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?

<table>
<thead>
<tr>
<th>Life</th>
<th>Death</th>
<th>Dying</th>
<th>Ageing</th>
<th>Youth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sudden Death</td>
<td>Patient Autonomy</td>
<td>Identity</td>
<td>Doing Good</td>
<td>Avoiding Harm</td>
</tr>
</tbody>
</table>

Issues affecting discussions

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

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

<table>
<thead>
<tr>
<th>Survival to hospital discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td>In hospital arrest</td>
</tr>
<tr>
<td>Out of hospital arrest</td>
</tr>
<tr>
<td>In hospital arrest frail older patient</td>
</tr>
<tr>
<td>Public perception</td>
</tr>
</tbody>
</table>

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

**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 comorbid 1.4%)

**Data from Italy**
- >70 years represent 89% of COVID related deaths
- >80 years - 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)
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

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
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

What do we need to discuss?

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

Curative/Restorative
Will patient have same life expectancy/function on recovery and discharge from hospital?

Palliative/Supportive
Would I be surprised if this patient died in the next 12 months?

Terminal
Would I be surprised if this patient dies in the next few hours/days?

How does COVID-19 pandemic change these discussions

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)
Clinical Frailty Scale

1. Very Fit - People who are robust, active, energetic and motivated. They 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, they need help often for daily activities. A common complaint is being "slow" or "tired".

5. Moderately Frail - These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy household; medication). Typically, mild frailty progressively impairs activities, including the ability to do personal care.

6. Severe Frail - Completely dependent for personal care. They have one or more chronic diseases that result in a life expectancy of 6 months or less. They need help in all daily activities and might need minimal assistance (cuing, standing) with dressing.

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

8. Terminally Ill - Approaching the end of life. The category applies to people with a life expectancy of <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.

Weakness in moderate dementia: recent memory is very impaired, even if they seemingly can remember past life events well. They can do personal care with prompting.

In severe dementia: they cannot do personal care without help. Completely dependent for personal care.

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

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?”
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
How does COVID-19 pandemic change these discussions

<table>
<thead>
<tr>
<th>PROCESS</th>
<th>Business As Usual</th>
<th>Crisis Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Shared decision-making between pt (+family) and doctor</td>
<td>Context includes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- higher level decisions due to crisis response,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Less resources</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Less time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Increased anxiety</td>
</tr>
<tr>
<td>PREPARATION</td>
<td>Consider what medical interventions would be appropriate,</td>
<td>Consider what medical interventions would be</td>
</tr>
<tr>
<td></td>
<td>enquire about ACD and MTDM</td>
<td>appropriate and are available (this may change</td>
</tr>
<tr>
<td></td>
<td></td>
<td>with time)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>enquire about ACD and MTDM</td>
</tr>
<tr>
<td>PARTICIPANTS</td>
<td>Patient, doctor, MTDM / Family as appropriate</td>
<td>Support person may not be available or only by</td>
</tr>
<tr>
<td></td>
<td></td>
<td>phone</td>
</tr>
<tr>
<td>RECOMMENDATION</td>
<td>Shared decision incorporating medically appropriate treatments and patients</td>
<td>Shared discussion with limitations due to context,</td>
</tr>
<tr>
<td></td>
<td>values/concerns</td>
<td>important to focus on what will be offered and how this will help with care.</td>
</tr>
</tbody>
</table>

Adapted from The collaboration: Communication Challenges with COVID-19 a.scallaghan

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
How to Start

Conversation may be part of an 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

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?”
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.”

---

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

<table>
<thead>
<tr>
<th>STEP</th>
<th>WHAT YOU SAY OR DO</th>
</tr>
</thead>
<tbody>
<tr>
<td>SHOW the guideline</td>
<td>“Here’s what Dartmouth-Hitchcock is doing for people with this condition: [describe the intervention relevant to the patient]”</td>
</tr>
</tbody>
</table>
| HEADLINE what it means for the patient’s care | “So for you: this means that,
- 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 will 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.” [see other strategies below] |
| 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.” |

https://drive.google.com/drive/mobile/folders/1jc2KXERCHcQm90cCQ_u6kpDoOYf1y?usp=drive_open
Responding to Emotion

NURSE

- name it
- understand the core message
- respect/reassurance
- support
- explore

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 2016.3.20

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

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 in pain or sound.”

With the patient

RECOMMENDED expressions

- “Good evening, Mr/Mrs Jones, I am Doctor/paramedic [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 nervous/anxious I hope the team and 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 one around you, but as you can see, 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

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 using:
“a patient in the 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 sudden situation we cannot meet in person to talk about your father/mother/etc.”

Try to provide information gradually, if possible, using simple language:
“We understand your anxiety/despair—desperation… It is perfectly reasonable.”

Provide information gradually:
“We have done everything in our power for you/your father/mother/brother/listen at this very difficult time…”

“…”Unfortunately, medicine has its limits and now with Mr/Mrs/Mr (please the patient) we have reached that time…”

“…”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

https://vimeo.com/142942963
1.58 – 3.20 mins Listen more than you talk

3.22 – 3.54 mins Evaluate medically

1.58 – 3.20 mins Evaluate medically

3.35 – Discussion of Goals of care on post take ward round
Vitaltalk tips - Covid Ready Communication

crowdsourced document of useful phrases

Deciding

<table>
<thead>
<tr>
<th>What they say</th>
<th>What you say</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want everything possible. I want to live.</td>
<td>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? <strong>What do I need to know about you to do a better job taking care of you?</strong></td>
</tr>
<tr>
<td>I don’t think my spouse would have wanted this.</td>
<td>Well, let’s pause and talk about what they would have wanted. Can you tell me what they considered most important in their life? <strong>What meant the most to them, gave their life meaning?</strong></td>
</tr>
</tbody>
</table>

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?”

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?
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

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

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
Summary

Check-in with yourself first – seek support if needed

Respond with honesty and compassion for patients and ourselves

Emphasise what we can and will do to support care

Be conscious of our own values and their impact on the process

Use a variety of communication tools and skills depending on context
  • Phone / Video discussions will need more attention to verbal cues and more checking-in

Consider further opportunities for feedback, debriefing and self care
Further reading

  Western Health COVID guidelines 2020
- https://docs.google.com/document/d/1uSh0FeYdkGgHsZqem552iC0KmX1qaGKohl7SoeY2UXQ/edit
  Vitaltalk - COVID ready Communication – crowdsourced document with communication tips and phrases
  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/1jc2KXRCHcQm9sCQ_ufIkzDoLOY1-fr/?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)

Social Media

@drkathrynmannix
#pallicovid
#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
COVID-19 References


General References

- [http://eprognosis.ucsf.edu/default.php](http://eprognosis.ucsf.edu/default.php) Eprognosis prognostic indicator
- [https://www.spict.org.uk](https://www.spict.org.uk) “Supportive and Palliative Care Indicators” tool for identifying people with deteriorating health due to advanced conditions


