

End of Life discussion starters with patients and their families

If someone has a 'terminal' diagnosis then the goal may no longer be to prolong life, but to focus on comfort and symptom management about end of life care. If you are attending an emergency with someone who has a terminal diagnosis you need to work out the goals of care and what treatment/transport/resuscitation aligns with this.

1. Clarify the patient's diagnosis (What is X's diagnosis? Are there any others I should be aware of? What medicines is X on and what are they for?). Is there any important documentation such as an Advance Care Plan?
2. Check whether the patient and family are aware that the person's condition is terminal (That diagnosis sounds like the illness is quite advanced and my understanding is that it is a terminal illness – is that your understanding?).
3. Check whether the patient and family are aware that the patient is for palliation and that the goals of care are to keep the person comfortable, rather than prolonging life (Therefore, I am thinking at this point, our goal is to keep X comfortable for the time X has left? Is that your understanding?).
4. Does the presenting complaint align with their terminal illness or is there another issue to be addressed? (New or underlying infection, issues with medication administration, carer fatigue).
5. Ask patient and family what other services are involved in providing end of life care (e.g. palliative care) and consider whether they should be contacted?
6. In relation to the current situation, assess the options and provide them to the patient and family. Consider if the person's symptoms are part of the dying process and indicate death is imminent.

Below are some useful phrases:

- Right now, the main issue is X. Our options are to transport them to hospital for care or to try and make them a bit more comfortable at home.
 - I think that X may be imminently dying and that their body is shutting down. If we take them to hospital, X may not come home. Does X or yourself have a preference about where X is when they die?
 - Sometimes when people are close to death you see these symptoms. It looks like X may be dying. I think the focus is on how to keep X comfortable and where you would like X to be for their remaining time.
 - While you were hoping to manage X's care/symptoms at home, would you feel better if X was managed at the health service/hospital?
7. On resuscitation, consider:
- If the person has a terminal illness, you need to question whether resuscitation is in their best interests.
 - Maybe at this point, X is not breathing and the option of resuscitation is no longer a realistic option.
 - Does the person have an Advance Care Plan, Goals of Care or DNR order that provides clear direction on resuscitation? Ask the substitute decision maker (or family) what they think X would have wanted?
8. The person can refuse treatment from you. They can refuse to be transported to a hospital. If the person is unconscious or

unable to consent, then who is the substitute decision maker (is there someone there that is the next of kin or a close family member)? If the person has an Advance Care Plan then this may be helpful in deciding what to do.

9. In relation to treatment and transport to hospital consider:

- Does the person want to prolong their life?
- If the person is close to dying, where would they like their last hours or days to be?
- If the person wants to be at home, can the carer keep them comfortable (do they have the necessary medicines, equipment and capacity?). If not, can you help to organise any of those things.

To help gather information or put additional supports in place, you may also like to call:

- The person's treating doctor, palliative care team, or General Practitioner
- The state or territory palliative care advice line
- Your supervisor

