

EOLC
Module - 5
Facilitator Guidelines

General Points

- The modules have been developed for presentation by facilitator(s) who are acute hospital-based clinicians, though not necessarily practicing specialist palliative care.
- The modules have been designed as a group (of six), though are independent of each other and can be delivered individually, or out of sequence.
- The target audience is junior medical staff, post graduate years 2-4 of all training streams.
- It is envisaged that each module will take about an hour in total (including discussion time).
- Technical requirements include a computer and data projector, able to run PowerPoint and play DVD's. It is suggested that pre-reading be distributed, electronically or by hard copy prior to the presentation.
- It is hoped that the presentation will stimulate discussion amongst the group and sharing of clinical experiences. Appropriate facilitation and management of these discussions is an essential role of the facilitator.
- The presentations aim to enable attainment of the objectives outlined below.
- There is an accompanying evaluation form, based on the stated objectives.
- A short video is accessible on the accompanying DVD and will be called for during the presentation.
- It is recommended that facilitators familiarise themselves with the material prior to presenting it and contact the authors or local palliative care consult service with any questions.

Module Summary

Most Victorians die in acute hospitals and the majority will receive end of life medical care from non-palliative care specialists. All doctors, regardless of specialty, provide end of life care and have an obligation to provide the best care they can. To do so, and therefore improve the care of our dying, we need to ensure they have the appropriate knowledge, attitudes and skills. This module, though it can be completed individually, draws from the skills and content developed in the earlier modules.

Objectives

Knowledge:

- Recognize the symptoms and signs of the dying
- Know the statistics of dying, particularly that most people die under generalist care in acute hospitals
- Be aware of the literature describing patient preferences and expectations of death and dying
- Be able to describe a 'normal death' and consider how this may compare with community expectations of a 'good death'

- Be able to dispel the myths about the pharmacology of dying, particularly the “triple M” therapy
- List the legal and organizational procedures of death, with particular understanding of:
 - Certification of death
 - Coroner’s cases, the process and implications
 - Hospital autopsies, when (and how) to ask
 - ‘Where the body goes’

Attitudes:

- Acknowledge that caring for the dying is important and a routine part of medical practice.
- Recognise that caring for the dying is often immensely rewarding

Skills:

- Be able to ‘diagnose’ that a patient is dying
- When appropriate, to describe and discuss, sensitively the process of dying with patients and their families
- Use a framework to review and attend to the needs of patient and their families in the last few days of life

Pre-Reading

- Von Gunten, CF **Teaching the family what to expect when the patient is dying #149** *Journal Palliative Medicine* 2008;11(3):503-5 (see attached)

Handouts

- Death Certificate, note particularly details of reportable deaths *
- Hospital autopsy consent forms #

* Originals will be readily available at your Hospital, and are therefore not provided.

Hospital autopsy consent forms are specific to your hospital, and are therefore not provided.

PowerPoint Presentation - notes

SLIDE 1

- *Be clear about nomenclature, we are talking about “terminal care”, “end of life care”, the last days-weeks.*

SLIDE 2

- *Essential to emphasise the relevance to every day practice*

SLIDE 3

SLIDE 4

- *This is an outline of the presentation*

SLIDE 5

- Doctors are optimistic people!
- The SUPPORT Study, a landmark paper published in JAMA in 1995, showed among other things that we are even more optimistic in our prognosis the more familiar we are with our patients. This observation been confirmed in several published studies since, including that by Christakis and Lamont published in BMJ in 2000.

Their prospective cohort study also showed that this prognostic optimism is common to most types of doctors and most types of patients. Though greater experience was associated with greater accuracy, the stronger patient-doctor relationships were associated with lower prognostic accuracy.

SLIDE 6

SLIDE 7

- The concept of a good death has been studied extensively and obviously is very much dependent on your perspective - whether you are a patient, a family member or a doctor. But also whether or not you have a terminal illness and where you are in the course of that illness. You can imagine the huge differences between these groups, and what changes must occur over time – clearly it is very heterogenous. Though there are some unifying themes...
- Here we are focusing on the 'good death' from the patient's perspective, though it is essential to be mindful of disparate views and perspectives, particularly in communication with caregivers.

SLIDE 8

- In their Canadian study, Heyland and colleagues findings focus more on the care at the end of life and particularly the doctors' role. The themes are (not surprisingly) around good communication and clear goal setting.

SLIDE 9

- A very common question we are asked is "how long?" While often this is exactly what it seems – a question about prognosis; it can often also be a way of asking (the often unspoken) "what is going to happen?"
- Talking about death trajectories can be a way of approaching this question
- It is useful conceptually, and can be empowering for the patient and their caregivers (though they should be carefully selected).
- The limitations for the individual are obvious, and by no means do these provide 'hard and fast' rules.

SLIDE 10

- Murray and colleagues describe "the short period of evident decline". This is typically a cancer type trajectory with predictable decline in physical health, mostly occurring in the last few months of life. This fits well with the traditional sequential model of palliative care, and is indeed the trajectory best studied and predicted.

SLIDE 11

- The second trajectory describes the heart failure or COAD trajectory commonly seen in acute hospitals, and described by Murray et al as "long term limitations with intermittent serious episodes".
- The patients are ill and limited for many months or years with occasional acute, severe exacerbations (usually leading to hospital admission and intensive support).

- The value of recognising this trajectory is though each exacerbation **may** result in death, often times the patient will survive. However the gradual decline in health and functional status is typical.

SLIDE 12

- Those not described make up the final of Murray's trajectories "prolonged dwindling" – those who die of 'brain failure' or generalised frailty of multiple body systems. This trajectory is of progressive debility from a poor baseline level of function. Acute events, such as pneumonia or fractured NOF can precipitate an earlier than anticipated death.

SLIDE 13

- As have discussed diagnosing dying is complex and depends on the disease trajectory and underlying illness.
- It is certainly more apparent in the last days of life, and Ellershaw and Ward have developed this list of signs that are often associated with the imminently dying. They are not absolute and certainly will not apply to every situation, but will hopefully serve as a prompt so that appropriate communication and care can be provided.

SLIDE 14

- The signs and trajectories are useful, but the question remains, what is the 'normal' dying process? It may not necessarily be something we have any experience with (and can hard to find in a textbook!)
- Refer to pre-reading (article from von Gunten), how to discuss with families what to expect from the dying process

SLIDE 15

- Where saying 'there is nothing more we can do' is particularly harmful and our patients can feel most abandoned.
- Very common fear that dying has to be painful and symptomatic...

SLIDE 16

- Fatigue is not only common, but also frequently distressing to patients during the terminal phase. As we have seen it is also an expected and 'natural' part of the dying process.
- Dyspnea in the terminal phase may still have a wide differential diagnosis, however by this time the reversible causes will have been addressed. The focus is management with techniques appropriate to the stage of the patients' illness, and therefore most likely pharmacologically with opioids +/- anxiolytics +/- oxygen (refer to the 2nd symptom module).
- Pain is the most dreaded symptom of the terminal phase (and its management has been addressed in the 1st symptom module). Close monitoring is required for new pains, which may occur in up to 50% and to consider appropriate routes and treatments for ongoing pains. While about 10% of pain may not be completely relieved; patients can be reassured that severe, unrelieved pain is both rare and avoidable.

SLIDE 17

- Two end of life symptoms are worthy of special mention....

- The first, agitated delirium is most certainly a red flag, and some may argue a palliative care emergency. It always requires timely assessment and treatment, given the profound distress it causes the patient, their family and staff.

SLIDE 18

- The management strategies must be tailored to the individual and their prognosis. This is why these strategies should be 'considered', but may be inappropriate for an individual at a given time.
- Sedative therapy may be required if other management strategies fail. Sedation should only be undertaken after the involvement of senior doctors and preferably referral to palliative medicine specialists. It may however be appropriate in a particular case if symptoms are distressing and refractory to other management options.

SLIDE 19

- The second end of life symptom, accumulation of respiratory secretion while not technically an emergency, requires prompt intervention and management. It is also exceptionally common and often distressing to families, though rarely so for patients since they are usually deeply unconscious by this time.
- This is the gurgling sound often referred to as the 'death rattle' – though this term is best avoided.
- It is distinct from lower respiratory tract pathology, such as edema or sputum, but instead is an oro-pharyngeal sound made when a patient is too weak to swallow or expectorate.
- Explanation is vital, especially since medication cannot dry up the secretions already present. This also highlights the importance of non-pharmacological techniques, which are often extremely effective.

SLIDE 20

- There **are** clear medical responsibilities during the end of life

SLIDE 21

- Discussion about the medication review may be beneficial, certainly in this, as in much of medicine, there is no 'black and white'. However all decisions should be made with clear reference to the goals of care.

SLIDE 22

- A prolonged pharmacological discussion is not intended, though questions and discussions point may be raised. Reference to the symptom modules, the palliative care therapeutic guidelines or palliative care service may be helpful.
- Special mention about catastrophic orders should be made. They are to be reserved for a catastrophic (ie. terminal event), such as an acute large bleed or acute airway obstruction (*encourage consideration of some patient examples where such events may occur eg. thyroid cancer, head and neck cancer*). Specifically when medical staff may not be able to respond before the patient dies, but where medications to induce unconsciousness and ensure analgesia may be beneficial. In reality the medications, even if

charted, are often not available prior to death. The doses are with the intent to induce unconsciousness (usually a combination of morphine and midazolam). Obviously these should be charted and documented clearly and only in appropriate patients with the clear understanding of all members of the multidisciplinary team. Discussion with a senior is essential.

SLIDE 23

- Syringe drivers deliver medications by subcutaneous infusion over 24 hours. They are convenient, minimally invasive, can be used in the community setting and ensure absorption in situations where it may otherwise be uncertain. They are not however synonymous with palliative care or terminal care.
- The 'no more than 3 drug' rule is to avoid precipitation in the syringe and reduce the risks of incompatibility. Pharmacy, therapeutic guidelines and well as a number of online resources (eg. palliativedrugs.com have compatibility tables)

SLIDE 24

- Intravenous cannulae are reasonable to use if they already in situ, but insertion is neither appropriate or necessary for ongoing drug delivery during EOLC. The subcutaneous route is reliable and easily accessible. Patients should not be denied medication while awaiting a re-site of an intravenous cannulae.
- Drugs may be given safely via the subcutaneous route, even if MIMS/product information does not state this. Again, check with your pharmacy, therapeutic guidelines, your local palliative care service or online reference.

SLIDE 25

- At the end of life, the goal of care is comfort only. We are unable to, and nor is it appropriate to prolong this period. Hence most discussions about food and fluid are easily managed...
- Patients who can communicate rarely complain of hunger, and a diminishing appetite and intake is one of the cardinal features of the dying process.
- Fluid intake also diminishes, and in the dying patient mouth care has been shown to improve comfort and effectively manage the sensation of thirst in dying patients (Cassaret and Caplan 2005).
- It can be more complex and less certain in patients who may have several weeks to months and cannot tolerate oral fluids for eg. bowel obstruction. Or in patients with an agitated delirium and in whom opioid toxicity and/or renal failure is thought to contribute – in that situation artificial hydration, as a time limited trial may be a reasonable consideration.
- Often the ethical imperative is to not be doing anything which will prolong the dying process. Clear goals of care should guide decision-making at the end of life as well.

SLIDE 26

- Pathways, of which the LCP is the 'prototype' are being developed and implemented throughout the world and perhaps even in your hospital. They are an attempt to formalise the process of EOLC.

While it can never be a 'formulae' and must be individual by its very nature, this kind of tool serves as a useful reminder of the essentials we have discussed.

- The idea is to use common documentation as a prompt to staff to ensure a patients needs at the end-of-life are being met. For instance to ensure:
 - Clear documentation about the patients physical condition (conscious state, ability to swallow, symptoms)
 - Medication are assessed and rationalised
 - Appropriate prn's are charted
 - Interventions are reviewed and minimised (both medical and nursing)
 - The patients religious/spiritual needs are assessed
 - Family are aware of the impending death and understand the care plan
- This is then reviewed daily, with prompts for specific symptoms, basic guides for management and suggestions about how further assistance may be accessed. Nothing that we haven't discussed, or considered, but a universal tool and prompt.
- *Comment and discussion about experiences with EOLC pathways, are they a useful tool?*

SLIDE 27

SLIDE 28

- Help is always available
- *Customise this to your hospital, with names and contact details (if able) – a good opportunity to promote the service and referral pathways.*

SLIDE 29

- *Ask the audience to briefly consolidate the procedure of certification.*
- Encourage respect for the patient and family (who may often be in the room during the process). It is appropriate to express your condolences and explain what you are doing (eg. "I am just going to listen to his chest").
- *Discuss your hospitals post mortem policy (ie. separate to coroners cases) and ensure all are aware of the required documentation.*

SLIDE 30

- It should not be forgotten that the patients we care for at the end of life are family members and loved ones. Their death and dying, and therefore your role, has a profound impact on those who know them and love them. This intense and powerful relationship with the patient and family can be immensely rewarding and should be regarded as a privilege.
- *Play Carer's perspective on EOLC (video).*
- *Invite comments and discussion.*

SLIDE 31

SLIDE 32

SLIDE 33

References

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