DNR AND END-OF-LIFE CARE
DECISION, COMMUNICATION, AND MANAGEMENT

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Content:

A. Ethical Question

How should clinicians decide on DNR/DNACPR in the context of end-of-life care, and how should these conversations take place?

B. Scenarios

1. A 75-year-old man in the SARI ward presented with cough and cervical lymph nodes enlargement with lung nodules on CXR, possible malignancy or TB. He's lonely & depressed, eventually refused any blood monitoring & lymph nodes biopsy.
2. An 80-year-old man with triple vessel heart disease, NYHA Class III, and two previous ICU admissions, currently suspected to have COVID-19 and needs ventilatory support. Patient's goals and wishes unknown, eldest son from overseas wants "all-out."

C. Background on CPR and DNACPR during COVID-19 Pandemic

1. **Survival rates for cardiac arrest:** Pre-COVID, hospital survival for in-house cardiac arrest (IHCA) with non-shockable rhythms is often < 15% (1). The mortality for critically ill COVID-19 patients increases with advancing age and co-morbidities, particularly cardiovascular disease (2). Thapa et al. (1) reported that for in-house cardiac arrest (IHCA) involving 54 patients, 52 (96%) had a non-shockable initial rhythm, 29 (54%) achieved return of spontaneous circulation, and none survived to hospital discharge (95% CI, 0%-6.6%). Many had non-shockable initial rhythms, presumably as a result of progressive respiratory pathology, and potential delays in resuscitation from donning of PPE. Nevertheless, these results must be interpreted with caution, given the small sample (3), and the effectiveness of CPR in the era of COVID-19 must be taken into consideration. Hayek et al. (4) in a multicentre cohort study across 68 ICU in the U.S. reported out of the 5019 patients, 701 (14%) had an IHCA, and 48 (12%) survived to discharge, and only 28 (7%) discharged with normal or mild neurological impairment. Pulseless electrical activity (49.8%) was the most common rhythm, followed by asystole (23.8%). They concluded that cardiac arrest is common in critically ill patients with COVID-19 and is associated with poor survival, particularly among older patients.
2. **CPR safety, timing, and effectiveness:** Adequate training and PPE during CPR are crucial for safety. Further information could be obtained from the MOH Guidelines on Resuscitation during COVID-19 Pandemic – Version 3/2020 (2). CPR should not be withheld due to a shortage of beds, COVID-19, or social status. Any delays could be mitigated by the anticipation of a cardiorespiratory arrest, preparation of PPE and space in advance, and adequate training for different scenarios to ensure effectiveness. DNACPR orders assist the resuscitation team in situations where outcomes may be less favourable. Delays should be minimised in confirming code status.

3. **DNACPR:** A do-not-attempt-cardiopulmonary-resuscitation (DNACPR) order provides a mechanism to withhold cardiopulmonary resuscitation (CPR) in the event of a cardiac arrest. This may be respecting the wish of a patient with decision making capacity who refuses CPR, or the medical team determining that the risks outweigh the benefits, or the likelihood of CPR success being low owing to the underlying medical condition. Where it is warranted, and appropriate, all other treatments including life sustaining therapies, analgesia, antibiotics, inotropic support, ventilation, nutrition, hydration, investigations, for managing medical conditions or symptom control should be continued.

D. Decision-Making for DNR Order and End-of-Life care during COVID-19 Pandemic

Definition

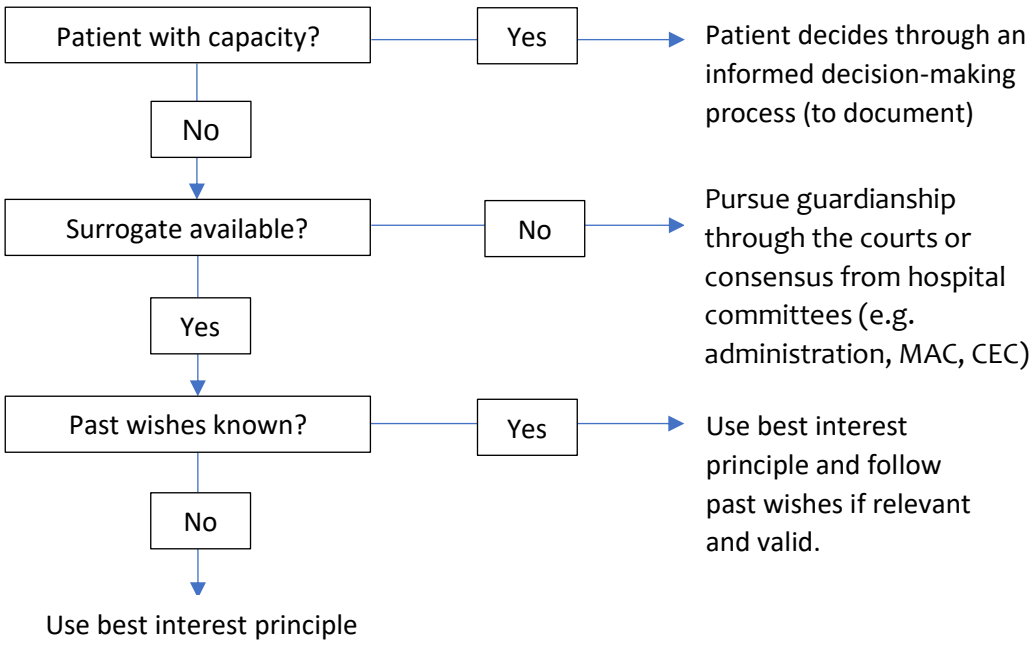
1. **DNR and end-of-life discussions:** It is rarely appropriate to discuss DNR decisions in isolation from other aspects of end-of-life care (5). Often, healthcare providers view DNR orders as a blanket decision for conservative management (e.g. not for intubation, chest compression, and other life-saving therapies such as dialysis). In fact, discussions should revolve around disclosure (breaking bad news including on death-in-line, DIL), aligning expectations, and the goals of care. Goals of care (GoC) discussions are based on disease trajectory, the patient's goals and values, the risks/burdens/benefits of each intervention and its feasibility – to decide on resuscitation, ceiling of care (on life-sustaining therapy), and comfort measures.

Exploring patient's values and preferences

2. **Where to locate patient's preferences?** Some patients with terminal illnesses or life-limiting diseases may have wishes or goals. These conversations may be accessible to the ED in the form of advance care planning, special patient-held medical record/note, electronic medical record, or contact number of the palliative care team or primary physician.

3. **Who decides?** If the patient has the capacity, he/she could decide or defer to others if preferred (e.g. a family member or the physician) (2,3,4). If he/she is incapacitated, the available surrogate decision-maker could use substituted judgement and consider based on what the patient would have wanted. Through an informed decision-making process, the physician and surrogate decision-maker should rely on best interests principle in consideration of patient's values and preferences in further interventions (Figure 1).

Figure 1: Proposed Framework for "Who Decides?"



Note:

- Capacity: C - communicate a choice, U- understand the relevant information, R - reason about treatment options, A - appreciate consequences.
- Patient could decide to consent, refuse, or defer to others (e.g. family member or physician).
- Past wishes: through substituted judgement (what is known to family), advance care or resuscitation plans, goals of care discussion notes.
- Best interests: promoted beneficence, which considers the benefits and harms/burdens of care, prognosis, and quality of life. It may also cover known values and the patient's goals.
- MAC: Medical Advisory Committee; CEC: Clinical Ethics Committee.

Psychosocial and cultural dimensions

4. **Personalised approach** – There are extensive background psychosocial and cultural dimensions to consider in the context of death and dying. Clinicians need to be culturally competent about various cultures and faiths (6,7) and embrace cultural humility (8) in recognition of knowledge gaps and biases. They could undertake a personalised approach to explore the psychosocial and cultural dimensions of individual patients that may, or may not, be related to their original socio-cultural backgrounds and upbringing, stated faith, educational level, past experiences, perceived identities, and their relationships with others. It is prudent for clinicians to ask and not assume while taking a psychosocial history, understand the "how" and

"why" of decision-making through the patients' perspectives, and be conscious of their own cultures, including the culture of medicine.

What to decide?

5. **Best interest principles (BIP**) should be used for critical decision-making. BIP is used when a patient does not have the capacity to decide for him or herself, especially for life-sustaining treatment, e.g., no CPR or dialysis or vasopressors. BIP is a promoted beneficence framework, which includes the considerations of disease trajectory, survival, prognosis, quality of life, and benefits/harms/burdens of care. It may also cover known values and the patient's goals. The clinical and ethical principles in decision-making should apply to both COVID-19 and non- COVID-19 patients.
6. **Initial resuscitation -** During the COVID-19 pandemic, although "it is reasonable to consider age, frailty, comorbidities, and severity of illness in determining the goals of care and establishment of DNACPR directives" (2), it is clinical and ethically justified that patients with severe co-morbids receive treatment and intensive care at the start, including CPR, especially when the underlying diagnosis and prognosis have not been established. In fact, timely intervention is needed, given pre-existing co-morbids (9).
7. **What's next?** Healthcare providers should focus on care that matters to the patient, avoid intensive life-sustaining therapy when they are non-beneficial, burdensome, or unwanted. Avoiding non-beneficial or unwanted high-intensity care also becomes especially important in times of stress on healthcare capacity (10).
8. **Exceptions to be treated** during COVID-19 could be considered in the presence of previously stated wishes from terminally ill or dying patients. An informed refusal for unwanted or non-beneficial interventions should be respected. Nevertheless, if the patient has the capacity, it is important to confirm their wishes. At times, they are temporarily incapacitated secondary to the disease, e.g. hypoxic or uremic. Thus, it is prudent to consult with families if needed.
9. **End-of-life care:** It is ethically acceptable to proceed with non-escalation of therapy, withdrawal or withholding of non-beneficial or medically high-burdens life-sustaining therapy (LST) in the presence of futility through team consensus and shared decision-making framework, when time permits. Ethically required measures for end-of-life care include palliative care steps and intensive symptoms management.
10. **Time pressure situation** – When time permits, always aim for team consensus and an informed approach. Under time pressure, such as during the critical phases of the COVID-19 pandemic, decisions should be made desirably by at least two specialists (one from the primary team), and communicated empathetically to family members by the senior members of the team.

When and what to discuss?

11. **Disclose first, then discuss -** To ask about DNR/DNACPR before breaking bad news or assessing values and goals leads to ineffective code status (10) and end-of-life discussions. At the onset of serious acute illness during COVID-19 pandemic, disclosure (breaking bad news/DIL) should be held early (e.g. at the ED) to align expectations, followed by goals of care discussions if indicated. Once the patient/family is ready, specific decisions could be informed, and necessary management steps carried out.

Figure 2: Quick Note on Breaking Bad News

Breaking Bad News

When?	Grave diagnosis Clinical deterioration Presence of futility Imminent death
Who?	Specialists or senior medical officers
Where?	Private room at ED, general wards, ICU, PICU
How?	Use SPIKES (Appendix B)

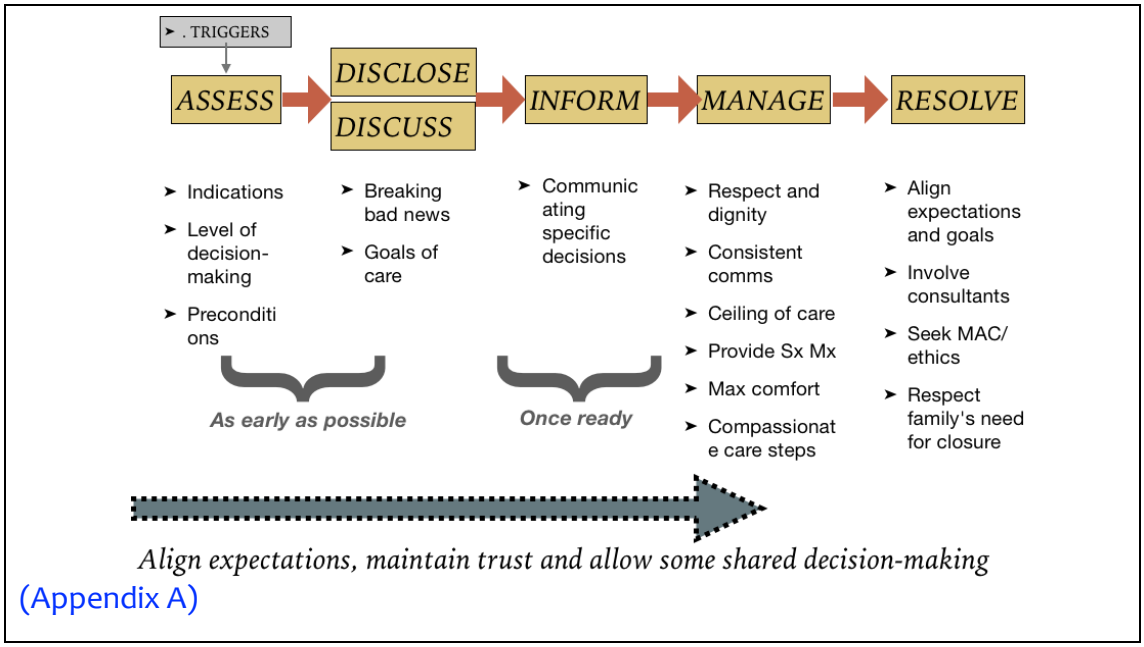
12. **Goals of Care (GoC)** discussions (11) involve the critical conversations between the primary or palliative team with the patient and/or family on the overall disease trajectory, and agreed revised care plans, which may include ceiling of care (limiting life-sustaining therapy), resuscitation orders, palliative and symptom management, and other wishes.

Figure 3: Quick Note on Goals of Care Discussion

Goals of Care Discussion

When?	Presence of futility Disease worsening/progression Repeated hospitalisations or ICU admissions Routine discussion for patients with life-limiting conditions
Who?	Specialists and medical officers with patient/family
Where?	Clinic or private space in ED, general wards, ICU, PICU
What?	Disease trajectory, ceiling of care, resuscitation orders, palliative and symptoms management, and other wishes
How?	Use RE-MA-P (Appendix C)

Figure 4: Proposed DNR And End-Of-Life Care Steps
Assessment, Communication, And Management (Summary)



(Appendix A)

E. Communication for DNR and End-of-Life Care during COVID-19

1. **General principles** - During the COVID-19 pandemic, opportunities to build rapport and hold proper family conferences are hampered by infection control measures, physical barriers, and time limitations. End-of-life discussions should always be held as early as possible, conducted by the senior members of the team, preferably face-to-face or in-person, considering the patient's wishes and values, and aligning patients/families' expectations and emotions.

2. **Communication tools** such as SPIKES (Appendix B) and RE-Ma-P (Appendix C) can be used for difficult conversations. Palliative care (Palliative Care Section) and other compassionate care steps (visitation and saying good-byes) (Compassionate Care Section) must be considered at this point.

3. **Informed assent –** Assent means to agree or to give permission. Advantages of informed assent include:

    a. Clinicians could ask family members to allow them to decide and alleviate any psychological burden (10).

    b. Family can focus on other end-of-life aspects, including bidding farewell.

    c. Clinicians have greater obligations to provide careful prognostication and respectful, open, and thoughtful communication with family members.

When it is clear that resuscitation (CPR) or life-sustaining therapy (LST) will not be beneficial, it is ethically acceptable that a decision is made and an informed assent is provided to the family (10). Offering the family an option to decide or withhold an intervention with no benefit may cause more confusion, emotional burden, and guilt to families (5). Thus, a written authorisation for DNR is not required. Clear documentation on DNR or end-of-life discussions will be adequate and should be easily accessible to all teams and during future ED visits or admissions.

F. Implementation of DNR and End-of-Life Care Steps (Appendix A)

1. **Trigger for DNR and other end-of-life care decision and discussion:**
    a. Poor response to current treatment
    b. Disease worsening/progression with severe major organ(s) dysfunctions/failure
    c. Repeated hospitalisations or ICU admissions
    d. Wishes to limit care explicitly expressed by the patient or family members.
2. **Assess for indications of DNR and other end-of-life care** (5,12):
    a. Physiological futility – Patient is facing imminent death (cardiorespiratory failure despite maximum support).
    b. Medical futility - Patient's condition indicates CPR or LST would fail or not sustainable, e.g. in the setting of irreversible organ failure
    c. Quality of life – Patient is terminally ill, and the burdens or risks of CPR/LST outweigh the benefits to the patient and unable to achieve his goals or values.
    d. The burden or risks of CPR/LST are more than what the patient/family is willing to accept.
3. **Ensure the right level and approach of decision-making:**
    a. Team(s)-based consensus could be considered if time permits, especially when there is a dilemma – with a shared decision-making approach.
    b. Under time pressure, decisions could be desirably made by at least two specialists (one from the primary team) and communicated empathetically to family members (12).
4. **Ensure preconditions are met before DNR or end-of-life/goals of care discussion:**
    a. Adequate assessment by senior members of the team or consensus among team/s.
    b. Disclosure (breaking bad news/DIL) has been done by senior members of the team.

c. There is some family acceptance, and expectations are somewhat aligned.

5. **Disclosure and Discussion if not done yet:**

   a. Disclose and break bad news on imminent death, clinical deterioration, presence of futility, or grave diagnosis (Using SPIKES - Appendix A)

   b. Discuss goals of care on overall disease trajectory, a revised care plan, ceiling of care (limiting LST), resuscitation orders, palliative and symptoms management, and other wishes. (Using RE-MA-P - Appendix B)

6. **Inform the family of specific decisions in an empathetic manner:**

   a. Within the framework and communication as figure below. (Figure 6)

   b. Communicate face-to-face (video or in-person) with the specialist or senior member of the team.

7. **Implement necessary management plans:**

   a. Maintain respect for persons and patient's dignity at all times.

   b. Maintain consistent and empathetic communication with family.

   c. Consider goals of care and ceiling of care – limiting LST and resuscitation (13) – "Withdrawing and withholding Life-Sustaining Treatment" from ICU Management Protocols 2019 (page 67-73) http://www.msic.org.my/download/ICU_Protocol_Management.pdf

   d. Consider palliative care steps (Palliative care section) - provide symptoms management and care that maximise comfort, e.g. adequate control of pain and dyspnoea.

   e. Consider compassionate care steps (Compassionate care section) – psychosocial and spiritual support, allow visitation, and saying goodbyes.

8. **Maintain quality of care and good clinical governance:**

   a. Document all decisions and discussions.

   b. Inform team(s) of plans, ensure continuity and communication of plans.

   c. Debrief teams whenever possible.

   d. Mortality audits or reviews at the department/hospital/state/national level.

   e. Regular review of the processes and workflows according to the latest evidence and feedback from the team(s), with ethics input in policy-making.

9. **Consider resolution options in the event of a disagreement (between teams/team-family):**

   a. To align team(s)-family expectations and common goals.

b. To involve consultants or heads of department to arbitrate and resolve the conflict.

c. To seek administrative, medical advisory committee, or ethics consultation/facilitation

d. To respect the family's need for closure by assuring that maximum effort and comfort have been provided.

Figure 5: Informed Assent Framework and Communication for DNACPR

(adapted from Curtis JR et al., JAMA March 2020)(10)

1. Assess patient's values and goals
(elicit value and preferences for therapies and outcomes)
Is it important to your mother to live as long as possible, no matter what her quality of life, or are there circumstances in which she would not want to receive life support?

2. Discuss CPR or LST as part of the overall goals-of-care discussion
(describe how, when, and why CPR is performed)
We want to be sure we are taking the best possible care of your mother, so I would like to talk to you about CPR and also other parts of care and treatment.

3. Summarise the role of CPR or LST
(explain the lack of ability of CPR to achieve patient's goals)
Given what you have told me about your mother and her goals, performing CPR (and/or these interventions) may not help her reach her goals (or may not be in her best interest).

4. Present a definitive assent statement
(inform patient or family that CPR will not be offered)
Since CPR will not achieve your mother's goals in this situation, we do not provide it. We want to discuss other parts of care that are more important to her at this point.

5. Assess understanding and allow for objection
(discuss family's understanding of decisions made, & any objections they may have)
I want to make sure you understand. Do you have any questions?

G. Practical Pointers from MSIC 2021 Consensus Statement on Withholding and Withdrawing Life-Sustaining Treatments in COVID-19 (16)

"Continuing medically inappropriate care in critically ill patients can lead to burdens of disease and treatment for patients and families, moral distress for HCP and depletion of finite resources… similar principles apply when managing patients with COVID-19." (pg 3)

"Any form of life-sustaining treatment should be considered a trial and should continue as long as there is a reasonable prospect of recovery to a meaningful patient-centered quality of care (17). This plan of treatment should be informed and discussed with families prior to or on ICU admission." (pg 3)

"The minimum duration of time to assess for effectiveness of treatment should take into account the natural history of the disease. In COVID-19 patients, most studies found a median duration of invasive ventilation to be 10 to 12 days, thus considering this as the minimum duration before assessment would be appropriate (18). However, the decision to withdraw or withhold LST can be considered earlier if the condition is worsening significantly." (pg 3)

Figure 6: Factors in decision-making on withdrawing or withholding LST (MSIC 2021)

1. **Imminent death**
Despite aggressive intervention, patients deteriorate and are expected to die in the near future, regardless of whether treatment is continued or stopped.

2. **Poor response to treatment or development of severe complications**
Poor response implies not only worsening or prolongation of the disease state, but also when further intervention is expected to have a negligible impact on recovery of independence or pre-admission quality of life. Examples: recurrent cardiac arrest, persistent multi-organ dysfunction despite optimal treatment.

3. **Expected poor neurological outcome resulting in severe cognitive and physical disability**
Examples: hypoxic ischaemic encephalopathy post cardiac arrest, massive stroke.

4. **Presence of severe systemic disease that predicts poor short-term survival**
Examples: advanced dementia or malignancy, end-stage cardiac, respiratory or liver disease.

5. **Age and COVID-19**
Current data show a strong correlation between elderly with COVID-19 and mortality. However, age should not be the sole factor in decision-making but weighed together with other factors, e.g. severity of current disease, frailty, and comorbidities. Ascertain if patients have expressed wishes on end-of-life decisions (documented or from surrogate).

Figure 8: Practical steps in withholding and withdrawal of LST (MSIC 2021)

1. **Medical team consensus**

- The intensive care team and the other managing team(s) should agree on EOL decisions made. In complex cases, where consensus cannot be reached, allow for repeated discussions and time-limited trial of therapy.

2. **Communication difficulties with patient and relatives**

- Important discussions with families done through phone or video calls, often behind the impersonal personal protective equipment (PPE) may result in conflict and stress.
- Acknowledge that families are anxious from not being able to contact and converse with their loved ones and knowing that they may feel alone and isolated.
- Make the first communication as early as possible with a minimum once daily contact at a pre-specified time to build trust and rapport.
- Allow families the opportunity to ask questions and check their understanding of the conversation frequently as phone communications have limitations.
- The same clinician involved in the active care of the patient should deal with the family, if possible.
- While families require sufficient time to reach and accept EOL decisions, the pressure of bed allocation in a pandemic may compromise this.
- If conflicts do occur, the principles of handling conflicts at the EOL remain the same. Face-to-face family meetings may still be arranged if required, especially for family members not restricted by quarantine.

3. **Management plan for withdrawal of LST**

- Approach to management plan is no different than in non-Covid-19 patients.
- A clear plan is essential to ensure that the withdrawal process occurs smoothly.
- Terminal weaning of the ventilator is preferred over terminal extubation which carries risk of aerosolisation.
- Terminal sedation use may be considered if opioids are insufficient for comfort and, rarely, neuromuscular blockade.
- Families request to be with the patient during the last hour through video call should be facilitated whenever possible. This may be distressing to some families and HCPs. When death ensues, allow a quiet moment between the families and the deceased (through video call).
- Document all EOL decisions.

4. **Complicated bereavement**

- Families may not have closure after the deaths of their loved ones and may suffer guilt, post-traumatic stress disorder and anxiety.
- Psychological support and spiritual care may be offered by tele-counseling or face-to-face meeting with counselor.

5. Support for staff

- Acknowledge the difficult conditions the staff caring for the critically ill COVID-19 patients are placed in. Delivering far from ideal palliative care can result in emotional distress, helplessness and burnout.
- Debrief as soon as possible and as often as needed by senior HCP.
- Encourage feedbacks to improve delivery of care and relief distress.
- Consider rotation or breaks in work schedule.

H. Hospital Policies and Guidelines

Hospital policies should exist for matters related to decision-making during the COVID-19 pandemic. Healthcare administration and policy-makers at the hospital, state, and ministry level could seek legal and ethics input/advice regarding liabilities, ethical issues, or patient-physician disputes resolution during the management of a pandemic.

1. Some of the legal and professional ethics resources:

    a. Malaysian Medical Council - Ethics and Law Unit - drfaizirosli@mmc.gov.my

    b. Medico Legal Section, Medical Practice Division medicolegalkkm@moh.gov.my with the advice and reference to the Ministry of Health Legal Advisors Office.

    c. Medicolegal Units at each hospital.

2. Some of the bioethics and clinical ethics resources:

    a. Hospital Ethics Support Service (HESS), Hospital Ampang ethicsampang@gmail.com. Ethics Case and Non-Case Consultation Referral Form - https://tinyurl.com/HAethicsconsult.

    b. Medical Ethics and Law Department, UiTM meld@uitm.edu.my. Clinical Ethics Consultation Service, UiTM marktan@uitm.edu.my or meld@uitm.edu.my

    c. Clinical Ethics Malaysia (CEM) COVID-19 Online Consultation Service by UM/UiTM/IJN: http://tinyurl.com/CEMConsultForm

I. Conclusion

Clinicians must be ready to adapt to the various situations during these unprecedented times; and be willing to engage in discussion and formulate, modify, or adapt to new guidelines or recommendations to optimize care. Bedside decision-making dealing with life and death under pressure can be challenging, and therefore early consensus among senior members of the clinical team is essential. Families must be engaged as early as possible in anticipation of patient deterioration to align their expectations. Clear and transparent policies should exist for matters related to end-of-life decisions, e.g.

withdrawing and withholding life-sustaining treatment, request of potentially non-beneficial or inappropriate treatment during COVID-19, and CPR.

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APPENDIX A: IMPLEMENTATION OF DNR AND END-OF-LIFE CARE STEPS

ASSESSMENT, COMMUNICATION, AND MANAGEMENT

TRIGGERS for DNR & End-of-Life (EOL) Decision

1. Poor response to current treatment
2. Disease worsening/progression with severe major organ(s) dysfunctions/failure
3. Repeated hospitalisations or ICU admissions
4. Wishes to limit care expressed by the patient or family members.

YES

ASSESS → *As early as possible* **DISCLOSE** → *Once ready* **INFORM** → **MANAGE**

FOR INDICATIONS

1. Imminent death
2. CPR/LST would fail (medical futility).
3. Terminally ill and risks/burdens of CPR or LST outweigh benefits.
4. Unable to achieve goals and values.
5. Risks and burdens more than what is acceptable.

LEVEL OF DECISION-MAKING

1. Team(s)-based consensus if time permits, with shared decision-making approach.
2. If time pressure, at least 2 specialists (one from the primary team) to decide & communicate with family.

PRECONDITIONS

1. Adequate assessment by senior members or team consensus.
2. Disclosure (breaking bad news/DIL) has been done by senior members.
3. There is some family acceptance and expectations are somewhat aligned.

BREAK BAD NEWS
by Specialist/Senior (video or in-person)

On grave diagnosis, imminent death, clinical deterioration, presence of futility

SPIKES:
S-etup
P-erception,
I-nvitation,
K-nowledge,
E-mpathy
S-ummary

DISCUSS

DISCUSS GOALS OF CARE
by Specialist/Senior (video or in-person)

On disease trajectory, ceiling of care, resuscitation orders, palliative & symptoms management, and other last wishes

RE-MA-P:
R-eframe,
E-xpect emotion,
M-ap out values,
A-lign values
P-ropose plan

COMMUNICATING SPECIFIC DECISIONS
by Specialist/Senior (video or in-person)

1. Elicit values/ preferences for therapies & outcomes.
2. Discuss CPR/LST as part of the overall goals-of-care discussion.
3. Summarise CPR/LST role and the lack of its ability to achieve patient's goals.
4. Present a definitive assent statement - Inform with empathy.
5. CPR/LST will not be offered.
6. Discuss family's understanding and objections they may have.

NECESSARY CARE

1. Maintain respect and patient's dignity at all times.
2. Maintain consistent & empathetic family communication.
3. Consider ceiling of care – limit CPR/LST & WW. (Refer to Chapter 2 Section F).
4. Consider palliative care steps and provide symptoms management & care to maximise comfort e.g. pain and dyspnea. (Refer to Chapter 3)
5. Consider compassionate care steps e.g. psychosocial and spiritual support, visitation and goodbyes. (Refer to Chapter 4)

CONFLICT RESOLUTION

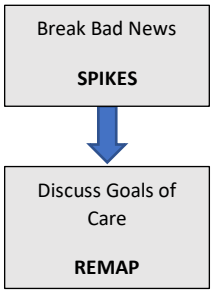
1. Align team(s)-family expectations & goals.
2. Involve consultants/HODs to arbitrate.
3. Seek administrative, MAC or ethics facilitation.
4. Respect family's need for closure by assuring max effort and comfort have been provided.

MAINTAIN QUALITY

1. Documentation decisions & discussions
2. Inform team(s) for continuity of plans
3. Debrief team(s)
4. Audits/reviews

Align expectations, maintain trust, and allow some shared decision-making

APPENDIX B: Breaking Bad News During Covid-19 With SPIKES



When? Grave diagnosis
Clinical deterioration
Presence of futility
Imminent death

Who? Specialists or senior medical officers

Where? Clinic, private room at ED, general wards, ICU, PICU

S = **SETUP.** Turn your phone off, so you are not interrupted. Sit down, make eye contact, get ready to engage with the patient/family. Prepare necessary medical facts and be aware of your own emotions and limitations. Introduce yourself and purpose of the conversation.

P = **PERCEPTION.** Find out what the patient/family knows about the medical situation. Eliciting their concerns can help them feel heard and help you plan. "What do you understand so far about…", "What concerns you the most?"

I = **INVITATION.** Find out how much information the patient/family wants.

K = **KNOWLEDGE.** Use language that matches the patient's/family's level of education, avoid jargon. Give a warning that bad news is coming. Break information into chunks. After giving the bad news, provide a suitable pause (several seconds) to allow information to sink in and to observe emotions and reactions - resist the urge to say something.

E = **EMPATHIZE & EXPLORE.** Wait until the patient/family are ready to talk. Use empathetic statements to name or acknowledge emotions. "I can see that you are worried," "Seeing your mom like this must be painful for you." You can help them hope for the best while preparing for the worst. "You have done your best." Take the opportunity to explore goals and values. "Could you tell me more about her?", "What do you think she would want?", "What matters to you the most?"

S = **SUMMARIZE AND STRATEGIZE.** Summarize the medical information and make plans for next step, including further goals of care discussion. Check understanding and emotions, ask if there is anything more they would like to know or you to help.

Steps to Improve Non-Verbal Communication during COVID-19 Pandemic

- Setting: Calm, private, non-interrupted, non-intrusive
- Attitude: Respectful, empathetic, slower tone
- Effective Listening: Nodding, leaning forward, pausing, mirroring
- Gestures: Good eye contact, hand or arm gestures (ok sign, thumbs up etc)

Pitfalls/Common Barriers to Good Communication

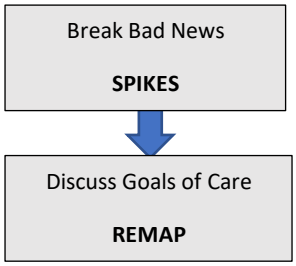
- Assuming that cure is the goal of all patients
- Talking too much and not pausing to listen.
- Feeling you are responsible for maintaining the patient's/family's hope
- Making assumptions about what the patient/family knows and doesn't know

Videos: Delivering bad news COVID-19 short animation - https://youtu.be/7MRPrP2mdl4, https://youtu.be/BC3Yklm88_Y (good video), https://youtu.be/HWAZnhCuAeE (bad video).

References: 1. Medical Oncology Communication Skills Training Learning Module Number 2 (2002). **2.** Dunlay, S., & Strand, J. (2016). How to discuss goals of care with patients. *Trends In Cardiovascular Medicine*, *26*(1), 36-43. doi: 10.1016/j.tcm.2015.03.018**. 3.** Chan L. L., Tan H. S., Chong L. A., Lim R. B. L. & Gopal K. S. (2020). Open and Effective Communication. In Tan H. S. & Tan M. K. M. (Eds.), *Bioethics and COVID- 19: Guidance for Clinicians* (1st Ed.) (pp. 79-86). Malaysian Bioethics Community

APPENDIX C: Discussing Goals of Care (GoC) during COVID-19 with RE-MA-P

When?	Presence of futility Disease worsening/progression Repeated hospitalisation or ICU admissions Routine discussion for patient with life-limiting conditions
Who?	Specialists and medical officers with patient/family
Where?	Clinic or private space in ED, general wards, ICU, PICU



Clinicians should converse on Goals of Care (GoC) when current therapies are not working, by discussing prognosis, exploring patient values, attending to emotion -- to develop a plan.

R = **REFRAME.** Assess patient's/family's understanding of the illness and trajectory, if necessary, to provide new information. Go for the "bigger picture" of the illness, and by re-evaluating the whole situation – "re-evaluate where we are", justify the need to revise the GoC.

E = **EXPECT EMOTION.** Emotional cues may be verbally explicit, or nonverbal such as crying. Reflective statements that acknowledge emotion help the patient/family feel heard. Questions asked right after the reframe are often expressions of emotion rather than requests for information.

Check if the patient is ready to move to the next step. "Would it be OK to talk about what this means for the future?". Give more time if the emotion does not dissipate.

M = **MAP OUT PATIENT VALUES.** Explore patient's values before discussing therapeutic choices. "To find out the best plan, let's talk about what is most important to your xxx and you at this point.". Use open-ended questions. Another way is to ask about the patient's life outside the hospital or previously, to discuss meaningful and unfinished goals.

A = **ALIGN VALUES.** Verbally reflect back what the patient/family has expressed, including any doubts. Make a hypothesis about what this means, and summarise these reflections in an understanding of the patient's values and priorities.

An alignment has occurred when the patient/family responds something like "That is exactly right—that's what most important."

P = **PROPOSE A PLAN.** If the patient/family is ready, propose a medical plan that one believes has the best chance of maximizing the patient's values and goals, using both information about the patient's values and the feasibility of medical treatments to help achieve the goals. Take account of what degree of burden and risk the patient/family is willing to accept.

Videos: Discussing goals of care with a patient - https://youtu.be/mQ0YVPDH87s

References:

1. Dunlay, S., & Strand, J. (2016). How to discuss goals of care with patients. *Trends In Cardiovascular Medicine*, *26*(1), 36-43. doi: 10.1016/j.tcm.2015.03.018. 2. Childers, J., Back, A., Tulsky, J., & Arnold, R. (2017). REMAP: A Framework for Goals of Care Conversations. *Journal Of Oncology Practice*, *13*(10), e844-e850. https://doi.org/10.1200/jop.2016.018796