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End of life care

The importance of advance care planning

Background

Communication about end of life care may involve difficult conversations for patients, family members and health professionals. However, a lack of understanding of a person's wishes about their future care may result in a loss of dignity for the person, and additional distress for their family members and health professionals and burden to the healthcare system.

Objective

This article discusses the barriers to advance care planning and provides some guidance for the general practitioner in undertaking advance care planning with patients and their families. Tips for initiating end of life discussions with patients and families utilising the 'PREPARED' acronym, and ensuring appropriate care delivery are included.

Discussion

Involving patients and their family members in advance care planning may be challenging and time consuming for GPs. However, there are a number of resources to support this activity in relation to training, communication support and Medicare item funding.

Keywords: aging; doctor-patient relations; palliative care and attitude to death



Issues surrounding end of life (EOL) decision making, continue to be topical and widely debated. Many people do not wish to think or talk about their death or dying until it is too late. This can have serious repercussions on a number of fronts. Resources may be utilised to provide patients with treatments they do not want, distress may be experienced by family members and considerable stress placed on staff, as well as creating difficulties in areas such as organ donation. With organ donation rates in Australia being one of the lowest in the world, this latter point needs also to be considered. Lack of knowledge and poor communication between patients, family members and health professionals may contribute to family trauma.¹

Barriers to end of life care discussions

While many general practitioners find talking about EOL difficult and often avoid these discussions with their patients,² maintaining a stable relationship³ and talking about EOL care and decision making is integral to ensuring that the care delivered to patients is aligned with their wishes. Patients are unlikely to be involved in decisions about their care unless they perceive a good rapport and open communication with a health professional.⁴ While some GPs may believe that patients are not willing or able to face discussions around death and dying,⁵ most patients expect their GP to initiate such discussions and would prefer to talk with a GP who they know and trust than a stranger or designated 'advance care plan professional' in the hospital following admission.^{1,6}

In this way, patients and their families are assisted to talk through this important issue while the patient is able to contribute to the discussion. Phrasing these conversations in a way that focuses on preservation of liberty, dignity and autonomy can also assist to open communication channels.⁷

Cultural, familial and religious beliefs of families also need to be considered, as these too will impact on the family's willingness to talk about EOL care and participate in decision making.⁸

Time can also be an important consideration for the busy GP as talking about EOL care and decision making with patients is not usually a 'one time only' conversation. Rather it is an ongoing process requiring more than one discussion,⁶ and often inclusive of multiple family members and significant others.⁵



Facilitating end of life discussions

The acronym 'PREPARED' has been recommended as a guide to assist health professionals in facilitating EOL discussions.⁹

Prepare for the discussion

- Ensure you have confirmed results of investigations and received relevant reports, ensure uninterrupted time, and arrange for those who need to be present

Relate to the person

- Ensure you have rapport and show appropriate empathy and compassion

Elicit patient and caregiver preferences

- Identify the reason for the consultation and elicit the patient's (and the caregiver's) expectations
- Clarify their understanding of the situation, and establish how much detail and what they want to know
- Consider cultural and contextual factors that may influence information preferences

Provide information

- Provide information that is specific to the patient's needs

Acknowledge emotions and concerns

- Check understanding of what has been discussed and if the information provided meets the patient's and caregiver's needs

Realistic hope

- Offer realistic hope and encourage questions

Document

- Document a summary of the discussion and communicate the decisions to appropriate other health professionals.

The discussion

Starting the discussion is often the most difficult point of the conversation. However, most advance care planning processes require multiple EOL conversations. In addition, individuals will also need time to comprehend and process the information, both with your expert support and away from the surgery.

General practitioners should initiate and normalise early discussions about EOL care with their patients by premising the discussion with, 'I make a point of talking about this with all of my patients,' as a way of making it part of routine care. Similarly, the use of scenarios such as, 'What would you want to happen to you if...?' can help aid the patient and their family in decision making.⁵ Scenarios can be posed in a way to illustrate possible outcomes including the use of life support, pain and suffering, extensive disability, chronic disease⁵ and dying, and consideration of organ donation as appropriate, so that patients can articulate how they would want to be cared for and what they may want to contribute, if faced with this situation.

Involving the family

When a patient is not competent to make their own decisions, and in the absence of an Advance Care Plan, decision making can become the responsibility of the family or other nominated decision maker. The GP can encourage patients to nominate a family member/significant other

to contribute to the decision making process regarding care. Being cognisant of the patient's wishes can help alleviate some of the burden carried by the nominated decision maker.¹⁰

Opportunity for family/nominated decision maker inclusion in care and decision making is essential.^{11,12} While they may not have the same understanding of the illness/disease process, it is acknowledged that they bring a valuable, yet different perspective to the process of care planning and death.¹³ Family participation in care and decision making may also provide families with a feeling of purpose and closeness to the patient,¹⁴ however, not all families will want to contribute. One recent study in an intensive care unit (ICU) reported that half of the family members in the study did not want to share in decision making.¹⁵ Symptoms of anxiety and depression are prevalent in nominated decision makers, who may be designated as 'proxy decision makers', where they are ill prepared for the responsibility and burden for their role.^{16,17} Many also have feelings of guilt, helplessness, and physical and emotional exhaustion as a consequence of their role.¹³ Families also report that their own needs for care and support go unmet.¹⁸ Including potential proxy decision makers in advance care planning discussions prepares them for their future decision making roles and may reduce the negative impact of proxy decision making.

The option for inclusion of family or other nominated decision maker in the decision making process, alongside clinicians, is a practice endorsed by New South Wales Health who developed guidelines for EOL care and decision making¹³ to assist clinicians when dealing with EOL management. These guidelines encourage a collaborative approach to care where families and healthcare professionals work together to make decisions, building consensus in determining the best course of treatment for individuals (see *Resources*).

The guidelines also encourage clinicians to start talking with patients and families about EOL early, before serious illness makes communication on such issues difficult.¹³ Indecision and conflict around care and treatment can not only delay treatment, but also result in ongoing suffering. One recent study revealed that up to seven discussions with family/nominated decision makers of intensive care unit patients, who were too acutely ill to speak for themselves, before agreement and consensus was reached between clinicians and family.¹⁹

While communication within the hospital setting is not the role of the GP, the GP is central to the preparation for EOL decisions for residents in nursing homes and aged care facilities, and for patients with life limiting illness living in the community.

Aids for the GP

Evidence suggests²⁰ that some GPs are not aware that they can claim Chronic Disease Management Medicare items (formerly known as Extended Medicare items) for time spent with patients and families in advance care planning for patients with chronic illness and those receiving palliative care (see *Resources*).



In recent years, programs such as 'Respecting Patient Choices'²¹ and various modifications of this, have been applied in some health services, including community services. Such programs may not be appropriate for use by individual GPs but will provide some guidance for initiating and recording EOL discussion.

The recent upsurge in promoting EOL planning in nursing homes²² has resulted in many developing their own EOL wishes form, which can be completed in consultation with the patient on admission to the home. The GP is a very important contributor to the development of this plan. How, or in what location this EOL plan is developed, its clear documentation and accessibility to future providers of medical care is essential for its appropriate execution.

Case study

Molly, aged 68 years, had been suffering from chronic kidney disease and hypertension for a number of years. She lived at home alone with support from primary healthcare services. After being found unconscious by a neighbour she was admitted to ICU in an acute hospital having been diagnosed with an intracranial haemorrhage. She had not prepared an advance care plan although her daughter found a note among Molly's belongings in which Molly had made it clear that she would not want extraordinary measures taken to preserve her life and that she would not want to be admitted to a nursing home. Despite family protest and their assertion that her current condition would be their mother's worst nightmare, Molly remained in ICU for 18 days with full active treatment including intubation and mechanical ventilation.

Following two family meetings with staff it was agreed that Molly would be listed as not for resuscitation and not for medical emergency treatment service (METS) calls. However, two more distressing METS calls took place and Molly remained on the ventilator.

A further 7 days later it was agreed that Molly would have no further active treatment and that the ventilator would be removed. Molly died 30 minutes after this action was taken. The prolonged treatment, subsequent distress and potential loss of dignity for Molly, in addition to the distress for her family and hospital staff, may have been avoided if an appropriate advance care plan had been developed when Molly had been competent to engage in conversation about her future care, and provided to the hospital staff on her admission.

Conclusion

General practitioners play an important role in assisting patients to consider their EOL plans and to share their wishes with family. Talking about death and dying in consultations can assist patients to think about the way they wish to be cared for and to ensure that they make their wishes explicit to their family. General practitioners should attempt to document these conversations comprehensively as these notes can assist later when care decisions need to be made.

Summary of important points

- Most patients look to their GP to initiate EOL care planning discussions.
- End of life care planning is a process which needs to take place over a number of discussions and to include nominated decision makers, family or significant others.
- End of life care planning is essential to ensure that patients receive the care they want, family members are relieved of the stress of making decisions without the benefit of knowing what their loved one would want for their care, or in relation to issues such as organ donation.
- Talking about EOL care enables staff to provide care in the manner to which is in the patient's best interest, having respected their wishes.

Resources

- A list of Medicare items that can be claimed when treating patients who have terminal medical conditions. Chronic Disease Management Medicare Items: www.health.gov.au (search for CDM Medicare items)
- Respecting Patient Choices. State based links and documents for advanced care planning: www.respectingpatientchoices.org.au
- Care Search (Palliative Care Knowledge Network): www.caresearch.com.au (click on 'Professional Groups' and 'GP home'. Multiple topics covered with printable resources.

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References

1. Cartwright CM, Parker MH. Advance care planning and end of life decision making. *Aust Fam Physician* 2004;33:815–9.
2. Calam B, Andrew R. CPR or DNR? End-of-life decision making on a family practice ward. *Can Fam Physician* 2000;46:340–6.
3. Pinkowish MD. End-of-life care: communication and a stable patient-physician relationship lead to better decisions. *CA Cancer J Clin* 2009;59:217–9.
4. Lee S, Kristjanson L, Williams A. Professional relationships in palliative care decision making. *Support Care Cancer* 2009;17:445–50.
5. Gallagher R. An approach to advance care planning in the office. *Can Fam Physician* 2006;52:459–64.
6. Burgess TA, Brooksbank M, Beilby JJ. Talking to patients about death and dying. *Aust Fam Physician* 2004;33:85–6.
7. Doukas D. Advance directives in patient care: if you ask, they will tell you. *Am Fam Physician* 1999;59:530.
8. Clark K, Phillips J. End of life care: the importance of culture and ethnicity. *Aust Fam Physician* 2010;39:210–3.
9. Clayton JM, Hancock KM, Butow PN, Tattersall MHN, Currow DC. Clinical practice guidelines for communication prognosis and end-of-life issues with



- adults in the advanced stages of a life limiting illness, and their caregivers. *Med J Aust* 2007;186:S76–108.
10. Vig E, Starks H, Taylor J, Hopey E, Fryer-Edwards K. Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *J Gen Intern Med* 2007;22:1274–9.
 11. Gries CJ, Curtis R, Wall RJ, Engelberg RA. Family member satisfaction with end-of-life decision making in the ICU. *Chest* 2008;133:704–12.
 12. Cook D, Rucker G, Giacomini M, Sinuff T, Heyland D. Understanding and changing attitudes toward withdrawal and withholding of life support in the intensive care unit. Improving the quality of end-of-life care in the ICU. *Crit Care Med* 2006;34:S317–23.
 13. NSW Health. Guidelines for end-of-life care and decision-making. Sydney: NSW Health, 2005.
 14. Azoulay E, Pochard F, Chevret S, Arich C, Brivet F, Brun F. Family participation in care to the critically ill: opinions of families and staff. *Intensive Care Med* 2003;29:1498–504.
 15. Azoulay E, Pochard F, Chevret S, Adrie C, Annane D, Bleichner G. Half the family members of intensive care patients do not want to share in the decision-making process: a study in 78 French intensive care units. *Crit Care Med* 2004;32:1832–8.
 16. Pochard F, Azoulay E, Chevret S, Lemaire F, Hubert P, Canoui P. Symptoms of anxiety and depression in family members of intensive care patients: ethical hypothesis regarding decision-making capacity. *Crit Care Med* 2001;29:1893–7.
 17. Pochard F, Darmon M, Fassier T, Bollaert P, Cheval C, Coloigner M. Symptoms of anxiety and depression in family members of ICU patients before discharge or death. *J Crit Care* 2005;20:90–6.
 18. Payne S, Burton C, Addington-Hall J, Jones A. End-of-life in acute stroke care: a qualitative study of the experiences and preferences of patients and families. *Palliat Med* 2009;24:146–53.
 19. Bloomer M, Tiruvoipati R, Tsiripillis M, Botha JA. End of life management of adult patients in an Australian metropolitan intensive care unit: a retrospective observational study. *Aust Crit Care* 2010;23:13–9.
 20. Tan H, O'Connor M, Miles G, Klein B, Schattner P. GP and nurses' perceptions of how after hours care for people receiving palliative care at home could be improved: a mixed methods study. *BMC Palliat Care* 2009;8:13.
 21. Hammes B. Update on respecting patient choices: four years on. *Innovations in End-of-Life Care* 2003;5:2.
 22. LaMantia M, Scheunemann L, Viera A, Busby-Whitehead J, Hanson L. Interventions to improve transitional care between nursing homes and hospitals: a systematic review. *J Am Geriatr Soc* 2010;58:777–82.