Guidelines for communication at end of life - When

Clayton et al MJA, 2007, 186:S77-S10-8

• All patients with advanced progressive life-limiting illnesses should be given the opportunity to discuss prognosis (including life expectancy, how the illness may progress, future symptoms and effect on function) and end-of-life issues

• Do not assume that the patient does not want to discuss the topic simply because he or she does not raise the issue, or because of cultural background

• Give the patient the option not to discuss it or defer the discussion to a later time.
Most participants believed that the patient could decide for or against CPR, thus stressing the importance of patient autonomy, or allowed a shared decision.

JUNE: Oh the patient….ultimately nobody else is involved as far as that goes…

LOIS: I think that that should be the patient….I don’t think you can just roar in and say no, we’re terminating if the patient said no.

MAUD: That should be between the patient and the doctor to make that decision….Yes, the patient and the doctor make that decision.
When to have a DNR Discussion

• Opinions as to appropriate timing of a DNR discussion varied

• A minority favored discussing early before possible mental incapacity

• Those who supported late discussions when the issue arises wanted to spare patients negative emotions of earlier discussion

• Some suggested that the patient should decide when, or whether to have a DNR discussion, while others deferred to the experience of the medical staff

• Any one-approach policy for practitioners dealing with these issues is thus problematic
Prepare for the discussion

- Before seeing the patient, read the clinical records and/or speak with relevant health care

- Find out what the patient has been told by other health care professionals in order to provide consistent information (where appropriate)

- Mentally prepare.
The setting of the discussion

If possible, ensure privacy, quiet (limit interruptions)

Ask the patient if he or she would like any family members or caregivers to be present during the discussion

If possible, ensure the health care professional leading the discussion is senior enough to be able to answer the patient’s and caregiver’s questions

Ensure enough time is allocated to answer questions or repeat information not understood.
How to discuss end-of-life issues

Use good generic communications skills and establish rapport with the patient and family

Make eye contact (if culturally appropriate), sit close to the patient, use appropriate body language, allow silence and time for the patient to express feelings

Be willing to initiate and engage in conversations about what may happen in the future and dying

Ensure the patient and caregiver are aware that they can openly discuss these topics with you or someone else in the health care team
How to discuss end-of-life issues

• Broach the topic in a culturally appropriate and sensitive manner

• Always give the patient and caregiver the option not to discuss these topics or to defer the discussion to another time

• Elicit and clarify the patient’s concerns, expectations and fears about the future, relevant to issues being discussed

• Clarify the caregiver’s information needs (provided the patient gives consent to discuss the illness with the caregiver), as they may differ from the patient’s needs.
How to discuss end-of-life issues

When spiritual or existential issues are raised, validate the importance of such topics and encourage the patient to continue to explore the issues with you, or refer where appropriate.
Semi-structured interviews with 15 cancer patients about how they would like their doctor to engage about spiritual issues

Regardless of religious background the patients wanted the doctor to ask about their source of spiritual support (God, family, themselves) and facilitate access to it

Patients did not want doctors to provide that support but to treat them holistically, allow them to discuss it and recognise the importance of the spiritual dimension
Why Doctors Find it Hard to Discuss Spirituality


♦ Qualitative studies of Australia and New Zealand palliative care clinicians and medical oncologists

♦ Themes identified

(1) confusing spirituality with religion
(2) peer pressure
(3) personal spirituality
(4) institutional factors (faith based institutions)
(5) historical factors (not accepting a biopsychosocial spiritual model)
A mixed qualitative/quantitative review of if doctors discuss religion and spirituality and how they do it

61 eligible papers were identified, comprising over 20,044 physician reports.

Religion and spirituality are discussed infrequently by physicians although this increases with terminal illness.

Many physicians prefer chaplain referral to discussing religion and/or spirituality with patients.

Such discussions are facilitated by prior training and increased physician religiosity and spirituality.

Insufficient time and training were the most frequently reported barriers.
Facilitate hope

• Emphasise the available support, such as the palliative care team

• Where appropriate, explore and discuss realistic goals and expectations: facilitate realistic goals and reframe the patient’s and family’s expectations

• It is important to respect and be sensitive to the patient’s ways of coping (e.g. denial can be a useful coping mechanism).
Discussing prognosis

Consider asking the patient to talk about how things have been going over the past several weeks or months and what changes they have noticed in their level of function.

Avoid being exact with timeframes unless in the final days of life. If giving a timeframe, explain that the lifespan will be limited by the cancer (or other illness), but that it can be very difficult to predict exactly how long a person with the condition may live.

With statistics explain their limitations (e.g. not specific individuals).
In our interviews hope was expressed as both a verb usually representing the active desire for a positive future outcome or a noun representing the possession of a property enabling maintenance of the desire for a future positive outcome.

As a noun it is a property which can be conferred or taken away usually by the doctor who can be reluctant to take away hope.

Treatment was seen as implying that there was a hope.
Hope as a verb

Although hope as a noun and verb can share the same meaning, participants using the verb were less likely to refer to a cure than to some other positive outcome.

Hope was stronger because it belonged to the patients.

The implication is that much is beyond their control but that there is an acceptance of what may come.

Participants often shifted between one use of hope and another, making it impossible for doctors to be sure of communication.
Conclusions

There are guidelines for end-of-life discussions drawing on the experience of those who regularly engage in such discussions.

Some fields like spiritual wellbeing are difficult to discuss but patients only want this area recognised as important to them.

Discussing prognosis may not reduce hope, particularly the verb where the source of the hope is through the patient.