Appendix 3 - Medical Communication Guide for Goals of Care and Future Care Planning

Tips for doctors having complex discussions in the clinic, on the wards and in the context of COVID-19

Ideally, goals of care discussions use a **shared decision making model.** This means that a patient's wishes and hopes are understood and acknowledged, and taken together with the medical opinion about what is possible and appropriate in terms of harms and benefits. The aim is to reach consensus on a plan for what will **fit best with the available options** and is aligned with what is **most important for this person**.
Having these discussions in the Emergency Department or on the Wards often feels pressured, and can be very challenging when patients are critically unwell. *It's ok to feel apprehensive or uncomfortable before these conversations*, especially in these extraordinary circumstances.

PREPARE. Before you begin:

- Does this patient have capacity to have these conversations?
  - If they do not have capacity, establish their person responsible first and involve them in the discussion.
- Do they already have an Advance Care Directive or Advance Care Plan that you can start with and build on?
- Take a moment to think about the things you are going to say.
- Try to find out about your patient's chronic health problems (severity, frequency of hospital admissions) AND their level of function/frailty (assistance with ADLs, mobility, ECOG status etc.). This will help you to frame your discussions

GENERAL TIPS

- Goals of care discussions are not just about resuscitation and dying – they are as much about **how the patient wants to live**.
- ALWAYS check the patient and / or family's understanding of the situation BEFORE you give any medical information
  - What does the patient/family **know, expect or want to know** about their current health situation?
  - Don't be afraid to ask several questions if you need to
- Acknowledge **emotion** during conversations. It's normal for patients/families to feel strong emotions in these discussions
  - Have a look at the guides below or use the NURSE acronym on page 2 to aid you
- Remember that you might be **breaking unexpected bad news**
  - Give information slowly in **chunks** with **pauses** for people to respond <u>especially if over the phone or if wearing a facemask</u>
- **Remember we're not obliged to offer futile interventions,** so avoid offering a choice about an intervention where there little chance of success.
  - If a patient would not benefit from CPR, do not say "Would you want CPR if your heart stops?"
  - If a patient would not benefit from invasive ventilation do not say "Would you want a breathing tube and ventilation if your lungs fail?"
  - Instead, use the guides below to **provide recommendations that align the patient's goals with what is medically possible**
- **If you say the wrong thing, it's ok** – "*I'm sorry, that didn't come out right, can I start again*?"

Resource prepared 17/07/2020 by Dr Lisa Potter (Palliative Care Specialist, The Sutherland Hospital).

AFTERWARDS

- Check-in with yourself – how are you feeling? Do you need to take moment for yourself? What went well/ what did you learn for next time?
- Consider debriefing with a colleague – what phrases do they use that you could incorporate for next time?
- Work with a Social Worker who can support the family/patient
- Struggling to reach consensus? Consider referral to another team for a second opinion e.g. ICU, Palliative Care or Aged Care
- Document these conversations in detail, even if you didn't get to talk about CPR

SUGGESTED SCRIPTS for FUTURE CARE PLANNING DISCUSSIONS

The three guides below all follow the **REMAP** acronym as a roadmap for goals of care discussions in different settings (adapted from VitalTalk[1])
Adjust the scripts below to suit you and your patient

R *eframe changes to patient's condition*
E *xpect emotion*
M *ap the future*
A *lign with patient's goals*
P *lan treatment*

TIPS FOR RESPONDING TO EMOTIONS

Use the **NURSE** acronym. Adapted from VitalTalk[2]

N ame the emotion "*You sound really **frustrated**" "You seem anxious*"
U nderstanding "*You've had a really hard time over the last few weeks" "It sounds like everything has changed very quickly"*
R especting "*You've done a great job looking after your mum at home for so long"*
S upporting "*We'll do everything we can to support you through this"*
E xploring "*Tell me more about that" "what worries you most?"*

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[1] VitalTalk
[2] VitalTalk

SETTING 1: Future care planning and goals of care discussions in clinics (eg, progressive chronic illnesses or frailty).

Triggers for these discussions might be a recent admission to hospital, a deterioration in health/test results, increasing frailty, patient interest in advance care planning discussions or specific prognostic criteria outlined by your department.

R eframe changes to patient's condition	1) Assess understanding 2) Confirm or correct understanding - reflect what the patient says 3) Reframe the changes	*"What is your understanding of your health situation and what is likely to happen?"* *"What have you been told about where things are up to with your cancer/kidney disease/lung disease?"* *"What did your cardiologist say about your heart last time you saw her?"* *"What kind of assistance do you need at home? Is that different to a month ago/6 months ago?"* *"Do you know what the last tests showed? Would you like me to take you through them?"* *"I agree, your lungs really are a lot worse than they were 6 months ago"* *"You're right, the cancer isn't responding to the treatment"* *"I agree, it sounds like things are changing / we are in a different place now"* *"Based on … we need to think differently about your care going forward"*
E xpect emotion	Address the emotions before you continue	"*I can see this is really upsetting for you*" "*I wish things were different*" "*This is a really hard thing to talk about*"
M ap the future	Explore possibilities Plan ahead together	"*Have you thought about what would happen if you become more unwell?*" *"With your current treatment we've been hoping for... It's possible that things won't improve"* "*This is so difficult/uncertain. Let's work out a plan together*"
A lign with patient's goals	1) Find out what matters to the patient and reflect this back to the patient 2) Establish their person responsible	"*Tell me what matters to you/what you're hoping for.*" "*Given this situation, what's most important to you?*" *"What worries you the most?"* "*I'm hearing from you that it's important to* [maintain your independence/ spend time with your family/be free from pain/spend time out of hospital/not be a burden/ not be a vegetable]" If the patient asks for something impossible "*I wish I could turn this around*" "*It's important that we make decisions about your care together whenever we can. If you become too sick to make decisions for yourself, who would you wish to make decisions on your behalf?*"
P lan treatment	Plan ahead and make recommendations based on their priorities and what is possible Keep the conversation open	"*It sounds like the most important things to you are* [reflect their goals]" "*Let's make a plan so you can do more of that*" "*I would recommend we* [start with what you CAN do] *and I would not recommend using machines to support your lungs or resuscitation if your heart stops as they're unlikely to be beneficial for you*" "*Thank you for talking about this with us. These conversations are difficult but so important"* *"We can continue to talk about our plan when we meet next time and you can ask me any questions"*

SETTING 2: Goals of care discussion for the acutely unwell hospital inpatient where ICU admission may not be / is not appropriate – "Late Goals"

R eframe changes to patient's condition	1) Assess understanding 2) Confirm or correct understanding - reflect what the patient says 3) Reframe the changes	*"What is your understanding of your health situation and what is likely to happen?"* *"What have you been told about where things are up to with your chest infection/kidney failure/cancer?"* *"What did your cardiologist say about your heart last time you saw her?"* *"Do you know what the last tests showed? Would you like me to take you through them?"* *"I agree, things are changing quickly/ your Dad is needing a lot more oxygen than when he came in / his kidneys are getting worse each day despite the fluids and medications/ the cancer isn't responding to the treatment"* "*This infection really changes things. We are in a different place now*", "*I agree, I'm worried too"*
E xpect emotion	Address the emotions before you continue	"*I can see this is really upsetting for you*" "*I wish things were different*" "*This is a really hard thing to talk about*"
M ap the future	Explore possibilities Plan ahead together	"*Have you thought about what would happen if you become more unwell?*" *"Has your mum ever talked about what sort of treatment she would want in this situation?"* "*This is so difficult/uncertain. Let's work out a plan together*"
A lign with patient's goals	1) Find out what matters to the patient and reflect this back to the patient 2) Establish their person responsible	"*Tell me what matters to you/what you're hoping for*". "*Given this situation, what's most important to you?*" "*I'm hearing from you that it's important* [recover from this illness/ to spend time with your family/be free from pain/spend time out of hospital]" If patient asks for something impossible "*I wish I could turn this around*" "*If you become too sick to make decisions for yourself, who would you wish to make decisions on your behalf?*"
P lan treatment	Plan ahead and make recommendations based on their priorities and what is possible Keep the conversation open	"*It sounds like the most important things to you are* [use their goals]" "*Based on what we've just discussed, I would recommend we* [start with what you CAN do eg, support you with fluids, oxygen and antibiotics / stop these treatments that aren't working and focus on your comfort and dignity]. *I would not recommend using machines to support your lungs or resuscitation if your heart stops as they're unlikely to be beneficial for you*" *"If it looks like you are dying we will focus on keeping you comfortable"* *"We will continue to look after you and update your family every step of the way".*

SETTING 3: Initial goals of care discussions in a COVID-19 positive patient where ICU may not be/ is not appropriate

R eframe changes to condition	1) Assess understanding of their background health and COVID-19 2) Confirm or correct understanding - reflect what the patient says 3) Reframe the changes	*"Tell me about how your overall health has been recently before this infection?"* *"What have you been told about where things are up to with your emphysema/cancer/kidney disease?"* *"What did your cardiologist say about your heart last time you saw her?"* *"Have you been needing more help at home? Has this changed recently"* *"What do you know about the COVID swab we took yesterday?"* *"What do you know about COVID?"* "*You're right, this COVID result really changes things*", "*You're right, people in your situation often get unwell really quickly with COVID*", *"I agree, this is a serious infection and we need to plan ahead together"*
E xpect emotion	Address the emotions before you continue	*"I can see this is really upsetting for you"* *"I wish things were different"* *"This is a really hard thing to talk about"* *"You are in a very scary situation", "You seem really anxious about…"*
M ap the future	Explore possibilities Plan ahead together	"*Have you thought about what would happen if you become more unwell?*" *"Has your mum ever talked about what sort of treatment she would want in this situation?"* "*This is so difficult/uncertain. Let's work out a plan together*"
A lign with patient's goals	1) Find out what matters to the patient and reflect this back to the patient 2) Establish their person responsible	"*Tell me what matters to you/what you're hoping for*" "*Given this situation, what's most important to you?*" "*I'm hearing from you that it's important* [to recover from this infection/ not prolong suffering / spend time with your family/be free from pain/ get back home]" If patient asks for something impossible "*I wish I could turn this around/I wish things were different*" *"If you become too sick to make decisions for yourself, who would you wish to make decisions on your behalf?*"
P lan treatment	Plan ahead and make recommendations based on their priorities and what is possible Keep the conversation open	"*It sounds like the most important things to you is that you don't want to suffer/ your life prolonged unnecessarily if this infection gets worse. I think that's really sensible, and I'd recommend that we do everything we can to support you through your COVID infection but if you're getting worse despite all the treatment, we'll keep you comfortable here on the ward and we won't put you on a breathing machine* " *"If it looks like you are dying we will focus on keeping you comfortable"* *"We will keep you and your family updated every step of the way"*