community health worker/Aboriginal health worker to assist you?

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Legal considerations

For people subject to orders under the Mental Health Act or guardianship, specific considerations apply. Although a guardian cannot complete an ACD on behalf of a person, the person's views should still be sought in ACP discussions.[2] Even if the guardian has authority to make healthcare decisions, the individual should be supported to participate in ACP and express their values, wishes and preferences.

For older people under a community mental health order, capacity to engage in ACP should be assessed as detailed above. As with all individuals, they retain the right to autonomy of decision-making, unless there are reasons to question capacity.[37,46]

Specific primary care settings

Community and residential aged care homes

For most well-known older patients with mental illness living in the community, GPs can engage patients in ACP using standard processes.[24] However, in more complex situations, such as ongoing or fluctuating symptoms of mental illness, cognitive impairment or questions about decision-making capacity, GPs may need specialist support. This may include liaising with existing mental health clinicians or making new referrals to support optimisation of mental health and capacity assessment. Referrals to specialist services, such as older persons' mental health, may be appropriate for people with overlapping ageing-related syndromes, frailty, multimorbidity, and co-existing cognitive and mental health conditions. Just as mental health professionals are encouraged to draw upon the expertise of multidisciplinary colleagues, GPs can similarly collaborate to support ACP for these patients.[25]

Many residents of residential aged care homes will be engaged in ACP early in their move into care as part of aged care quality standards.[47] However, these ACP and ACD documents are often not included in the local hospital electronic medical records, rendering them inaccessible at times of greatest need.[34,48] Older people engaged with public mental health or medical outpatient services should be asked whether existing ACP or ACD documentation can be uploaded to the hospital records and My Health Record, and supported to do so where needed.

Rural settings

In rural areas, the GP remains central to end-of-life care, with comparatively less involvement from palliative care, geriatric medicine, mental health and allied health services.[45] The key difference in ACP for people with mental illness in rural and regional areas is access to mental health assessment and advice, particularly from specialist teams such as older persons' mental health.

Telehealth, community partnerships and locally embedded documentation strategies can support rural GPs to initiate ACP discussions with older adults with mental illness. Inclusion of ACP documents in a patient's My Health Record is especially important for patients in rural areas to ensure the information is available across multiple service locations (including telehealth) and across large geographical distances.[45]

Additional resources for ACP are provided in Box 3.

Conclusion

Older people with mental illness deserve equal access to high-quality, person-centred end-of-life care. ACP provides a crucial pathway to support dignity, autonomy and clarity for patients, carers and clinicians. GPs are trusted healthcare providers who often know the patient well, both personally and medically, over many years and are therefore well-placed to start these discussions. This is in contrast with other healthcare professionals who may meet the patient for the first time in acute or emergency situations or at entry to residential aged care. Through collaboration with mental health services, GPs can lead a compassionate, inclusive approach to ACP for this population. MT

3. KEY RESOURCES FOR GPS ON ACP WITH PEOPLE WITH MENTAL ILLNESS

- **Capacity Australia**
  www.capacityaustralia.org.au
  (see ACP resources, available in four languages and specific to stakeholder group-clinicians, older people with mental illness and carers)
- **NSW Health: Dignity, Respect and Choice: An Introductory Guide**
  https://www.health.nsw.gov.au/patients/acp/Publications/introductory-guide.pdf
- **NSW Health: Dignity Respect and Choice: A Comprehensive Guide**
  https://www.health.nsw.gov.au/patients/acp/Pages/comprehensive-guide.aspx
- **RACGP Toolkit**
  https://www.racgp.org.au/running-a-practice/practice-resources/practice-tools/advance-care-planning
- **Advance Care Planning Australia**
  www.advancecareplanning.org.au
  (including resources in other languages – www.advancecareplanning.org.au/other-languages)
- **My Health Record: ACP uploading**
  www.myhealthrecord.gov.au
- **For additional support related to ACP**
  The National Advance Care Planning Support Service on Tel: 1300 208 582
- **For any legal questions related to an advance care directive**
  the NSW Trustee and Guardian on Tel: 1300 109 290
- **Medicare items to support ACP**
  https://www.practiceassist.com.au/PracticeAssist/media/ResourceLibrary/Medicare%20Benefits%20Schedule/Advance-Care-Planning-Fact-Sheet.pdf

Abbreviation: ACP = advance care planning.

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A list of references is included in the online version of this article (www.medicinetoday.com.au).

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