

## Requests by family members to withhold prognostic or end-of-life information from the patient

Recommendation	Useful phrases (where applicable)
<ul style="list-style-type: none"> <li>Show respect for the family and the fact that they may have different views from your own about truth telling and patient autonomy.</li> </ul>	
<ul style="list-style-type: none"> <li>Clarify the reasons why the family wants to withhold information from the patient and explore their concerns with telling the patient.</li> </ul>	<p><i>"Why do you not want me to tell?"</i>  <i>"What are you afraid I will say?"<sup>1</sup></i>  <i>"I understand that you are worried about me talking to [patient's name] about what is going on at the moment. We certainly wouldn't want to tell [patient's name] about the situation either if [he/she] doesn't want to know. What is it that you think will happen to [patient's name] if we do have this conversation? What do you think will happen if we don't tell [patient's name] about what is happening at the moment?"</i>  <i>"What are you frightened may happen?"</i>  <i>"Has [patient's name] specifically asked you to have me withhold information?"</i></p>
<ul style="list-style-type: none"> <li>Explain that patients are often aware that they have a terminal prognosis even if it has not been openly acknowledged, and that it can be very frightening and isolating for the patient to not be able to talk about it.</li> </ul>	<p><i>"In my experience, people are often more stressed and frightened by the unknown than by the truth told gently."</i>  <i>"Do you think [patient's name] knows that all is not right at the moment? What must that be like for [patient's name] to suspect but not know?"</i>  <i>"It is likely that [patient's name] understands completely what is going on. Sometimes it is a huge relief to all concerned if it is brought into the open."</i>  <i>"By not acknowledging what is happening, we are blocking [patient's name]'s ability to have some really important conversations."</i></p>
<ul style="list-style-type: none"> <li>In a sensitive way, negotiate with the family to explore the patient's understanding of his or her illness, concerns and fears, desire for information, and wishes to be involved in decisions about his or her medical care (and if he or she does not wish to be involved or informed, who he or she would like to make decisions).</li> <li>Use an official interpreter if one is needed.</li> <li>Consider speaking with the patient both with and without the family present.</li> </ul>	<p><i>"I would like to ask [patient's name] what [he/she] thinks is happening to [him/her]. [He/she] may know more than you realise."</i>  <i>"We could talk to [patient's name] together and find out what [he/she] thinks is happening and what else [he/she] would like to know."</i></p>

Clayton JM, Hancock KM, Butow PN, et al. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Med J Aust* 2007; 286(12): S79-S108. © Copyright 2007 The Medical Journal of Australia – reproduced with permission.



Recommendation	Useful phrases (where applicable)
<ul style="list-style-type: none"> <li>Explain that you will not give more information than desired by the patient. However, you are ethically obliged to give the patient the opportunity to ask questions about the illness and to respond honestly.</li> </ul>	<p><i>"I will always answer truthfully if [he/she] asks a direct question. But I will not force or push any information on [patient's name] that [he/she] does not want."</i></p>

1. Pitorak EF. Learning to have difficult conversations leads to increased hospice referrals. *Home Healthc Nurse* 2003; 21: 629-632.

