

Discussing Adult Resuscitation Plans and End of Life Care

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Think about...

The last discussion of this kind you were involved in/witnessed

What were the triggers for the discussion?

When and how did it happen?

What influenced those choices?



What have you learnt about different how to initiate the discussion?

Who did you learn from?

How confident do you feel in initiating the discussion?

What are your values in relation to the offering of escalation of treatment?

Do you routinely ask about Advanced Care Plans/Directives?

Life Death Dying Ageing Youth
 Sudden Death Patient Autonomy Identity
 Doing Good Avoiding Harm Trust

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Issues affecting discussions



Patient and Family	Doctor	Other
Values and Priorities Previous experiences ?Capacity to discuss Understanding of likely outcomes Trust in medical professionals Religious or Cultural beliefs Concept of CPR as first aid ...	Values and Priorities Previous experiences Learning Timing Privacy/Context Euphemisms and (Mis)interpretations Concerns about distress/emotions ...	Resources Concerns re: impact of inappropriate resuscitation on pt Views of team members e.g. Nurses Concerns re effect of GOC plan on other of pt care

**What do we need to discuss?
 How best to communicate effectively?**

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General Outcomes

	Survival to hospital discharge
In hospital arrest	<20%
Out of hospital arrest	<10%
In hospital arrest frail older patient	<6%
Public perception	50%

Ehlenbach et al 2009; Paniagua et al 2002; Nolan et al 2014

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COVID-19 Specific Outcomes

Data from China

- 80% of deaths occur in 60+ population
- Case fatality for 80+ year olds - 21.9% (all ages and no comorbids 1.4%)

Data from Italy

- >70 years represent 89% of COVID related deaths
- >80years - 58%

US Data (up to March 16, 4226 cases)

65+ group comprise

- 31% cases; 45% hospitalisations
- 53% ICU admissions and 80% deaths
- 65-84 mortality 4-11%
- >85 years mortality 10-27% (7% went to ICU)

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COVID-19 Specific Considerations

Due to isolation family members will not be present – discussions and updates will be phone-based / video-conferenced

Aerosol Generating Procedures relevant to escalation of care

- NIV, generally not recommended unless other condition requiring NIV such as COPD (needs specialist approval)
- Risk of prolonged intubation – average 14 days, longer in elderly

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Adult Resuscitation Plans: defining Goals of Care

Consider

When?

- on admission (?Before admission)

Who?

- best practice to discuss with all patients, direction of discussion will depend of patient values and the appropriate medical interventions
- If patient not able/lacks capacity, discuss with medical treatment decision maker / NOK

Where?

- If able the discussion may be in person
- Likely to be having phone discussions due to isolation policies (this may be to discuss with MTDM or notify NOK of GOC decisions already discussed with patient)

What Next?

- Document clearly (use patient/family comments if able)
- Communicate to team and with relevant family

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Clinical indications for discussing end-of-life care

Urgent indications

- Imminent death
- Talk about wanting to die
- Enquiries about hospice or palliative care
- Recently hospitalized for severe progressive illness
- Severe suffering and poor prognosis

Routine indications

- Discussing prognosis
- Discussing treatment with low probability of success
- Discussing hopes and fears
- Physician would not be surprised if the patient died in 6–12 months

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Quill TE. Perspectives on care at the close of life. Initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room." *JAMA* 2000;284:2502-7

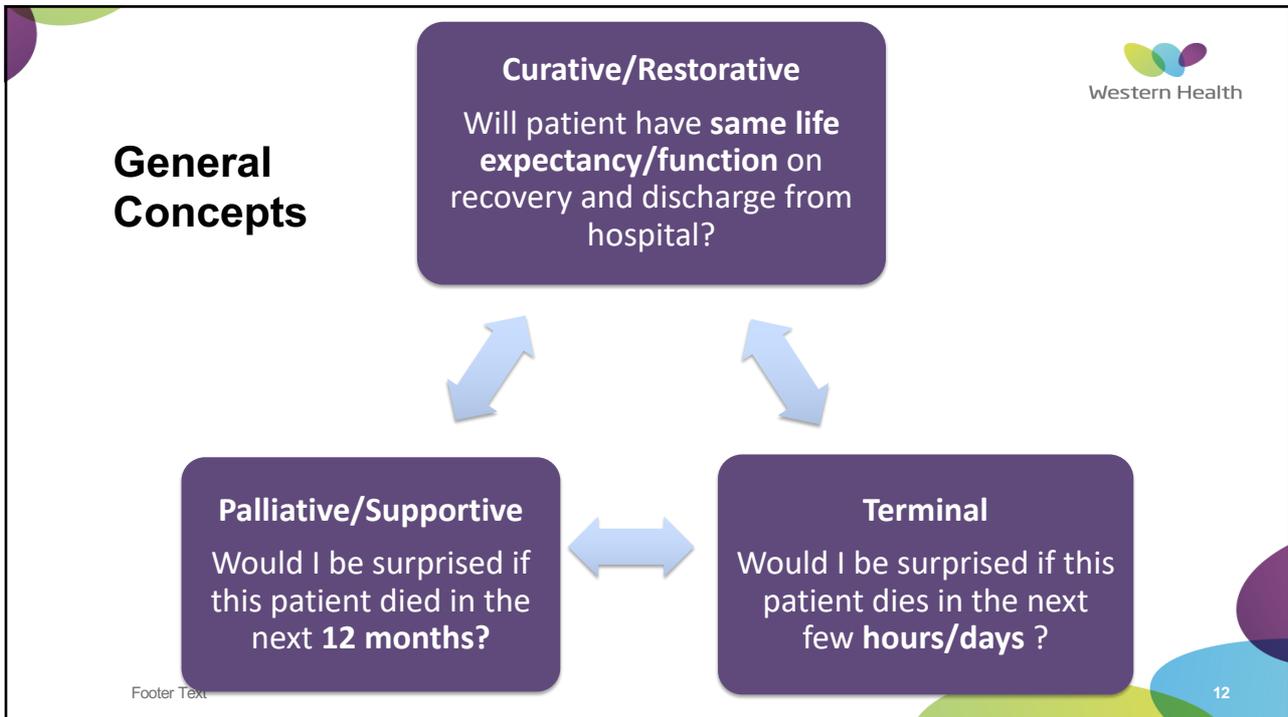
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What do we need to discuss?

- Context?
- Consider what treatment is medically appropriate to offer?
- Within this context discuss values to inform appropriate care?

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How does COVID-19 pandemic change these discussions

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DOCTORS CLINICAL GUIDELINES FOR PATIENTS WITH SUSPECTED OR CONFIRMED COVID-19

5. Adult resuscitation plan (ARP)

All patients require completion of an ARP **on admission** in discussion with the patient or, if not possible, their alternate medical decision maker. Factors to consider in the discussion:

- Older patients, with multi-morbidity, clinical frailty, or cognitive impairment, have an especially high mortality rate with COVID-19 disease. Consider and openly discuss pertinent issues including:
 - Long intubation period (average of 11 days) is likely to be longer in the elderly who need to be particularly robust to tolerate this
 - Very high chance of a prolonged and complicated post-acute stay, with poor functional outcomes even if patients do survive initial period of intubation
- Patients to consider for a supportive care pathway
 - Clinical Frailty Scale ≥ 5 ([see Appendix for further information](#))
 - Known dementia
- [Communication Toolkit](#): SICP (Italian Palliative Care Society communication guideline)

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Clinical Frailty Scale

Clinical Frailty Scale*

1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 Well – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 Managing Well – People whose **medical problems are well controlled**, but are **not regularly active** beyond routine walking.

4 Vulnerable – While **not dependent** on others for daily help, often **symptoms limit activities**. A common complaint is being “slowed up”, and/or being tired during the day.

5 Mildly Frail – These people often have **more evident slowing**, and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 Moderately Frail – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 Severely Frail – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail – **Completely dependent**, approaching the end of life. Typically, they could not recover even from a minor illness.

9 Terminally Ill - Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise evidently frail**.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.
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Consider usual function i.e. at least 2 weeks prior to illness

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Hayes - Decision-Making Framework

Would the patient survive CPR?

No

Dying patient

Medically unwell but not imminently dying

Discuss good dying

Discuss why CPR not being offered

Possibly yes

Very poor outcome likely

Uncertain CPR outcome

Discuss why CPR may be ethically inappropriate but accept opposite view

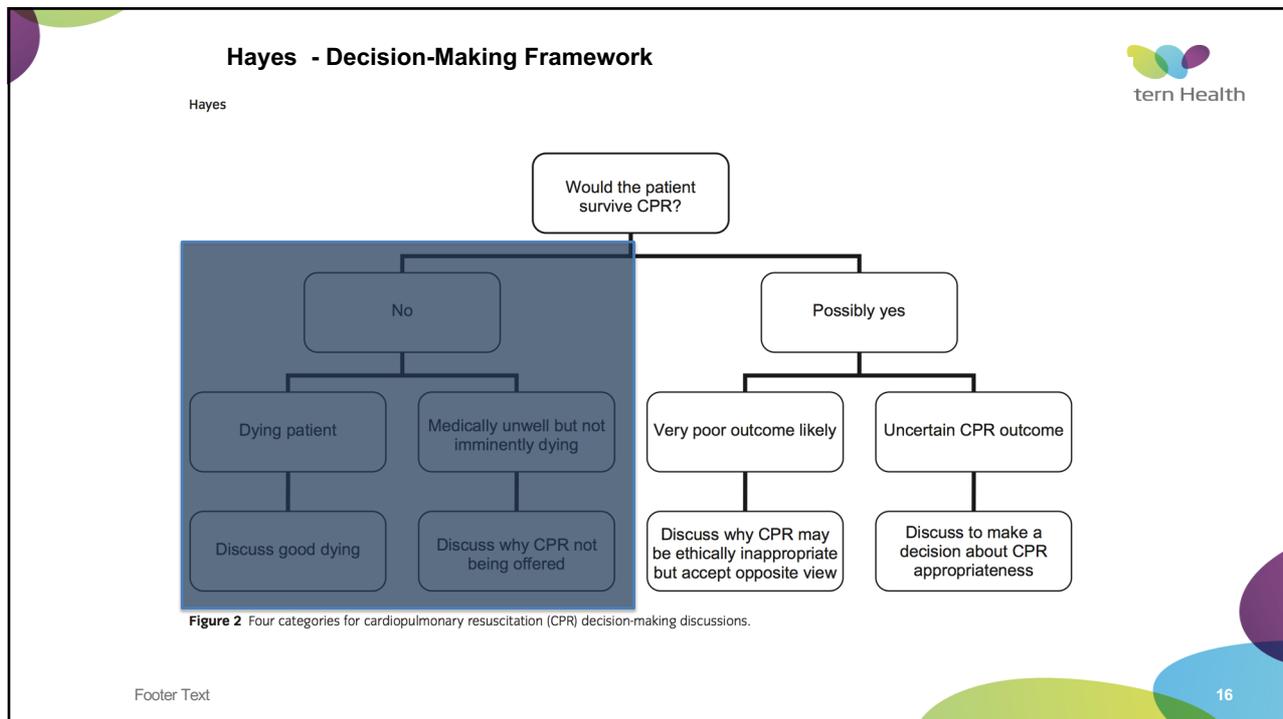
Discuss to make a decision about CPR appropriateness

Figure 2 Four categories for cardiopulmonary resuscitation (CPR) decision-making discussions.

In COVID-19 context the relevant intervention is intubation/ventilation
Principle is similar – only offer treatments that would be medically appropriate
i.e. ask the question **“would the patient survive COVID-19 related intubation?”**

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General Considerations

Deliberative discussion

CPR unlikely to be successful and likely to cause harm – decision made, informing patient and family of the decision

Interpretive discussion

outcome of CPR unclear or patient likely to survive but with poor outcome
discuss value of CPR for this patient.

Walling et al Arch Intern Med 2010

Approach with Honesty and Compassion

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How does COVID-19 pandemic change these discussions

	Business As Usual	Crisis Mode
PROCESS	Shared decision-making between pt (+family) and doctor	Context includes <ul style="list-style-type: none"> - higher level decisions due to crisis response, - Less resources - Less time - Increased anxiety
PREPARATION	Consider what medical interventions would be appropriate, enquire about ACD and MTDM	Consider what medical interventions would be appropriate and are available (this may change with time) enquire about ACD and MTDM
PARTICIPANTS	Patient, doctor, MTDM / Family as appropriate	Support person may not be available or only by phone
RECOMMENDATION	Shared decision incorporating medically appropriate treatments and patients values/concerns	Shared discussion with limitations due to context, important to focus on what will be offered and how this will help with care.

Footer Text Adapted from The collaboration: Communication Challenges with COVID-19 a.ocallaghan 18

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EOLC COMMUNICATION BY PHONE / VIDEO CALL

Consider that

- Verbal and non-verbal cues may be harder to follow
- Recognising and responding to emotions may be more difficult but is still an important part of communication in this setting
- Non-verbal strategies (e.g. use of silence) may feel more awkward or unnatural
- You may find the situation difficult to adjust to as it is not our usual practice
- Videoconferencing considerations

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How to Start



Conversation may be part of a initial admission, wider discussion about health
Or may be specifically about GOC

Some suggestions to start the conversation:

- Hello my name is ... I am **(role)** (if talking with a relative check you are speaking to the right person)
- How are you doing with all of this? **(checking in)**
- I am so sorry you are feeling unwell **(empathy)**
- Are you the sort of person who wants to know a lot of detail about your health or do you prefer to take each thing as it comes?
- Can you tell me/Can I start with what you understand (about your health) so far? **(check understanding)**
- I'd like to discuss something with you, I'd like to discuss what care we might give you if things took a turn for the worse / if you were to get very sick... **(signposting)**
- ...so sick that you might die / sick enough to die...
- Its difficult to discuss these things but it is important for us to know what is important to you, to help us/the doctors make decisions about your care

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Vitaltalk tips - Covid Ready Communication

crowdsourced document of useful phrases



“CALMER”

Check in

Take a deep breath (yourself!).

“How are you doing with all this?” (Take their emotional temperature.)

Ask about COVID

“What have you been thinking about COVID and your situation?”

(Just listen)

Lay out issues

“Here is something I want us to be prepared for.” / “You mentioned COVID. I agree.”

“Is there anything you want us to know if you got COVID / if your COVID gets really bad?”

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Motivate them to choose a proxy and talk about what matters

“If things took a **turn for the worse**, what you say now can help your family / loved ones”

“Who is your **backup person**--who helps us make decisions if you can't speak? Who else? (having 2 backup people is best)

“We're in an **extraordinary situation**. Given that, **what matters to you?** (About any part of your life? About your health care?)

Make a recommendation--if they would be able to hear it. “**Based on what I've heard**, I'd recommend [this]. What do you think?”

Expect emotion

Watch for this – acknowledge at any point; “This can be hard to think about.”

Record the discussion

Any documentation – even brief -- will help your colleagues and your patient

“I'll write what you said in the chart. It's really helpful, thank you.”

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SHARE – COVID-19 GOC discussion – when resources are limited

STEP	WHAT YOU SAY OR DO
SHOW the guideline	“Here's what Dartmouth-Hitchcock is doing for people with this condition: [describe the intervention relevant to the patient]”
HEADLINE what it means for the patient's care	“So for you, this means that. <ul style="list-style-type: none"> - we will give your loved one intensive comfort measures here on the floor. We don't do CPR if her heart stops” - we will care for you on the hospital floor, and will not transfer you to the ICU. We don't do CPR if your heart stops” - we will support your loved one with a breathing machine in the ICU”
AFFIRM the care you <i>will</i> provide	“We will provide [describe treatments] and we hope you/your loved one will recover.”
RESPOND to emotion	“I wish we weren't in this terrible situation.” <i>[see other strategies below]</i>
EMPHASIZE that the same rules apply to everyone	“We are using the same rules with every other patient at D-H. We are not singling you out.”

Vitaltalk
DHMC resources

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https://drive.google.com/drive/mobile/folders/1ic2KXERCHcQm9oCQ_uItkpDoI0Yf-1pv?usp=drive_open

Responding to Emotion

NURSE

- n**ame it
- u**nderstand the core message
- r**espect/reassurance
- s**upport
- e**xplore

Rather than saying “I know how you feel”
consider trying “I imagine that if I was in this situation I might feel...”

EOLC COMMUNICATION BY PHONE

Themes

- Express empathy and compassion
- Recognise the very particular challenges of the situation for families
- Explain what we can and will do to support their relative at the end of their life



Appendix 3: Communication in EOLC- sourced from the SICP 24032020



COMMUNICATION
COVID EMERGENCY



Basic tips for managing communication with families and patients who are deteriorating, aimed at helping colleagues heavily occupied with the emergency

In the case of a
CONSCIOUS PATIENT
 Tips for communicating
 with the **PATIENT**

With the patient
Avoid sentences such as 

“There is nothing more we can do for you.”

“Don’t worry, you’ll die quietly and peacefully with these drugs.”

“These drugs will let you die without suffering.”

“You must be strong/brave for your family.”

“You’ll see, our treatment will stop you being anxious or scared.”

With the patient
RECOMMENDED expressions 

“Good morning Mr/Mrs/Ms (address the person by name), I am Doctor... (introduce yourself by name)

...we’re doing our best to look after you and take care of you...”

*“I understand that this is an emotional time, anyone would be scared/anxious (repeat the term used by the person)...
 ...it is normal to be worried and scared.”*

“We are doing our best to help you and make sure you don’t suffer.”

“I am very sorry that you cannot have your loved ones around you, but as you can see, you are here with us, you are not alone, we will stay with you.”

“Even though your family cannot stay in the ward, they are very close. They call every day to find out how you are, and we make sure we talk to them every day.”

EOLC COMMUNICATION BY PHONE

Themes

- Express empathy and compassion
- Recognise the very particular challenges of the situation for families
- Explain what we can and will do to support their relative at the end of their life

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When on the phone to the **family**

Avoid sentences such as



DO NOT introduce yourself in an impersonal way:

"Good evening, I'm the doctor on duty."

Never refer to the patient by saying:
"A patient in this pathological stage..."

DO NOT say that the patient is worse in a way that is too direct or blunt by using sentences such as:

"There is nothing more we can do for your father/mother/etc."

"Don't worry, your father/mother/etc. will die peacefully with these drugs."

"These drugs will let him or her die without suffering."

When on the phone to the **family**
RECOMMENDED expressions



Introduce yourself by your full name and role:
"I'm so sorry that due to this awful situation we cannot meet in person to talk about your father/mother/wife/etc."

Try to provide information gradually, if possible, using simple language:

"We understand your anxiety/fear/desperation... it is perfectly reasonable."

Provide information gradually:
"We have done everything in our power for you/your father/mother/brother/sister at this very difficult time..."

"...Unfortunately, medicine has its limits and now with Mr/Mrs/Ms (name the patient) we have reached that limit."

"...his/her condition is deteriorating... We are so sorry."

At the moment we are doing our best to prevent any suffering..."

"...he/she will be settled and won't feel any pain..."

"...he/she will be settled at the end and won't feel any pain in the final moments of his/her life..."



CPR Discussion Videos - DR Nick Waldron

<https://vimeo.com/112664072>

1.00 -2.10 mins **Embed the conversation within the context of patients understanding of their illness**

3.22 – 3.54 mins **Listen more than you talk**

<https://vimeo.com/142942963>

1.58 – 3.20 mins **Evaluate medically**

3.35 - Discussion of Goals of care on post take ward round

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Vitaltalk tips - Covid Ready Communication

crowdsourced document of useful phrases

Deciding When things aren't going well, goals of care, code status

What they say	What you say
I want everything possible. I want to live.	We are doing everything we can. This is a tough situation. Could we step back for a moment so I can learn more about you? What do I need to know about you to do a better job taking care of you?
I don't think my spouse would have wanted this.	Well, let's pause and talk about what they would have wanted. Can you tell me what they considered most important in their life? What meant the most to them, gave their life meaning?

Eliciting relatives agenda



Vitaltalk tips - Covid Ready Communication

crowdsourced document of useful phrases

Responding to patients cues

I don't want to end up being a vegetable or on a machine.	Thank you, it is very important for me to know that. Can you say more about what you mean?
I am not sure what my spouse wanted—we never spoke about it.	You know, many people find themselves in the same boat. This is a hard situation. To be honest, given their overall condition now, if we need to put them on a breathing machine or do CPR, they will not make it. The odds are just against us. My recommendation is that we accept that he will not live much longer and allow him to pass on peacefully. I suspect that may be hard to hear. What do you think?

How to start?



“I’d like to talk with you about possible health care decisions in the future.”

“I’d like to review your advance care planning.

Would you like your daughter to be here with you?”

“I’d like to discuss something I discuss with all patients admitted to the hospital”

Ask -Tell - Ask

“Do you mind if we talk about if your health was to change and something unexpected happens?”

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More General Phrases



Tell me about how you see **your health**.

What do you understand about of where you are with your illness?

How much information about what is likely to be ahead for you would you like from me?

If your health situation worsens, what are your **most important goals**?

What are you **hoping** for?

What are your **biggest fears and worries** about the future with your health?

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If things were to get worse what is **most important** to you?

What would be a **good outcome**, what would you **want to avoid**?

What abilities are so **critical** to your life that you can't imagine living without them?

If you became sicker, **how much are you willing to go through** for the possibility of gaining more time?

How much does your **family** know about your priorities and wishes?

Calgary-Cambridge Communication Skills Method Agenda-led and Outcomes-based

Introductions even more important over the phone

- check they have the time and space to talk

Elicit the persons **agenda/concerns** first

- **Respond to cues** they may already be ready to have this discussion

Consider tools such as

- **Chunking and checking** ("Let me check that I understand...")
- **Signposting** ("I'd like to talk about something fairly serious with you..." "I'm afraid its not good news...")
- Respond to emotion (**NURSE**)
- Use **silence**, more than you think

More General Tools

7 Steps to effective end-of-life communication



- Ask** Patient's or family's understanding of their diagnosis and prognosis
- Explain** current medical situation
- Explore** functional status, values and attitudes
- Options** outline options and consequences
- Advise** give honest advice
- Agree** agree on a plan
- Communicate** - document, inform nurses and explain to relatives

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'When enough is enough' Dr Charlie Corke, A/Prof John Agar, Barwon Health

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More General Tools



PREPARED

- Prepare** for the discussion (dx, privacy, who is present)
- Relate** to the person (rapport, empathy)
- Elicit** the patient's preferences
- Provide** information
- Acknowledge** concerns
- Realistic hope**
- Encourage** questions and further discussion
- Document**

Clayton et al 2007. MJA Clinical guidelines for communicating prognosis and end of life issues

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Further reading

- <https://coronavirus.wh.org.au/wp-content/uploads/2020/03/Doctors-Clinical-Guidelines-for-patients-with-confirmed-or-suspected-COVID-19-27.03.20.pdf>
Western Health COVID guidelines 2020
- <https://docs.google.com/document/d/1uSh0FeYdkGgHsZqem552iC0KmXlgaGKohI7SoeY2UXQ/edit>
Vitaltalk - COVID ready Communication – crowdsourced document with communication tips and phrases
- https://ww2.health.wa.gov.au/Articles/F_I/Goals-of-Care-and-End-of-life-in-the-COVID19-environment
WA resources for Goals of care discussions with specific reference to COVID-19 also has link to Vitaltalk document
- https://drive.google.com/drive/mobile/folders/1jc2KXERCHcQm9oCQ_ujtkpDoIOYf-1pv?usp=drive_open
DHMC useful phrases and tips for GOC discussions and palliation of symptoms (if using suggestions ensure these are consistent with WH guidelines)
- <https://vimeo.com/112664072>
Dr Nick Waldron Advanced CPR decision-making education video ~18 mins
- <https://vimeo.com/142942963>
Goals of Care - a clinicians guide ~14 mins
- http://amavic.com.au/page/Member_Services/Policy_and_Media/Current_Projects/AMA_Victoria's_Advance_Care_Planning_Project/
AMA Advanced Care Planning training modules (membership required)

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Social Media

@drkathrynmannix
#pallivicoid
#comcomcovid (compassionate communities)

<https://www.thekindnesspandemic.org>
<https://www.realtalktraining.co.uk/covid19-evidence-based-advice-difficult-conversations>
<https://www.geripal.org/2020/03/palliative-care-on-front-lines-of-covid.html>
<https://learn.nes.nhs.scot/741/quality-improvement-zone>

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COVID-19 References

Clinical course and risk factors for mortality of adult inpatients with COVID-19 in Wuhan, China: a retrospective cohort study. Zhou F, et al., Lancet. 2020 Mar 28;395(10229):1054-1062.

Severe Outcomes Among Patients with Coronavirus Disease 2019 (COVID-19) - United States, February 12-March 16, 2020. CDC COVID-19 Response Team. MMWR Morb Mortal Wkly Rep. 2020 Mar 27;69(12):343-346.

General References

- <http://eprognosis.ucsf.edu/default.php>

Eprognosis prognostic indicator

- <https://www.spict.org.uk>

“Supportive and Palliative Care Indicators” tool for identifying people with deteriorating health due to advanced conditions

It's time to understand the dynamics of “Do Not Attempt Cardiopulmonary Resuscitation” orders. Mancini ME. Resuscitation 2015 88:A1–A2.

Do Not Attempt Cardiopulmonary Resuscitation orders in acute medical settings: a qualitative study. Cohn S, Fritz ZBM, Frankau JM, Laroche CM and Fuld JP. Q J Med 2013 106:165–177

DNACPR decisions: challenging and changing practice in the wake of the Tracey judgment. Fritz Z, Cork N, Dodd A, Malyon A. Clinical Medicine 2014 14;6:571–6

Goals of care: a clinical framework for limitation of medical treatment. Thomas RL, Zubair MY, Hayes B, Ashby MA. MJA 2014 201;8:452-455

Bernacki R, Block S. Communication about serious illness care goals. A review and synthesis of best practices. JAMA Intern Med. 2014;174(12):1994-2003

Clayton J et al. Clinical practice guidelines for communicating prognosis and end of life issues with adults in the advanced stages of life limiting illness and their caregivers. MJA. 2007. 186(12): 77