Advising a patient they might be at end-of-life is never an easy conversation to have. Delivering this news can be confronting not only for the person receiving it but challenging for the health practitioner who has to deliver it.

Upon hearing such news a patient might experience a range of emotions from denial, fear, hope, acceptance, anger and despair. The health practitioner who sees their role as making people “well” might feel a sense of failure, and hopelessness. Feelings of trepidation can also be experienced by the person who has to deliver the news fearing the patient’s reaction.

Whilst a health practitioner may be unable to re-orient their patient toward ‘wellness’ they can however make a difference to the patient’s wellbeing based on how this news is delivered.

Engaging with the patient in a sensitive, empathic, honest and compassionate manner to discuss their prognosis can be life affirming. This can sometimes make a positive difference to the patient in the next stage of their journey.

Conversations with a patient about end-of-life, death and dying require compassion, knowledge, experience, sensitivity and skill on the part of the health practitioner. The following tips may prove useful:

1. Prepare

Understand the patients’ illness, prognosis, available treatment and care options

> Be familiar with the patient’s illness and their prognosis.
> Closely examine the patient’s clinical notes.
> Confirm what and how much the patient knows and understands about their illness and its progression, and what their reaction has been to this.
> Know what can or can’t be realistically offered to a patient as they move towards end-of-life, including any medical, medicinal, psycho-social, religious or spiritual supports. Consult with other health practitioners to identify what is available in the way of appropriate treatment and care options for the patient.
> Anticipate what a patient might ask when you come together to discuss and how you will respond. Prepare and practice your responses in advance.

Setting up a time to talk

> Have another member of the health care team present to provide support. Ideally this should be someone the patient is familiar and comfortable with. Brief the person about the nature of the consultation so they are prepared and can anticipate how to provide support.
> Set aside designated, uninterrupted time, in a private space to hold the conversation.

Who should attend?

> Prepare the patient in advance and advise that you will be speaking with them about their prognosis. Invite them to nominate who else they would like to have attend the consultation. This could include their Substitute Decision Makers (SDM)/Person Responsible or others such as family, or carers. Ensure those nominated by the patient have been advised and will be attending.
> Where the patient does not have decision-making capacity a similar process applies but the meeting will instead be held with the patients SDMs (as appointed in their Advance Care Directive (ACD)) or their Person Responsible. They will be required to make decisions on the patient’s behalf and according to what the patient would have wanted for themselves, had they had decision making capacity ie they will be engaged in substituted decision-making.
> If an interpreter is required ensure they are advised and will be present at the designated date, time and place.

2. Discuss

The following assumes discussions about resuscitation and end-of-life, clinical care planning are taking place with the patient where they have decision making capacity, and including others the patient has nominated such as their SDM/Person Responsible, family, or carer.

Where the patient does not have decision making capacity it is assumed discussions are taking place with the patients SDM/Person Responsible or others such as the patient’s family or carer.
Communication style

- Pay attention to body language and adopt an open posture. Sit at eye level. Keep arms and legs uncrossed. Use a calm, warm tone when speaking.
- Pitch language to the recipient's comprehension levels. Be prepared to use jargon free, neutral language. Be clear and concise in your communication. Avoid being judgemental, blunt or distant.

Having the conversation

- Begin by asking the patient what their understanding of their illness and prognosis is. A patient's response will provide valuable insight into their perception and indicate whether they are being realistic or are in denial. Their response will also assist frame your responses and including the direction of the conversation. Be prepared to correct any misunderstandings or misperceptions the patient may have.
- Ask the patient how much information they are able to manage or would like to have about their prognosis. Patients can vary. Some may want very detailed information, others may want a brief overview, and others may not want to discuss at all and will choose to opt out.
- If the patient is unsure, begin by offering a summary or overview. Thereafter invite questions or indicate that another time can be established to provide more information or to answer any questions.

Review and assess

- Continually review how the patient is feeling. Assess their understanding about what is being said and its implications. It's important that there is a mutual but accurate understanding.

Emotions

- Expressing emotion is normal and is to be expected. Patients can vary. Some will openly express emotion and others will appear stoic. Regardless, allow for and accommodate the expression of emotions. If needs be, pause the conversation while the person takes time out to express their feelings. Be prepared to validate their emotions and to show empathy.

Concluding

- If the patient is able and willing, conclude by discussing future treatment and clinical care options including resuscitation planning. If the patient is unable or unwilling to do so at that time then make another time to discuss.
- Explore and discuss realistic care goals and expectations.
- Ensure the patient understands what is being discussed and its implications.
- Continue to show support and demonstrate empathy.
- Actively demonstrate that you continue to be part of the patient’s life's journey and are available to assist where you can.
- Ensure that you have documented the discussion and any decision's made.

3. After

Continue to provide support

If the patient requires or requests it, support the patient advise their family and close friends of their prognosis.

- Establish a follow up meeting to see if the patient has any unanswered questions or whether they wish to review information previously discussed.
- If the patient desires it, connect them with chaplaincy or social work support services.

For more information

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