

**Communication 2**  
**Module - 2**  
**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**

Determining, communicating and negotiating goals of care and appropriate treatment limits is a daily task in acute hospital practice that is often neglected, overlooked or poorly done. Not infrequently it is a task left to junior medical staff and even covering medical staff. This module aims to alleviate some of the anxiety and misconceptions about goals of care discussions and ultimately debunk the myth that it's 'all about the NFR'.

**Objectives**

Knowledge:

- Understand the implications of an in-hospital cardio-respiratory arrest and resuscitation; compare and contrast this with the expectations and understanding of the lay community.
- Be aware of some of the available evidence regarding patient preferences for resuscitation, and an appreciation of the complexity and changeability of these preferences.
- Understand the terms 'NFR', 'mPOA', 'refusal of medical treatment', 'advance directive' and how they impact on patient care.
- Understand that assessing and communicating a patient's goals of care is more complex (and of greater benefit) than simply determining whether attempted cardiopulmonary resuscitation is appropriate, particularly appreciating:

- the difference between full ward management and good palliative care
- the importance of non-abandonment and avoiding the implication of 'no care'
- the benefits (and art) of negotiation and flexibility
- Appreciate that there is no legal or ethical requirement to provide futile treatments.

#### Attitudes:

- Consider quality of life and cultural issues as they relate to a particular patient in particular circumstances.
- Be sensitive to differing expectations and perceptions of disease and treatment amongst patients and their families.
- Realise the importance of the medical role in initiating discussions about goals of care, providing appropriate information and ensuring that futile measures are not undertaken.

#### Skills:

- With the support of senior medical staff, go through the process of determining the appropriate degree of escalation for a given patient in a particular clinical situation using the available evidence.
- Again with support communicate this medical recommendation clearly, with sensitivity and compassion, particularly:
  - negotiate treatment limits and timeframes for their review.
  - explain the goals of conservative or palliative management, emphasizing the active medical role.
- Appreciate that inevitably there is ambiguity in clinical situations and also in the responses of patients and their families to the complexities of care.

#### Pre-Reading

- Medew, J **Grandmother labelled 'not for resuscitation' by hospital** *The Age* 2006, August 22<sup>nd</sup> Viewed 6<sup>th</sup> October at <http://www.theage.com.au/articles/2006/08/21/1156012474729.html> (file attached)
- Treadway, K **The Code** *NEJM* 2007;357(13):1273-1275 (file attached)
- Murphy B **What has happened to clinical leadership in futile care discussions?** *MJA* 2008;188(7):418-419 (file attached)

#### Handouts

- Refusal of Medical Treatment Fact-Sheet Office of the Public Advocate, Melbourne, Victoria 2004 (see attached)

## PowerPoint Presentation - notes

### SLIDE 1

- Hopefully the pre-reading articles have ‘set the scene’; with your own experiences of this complex area of practice being of particular importance.
- *Invite queries or comment about the pre-reading*
- The article from The Age aimed to highlight the community views about this area and contrast them with our own and some of the available literature, which we will review today. It also highlights the necessity of good communication and documentation.

### SLIDE 2

- The ‘lottery’ analogy used by Dr John Saunders in his paper “Perspectives on CPR: resuscitation or resurrection? is a useful one that seems to fit well with its’ subject.
  - The odds are good for some, and the winnings life itself
  - However for most the odds are poor and the outcome a far worse death than that which the CPR was trying to avoid

### SLIDE 3

- CPR was first described in 1960 and was developed for a select group of patients, described on the slide. These are very different to the majority of patients in acute hospitals and in whom it is currently considered and applied. The criteria for ‘sudden and unexpected deaths’ seems to have been lost and all too often CPR seems to delay expected deaths in the medically ill – regrettably in a resource intensive and profoundly undignified manner.

### SLIDE 4

- The US National Registry of Cardiopulmonary resuscitation describes the outcome of 14,720 in-hospital arrests, demonstrating a 17% survival to discharge. Similar results have been found in the UK, with a study of 1368 events in 49 British hospitals demonstrating a 17.6% survival. Smaller studies in NZ and Australia, show similar findings, references available below.
- Interestingly, despite improving technology and resuscitation training, these figures have remained remarkably static. Perhaps this relates to (inappropriate) patient selection, diverging from its original intent?

### SLIDE 5

- Smith et al. in their NZ audit of 243 resuscitation attempts, found that survival to discharge decreased by 36% for each additional decade of life. Indeed 32% of their resuscitation attempts were in the 80-89 years of age group and the most common group requiring resuscitation were 70-79 years at 38% of the arrests.
- Monitored patients do better, since they are more likely to have a single problem, a shockable rhythm, faster time to defibrillation and be younger. Smith et al. reflected this in their findings of the highest survival to discharge in the cardiology wards (41.3%) and the lowest in the general medical wards (9.0%).

### SLIDE 6

- Identifying this group is important to save unnecessary attempts and allow us to appropriately inform our patients. Not surprisingly patient

preferences for resuscitation are greatly influenced by the likelihood of a successful outcome.

- Most of these factors have been shown in several studies to reduce survival to discharge and also, in the Swedish study (Skrifvars et al.) to reduce long term survival after arrest.

#### SLIDE 7

- The definition of a successful outcome varies considerably across studies, and in many is overlooked. ‘Return of spontaneous circulation’ ROSC is the outcome used in much of the resuscitation literature. It is a deeply flawed measure, failing to account even for 24 hours post event survival and certainly isn’t a useful measure for patients or indeed their doctors trying to determine appropriate care.
- These other factors, largely neglected in the literature, require careful consideration.
- Some attempts have been made, but not surprisingly assessing QOL after resuscitation is difficult. Miranda, as part of a national survey of Dutch ICU’s, was able to undertake a QOL survey of ‘a select group’ of 69 patients who had undergone CPR. They were ‘select’ because they had survived CPR, they survived hospital discharge and, after all, they were capable and willing to answer the survey. Despite this selection, they found:
  - A significantly diminished capacity for resuming work
  - Poorer mental functioning, with ‘diminishing personal interest in the environment’ and an ‘increasing sense of disorientation
- Obviously these critical considerations need further study, and the answers will help inform clinical decision-making.

#### SLIDE 8

- While it is easy for us to dismiss the ‘realities’ of TV, studies show that the majority of our patients obtain information about CPR from the television. Not surprisingly, we also know that they overestimate the likelihood of its success. These ideas prompted this NEJM review (Diem et al. 1996) of survival rates after CPR on television – which as you can see is very different from what we have been discussing in the medical literature. The full reference is available and it makes interesting reading; as you can imagine the portrayal of death on TV varies considerably from the realities, *not for resuscitation* orders are not discussed at all, over 56% of survivals were described as miracles, and the outcomes are either full recovery or death with no mentions of disability, prolonged suffering or undignified deaths.
- It is then hardly surprising that the community, at large (including doctors!) have a number of misconceptions about the process of CPR and its likely outcomes.
- Indeed, as Heland et al showed in their survey of seriously ill hospitalised patients, even the potential ‘target’ audience of resuscitation treatments are misinformed. Despite the majority having considered whether they wanted resuscitation or not, few could describe more than two components and only 2.7% thought the success rate may be less than 10%.

#### SLIDE 9

- Our goal as doctors is to provide the best care possible to our patients. In the dying, that would translate to the best quality of life until death and

ultimately 'a good death'. To achieve this we need to acknowledge and help our patients and their families acknowledge what is happening - only then can we have the necessary discussions about preferences at the end of life, which in turn we hope will enable 'a good death'.

#### SLIDE 10

- The SUPPORT Study was a large scale American trial, involving in its first phase a 2 year prospective observational study of over 9000 hospitalised seriously ill patients with the intent to better understand prognoses, preferences for outcomes and risks of treatment.
- The first phase, from which these figures are derived documented shortcomings in communication, frequency of aggressive treatment, and the characteristics of hospital death.
- More specifically, SUPPORT and much of the subsequent literature confirms that doctors are often unaware of their patients' preferences for end of life care.
- We are less aware of patients who do not want resuscitation, and indeed the study authors note that physician, nurse, and surrogate understanding of their patient's preferences is only moderately better than chance.
- Our own perceptions of a patients' prognosis (which we have been shown to consistently overestimate) may cloud our understanding of their preferences. Equally the SUPPORT study showed that the decision to write NFR orders was entirely independent of patient preferences and that factors such as the patient's age, the physician's specialty, and the geographic site of care were the strongest determinants.

#### SLIDE 11

- Communication about end of life care preferences in seriously ill hospitalised patients is uncommon. And the fault is not entirely ours. Hofmann et al. showed that more than half of such patients who had not discussed their preferences had no desire to. This group, as much as the group whose desire for discussion is unmet (by our reluctance), are at risk of unwanted invasive interventions.
- Many of the polls, so widely reported in the media and met with such pragmatism, survey well people, without any particular risk of the outcomes described. Quite different to our 'in-hospital' population. Equally, our discussions are often with families and caregivers, rather than the patients themselves. Declining treatment for a loved one, a parent or a spouse, is a very different situation to talking about treatments an individual may never need in situations that may never arise. As we have discussed, surrogates are often unaware of patient preferences, and as Sonnenblick et al found, even when children are aware of their terminally ill parents preferences, most will not comply with them.

#### SLIDE 12

- It makes sense that the better we know the patient, the better we will understand their resuscitation decisions; which adds strength to our desire for the 'ideal' situation - where a doctor who knows the patient has these discussions early in a patients illness trajectory.
- The increase in NFR decisions at the end of life may reflect patients changing their mind as they gather more information and facts about their situation and the available therapies. This demonstrates the importance of our role as providers of accurate and easily digestible information. Equally

it emphasises the importance of raising these issues and at least offering our patients the opportunity.

- The last point is interesting in that it suggests that most patients won't discuss their resuscitation decisions with us, particularly not those who don't want resuscitation - an important group whose preferences we seem to be ignoring. Also we are missing opportunities to have these discussions so as to allow us to better respect their wishes.

#### SLIDE 13

- We are now moving to discuss some of the language and legal principles of this area...
- NFR is often misused and misunderstood, by patients and health professionals alike. It is exactly what it states and without further clarification or documentation patients with an NFR should receive all medical management up until resuscitation is required.
- The medical POA is distinct from other types of POA and is often confused with financial or other POA's. You should ask to see the original (or certified) documents to ensure it is indeed a medical POA and ask if it has been revoked – a copy of the mPOA and documentation that it has not been revoked should be put in the patients medical file.

#### SLIDE 14

- The refusal of medical treatment act, which is discussed in the Fact Sheet handout, is legally enforceable in Victoria. This kind of 'advance directive' has clear protection for doctors complying with valid certificates under existing laws.
- Advance directives are a complex area of considerable current interest. A complete discussion is well beyond the scope of this module. Suffice to say, the laws are less clear and advice should be sought. The Biegler article referenced from the MJA gives the example of a patient with HIV who completes an advance directive refusing resuscitation or ICU, who develops anaphylaxis to a drug early in his disease. Withholding treatment when the advance directive was not intended for this circumstance would constitute a serious harm ethically. In Victoria, legally the directive would not be valid because the condition (ie. anaphylaxis) was not present when it was completed. Not all are so simple and with the increasing use of advance directives we must keep ourselves informed and contact the hospital's medicolegal department for advice whenever we are uncertain.

#### SLIDE 15

- Brendan Murphy's perspective piece, one of the pre-reading articles will hopefully have set the scene.
- While the definitions of futility can often be fraught and the discussion of this takes up a lot of print in the literature, a lot of times in everyday practice it is fairly clear.
- The essential point is that there is no legal or ethical compulsion to provide treatments that are not of benefit to the patient (even if they request it). Indeed it is most certainly our duty to protect our patients from such treatments – it is the failure to recognise this essential task that Dr Murphy laments.

#### SLIDE 16

- Watch video, "It's not all about the NFR"
- Afterwards, discuss the scenario

- What might the nurses actually be telling us by asking a covering doctor to ‘get an NFR’
  - ? the patient is deteriorating
  - ? concerns about goals of care
  - ? concerns about patient / family understanding
- Clearly this is not a good approach and we will be talking about how discussion about goals of care, rather than simply ‘getting the NFR’ are not only more acceptable for patients and families, but will more often give us the result we are after.
- How might we handle these sort of requests, given they are frequent and really do happen?
  - Ask what the specific concerns are? And address them if feasible
  - Explain that such discussions are most appropriately managed by the treating team in hours, rather than a covering doctor, and negotiate an acceptable and timely solution (and means of altering the treating team).
  - Review the patient, consult the notes (and hope your colleagues have documented well). If you feel that goals of care do need to be addressed after hours, contact the covering registrar or consultant to ensure you are adequately prepared. Explain to the patient / family the reasons for your involvement and the need to talk out of hours, explaining the preparation you have done.
- ?Any other thoughts / experiences to share

#### SLIDE 17

- Hopefully we have demonstrated that talking about the ‘NFR’ is not only unhelpful (and confronting), but often doesn’t actually help us plan for and inform a patient and caregiver about their condition and agree on an appropriate plan of care – which after all really is the point.
- Before communicating about goals of care for a particular patient, we need to establish them for ourselves, with the aid of the multidisciplinary team. To that end, these categories suggested by Ashby et al. are a simple but useful guide to focus our own thoughts about patients’ condition, progression of disease and likely outcomes. Careful consideration and deliberation at a team level is important to ensure that the patient and family are not burdened with our uncertainty. Equally offering ‘choices’ that are not realistic is unhelpful, can lead to false hope, misunderstandings and the undertaking of futile treatments, not to mention burdening patients and family with decisions and choices that don’t really exist.
- We should always be explicit in what we say to avoid misunderstandings, and we would certainly advocate using the ‘dying’ word and ‘intensive care’ as appropriate. However the term ‘NFR’ is emotive (as demonstrated by our lay press article) and often unhelpful in the course of these discussions; and should most certainly not be the focus.

#### SLIDE 18

- The benefits of addressing ‘goals of care’, rather than ‘getting an NFR’ should be evident from our discussion. Certainly the patient and family receive much better communication, but equally it ensures the team

develop an appropriate plan of care for the patient – far more useful than simply determining whether resuscitation is appropriate or not.

- These discussions are again ‘not easy’, but use many of the skills you already have.

#### SLIDE 19

- The principles of goals of care discussions are listed here.
- These are not isolated discussions of resuscitations and indeed a useful ‘take home message’ is that NFR should never be raised in isolation, but rather in the context of a general discussion of the major medical issues, prognosis, patients’ values and expectations and goals of care.
- Reinforce limits are in place to avoid futile treatments which carry significant morbidity and are most unlikely to be successful.
- CPR and resuscitation is not “doing everything”, so be careful not to be misrepresented as “doing nothing” when a patient has a NFR order. “We will continue to do everything we can here on the ward, including [specific treatments], we will work hard.” Be clear that NFR does not mean “we are giving up”.
- Sometimes there may in fact be very little that can be done, still the management plan needs to be active. In this instance, ongoing monitoring, review and a referral to palliative care may be the ‘treatment’.

#### SLIDE 20

- Even with the very best communication skills, these are difficult discussions; often signifying significant changes in directions of care and ultimately are asking the family to accept that their loved one may be dying. It doesn’t get much harder than this.
- While it is essential to always have the patients best interests at heart and protect them from invasive, burdensome and futile treatments, as we have discussed, there are often huge benefits in having some flexibility and preparedness to negotiate.
- In these negotiations clear limits for review are essential, and need to be clearly spelt out (see sample phrase).
- It is also essential to emphasise that any negotiated measures do not preclude efforts to alleviate any suffering or distress (good palliative care). Indeed this can often ease the ‘transition’ to (only) comfort or palliative care and is, of course, our duty as the patients’ doctor.

#### SLIDE 21

- Requests for inappropriate treatments are common, and deserve some further discussion. They may reflect lack of understanding and misinformation, which can hopefully be resolved by clear discussion and negotiation as we have discussed. However they may also reflect denial. Determining the reasons behind the requests is an essential first step...
- Direct confrontation about denial is usually unhelpful and can lead to alienation, often at a critical time. Instead try carefully exploring for a ‘window’ where the situation can be realistically addressed – the “I wish” statement can establish some common ground, allowing for the exploration of whether they have ever thought about what if things don’t go so well. The ‘hope for the best, plan for the worst’ is a useful sentiment that sides with the patients hopes and wishes with a certain pragmatism that may be acceptable and provide a useful, less optimistic ‘window’ of opportunity.

- As always, the benefits of involving senior clinicians cannot be underestimated (and should by no means be seen as a failure).

#### SLIDE 22

- In some situations, inappropriate requests will require more detailed explanation. This is an example about resuscitation and draws on some of the information we have already discussed.
- You will note the clear recommendation, which relieves the patient or caregiver from the burden of choice – that doesn't actually exist when resuscitation is considered futile.
- As always following this statement with details of the active care you will provide.

#### SLIDE 23

- Watch the video and discuss what techniques worked, are there any that didn't.
- Ask about any previous experiences, what was helpful, not so helpful then?

#### SLIDE 24

- We expect a lot of our patients, and indeed very much want them to be active, informed participants in their care. No more so than at the end of their lives. Yet so often this desire on our part, leads to distress and much of the conflict that can unfortunately develop.
- So often 'the choices' and 'decisions' we require from patients and families are very much the source of the problem, as Drought and Koenig discuss in their very interesting paper "Choice in end-of-life decision making: researching fact or fiction?". In this paper the authors discuss the autonomy-based bioethics that is so focused on choice that it expects patients to embrace their dying in order to receive good end of life care. While this article specifically talks about choice in EOLC, the principles and discussion points are similar in many aspects of patient care.
- Here are three usually unacknowledged assumptions that Drought and Koenig raise as leading to the inherent difficulties with the idea of 'choice' in end-of-life decision-making.
  - The first point is one we are all well versed in, and I am sure we need no convincing that prognostication is extraordinarily difficult, though there are many proposed methods and much literature. Particularly in the realms of acute hospital medicine, disease trajectories are notoriously difficult to predict when anyone event may be the 'terminal' one.
  - Very often in medicine and most particularly in end of life decisions there is in reality little choice to be made, however the choice-model can seem to imply a broader range of options than are really available and at the most extreme appear to give dying patients the option between life and death. Indeed the patient may translate the choice about assumption of risk for the possibility of statistical benefit into the choice of doing something to live versus the option of giving up and dying. The irony of the choice paradigm is that it seems to present a choice that does not exist—the choice not to die of a terminal illness.
- *Encourage discussion and reflection about the assumptions of 'choice', an important concept in medical decision-making.*

## SLIDE 25

- It is an essential therapeutic task to take responsibility for the medical decisions; and take this terrible burden from the family. An all too common example is the patient extubated in ICU who continues to 'live' for several days after the family 'decided' to follow a palliative path. The burden of this supposed 'decision' can be overwhelming for individuals and has been known to split families at traumatic and difficult times with tragic consequences after their loved ones pass away expectedly. It also not infrequently is a source of complaints and threats of legal action as a response to the severe distress.
- Good quality documentation is essential, including the specific orders and a detailed note about any discussions with the patient and family. Such documentation is vital when working in large teams, on different shifts and may avoid unnecessary repetition or worse still inappropriate interventions. Good documentation is particularly important when a decision has been made without involving the patient or surrogate.
- Situations not infrequently arise where detailed discussions are in fact quite rightly deemed inappropriate. For example,
  - if the patient is well aware they are dying and has already clearly expressed wishes for comfort care only.
  - if the patient expressly does not wish to discuss these matters or make any decisions,
  - if the patient is clearly in the terminal phase of their illness and further detailed discussions are likely to be unhelpful if not impossible.
- Obviously decisions not to involve the patient and caregivers in these discussions require careful thought and should be made at a senior level.

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