A Note About These Guidelines:

These are unprecedented times. There is no roadmap yet. We are facing situations that we never expected or wanted to. Working together we can make it through with empathy, compassion and sense of service intact.

These guidelines have been rapidly assembled and should be seen as an acute response to a fast-moving pandemic. The situation is fluid, and best practice is likely to need to change quickly. As we learn more about the specific needs of people dying with COVID-19, these guidelines will be constantly updated, and we welcome your input and experience in helping to keep these as useful and relevant as possible.

Palliative Approach To Someone with Covid-19 Dying in ICU

This document is for the situation where a patient who has been on ICU (almost certainly with ventilatory support) is now at the end of their life. It primarily describes the process for removal of that ventilatory support in a way that optimises patient comfort and whānau support.

Communication.

Whānau (family) members may not be able to be present due to their own isolation status or the Intensive Care Unit's visitor restrictions, this can be a very upsetting thing to convey. However, if possible within the limits of the ICU and DHB visiting policy, a well-managed visit of a whānau member may be make a significant difference to the grief experience for whānau and staff.

Intensive Care Units could consider using IT to communicate with whānau (e.g. phone or video calling via apps e.g. Whatsapp, Zoom, Facebook, FaceTime).

If the patient is awake, there should be careful sensitive discussion that they are dying, if possible, with their chosen family member present, or on video/phone.

If the patient is unconscious, ensure that important loved ones have been personally communicated with, and that they understand that their loved one is dying.

Ask if there is a whānau spokesperson and consider setting a regular time to speak to the healthcare team, as resources allow.

Consider setting up a single ICU number for a family to phone in to, an easy to contact 'go to' person for family enquiries when someone is dying.

Consider palliative care service referral to assist with patient and/or whānau communication especially if patient conscious.

Sensitively discuss the process with the patient as appropriate, and/or with the whanau (or spokesperson).

Listen to their concerns about this specifically: acknowledge distress, sadness, worry. Their grief about their loved one dying without whānau may be marked.

You may need to be explicit that this is not euthanasia, and that they will be dying of natural causes. The intent is not to cause death, or to accelerate a natural process of dying. The goal is to recognise this person is dying despite all that we are doing, and we now need to allow life to end naturally, and ensure this time is dignified, and without suffering and distress.

Ask about any specific request or wishes they have for the remaining time left: e.g. a faith/spiritual based ritual before or after death, cultural needs, music playing, last words to/from family.

Give specific reassurance that they will not be aware or suffer as they will be asleep and unaware **after** hearing and addressing all their primary concerns.

Make clear that someone will be constantly with them – they will not be alone. This may not be a whānau member, but will always be a staff member.

Consider using videolinks should the patient or family wish during the extubation period. This is a practice described in some media reports from the UK.

Don't forget the importance of human connection and touch which may be comforting for families to know that their loved one was not alone as they died.

Symptom Management

In principle, the practice when weaning someone conscious who is dying of Covid-19 off a ventilator is to give medications to reduce anxiety/distress, then sedate (usually to level of unconsciousness), reduce any sensation of breathlessness, and reduce chance of coughing/aerosolization.

Consider palliative care team referral.

Intubated patients

- Attention to privacy and dignity is paramount.
- Ensure consensus from medical staff (doctors and attending nursing) and full understanding of reason for extubation. Document fully the reasoning.
- When extubating, full airborne PPE to be worn. If possible, in a side room with negative pressure.
- Place the patient into whichever position you feel would be best for the patient.
- Turn all monitors off.

- If conscious, ensure the patient is adequately sedated to a state of unawareness (usually midazolam) and opiated for dyspnoea and cough control: use PRN IV opioids/benzodiazepines to titrate sedation and relief of symptoms. This titration should use drugs proportionately titrated against the relief of distress/degree of sedation. The intent of using these drugs is not to cause death itself.
- Consider starting an IV infusion of midazolam and morphine prior to extubation in conscious patients. Note: some ICUs, low dose propofol infusion is used as an alternative
- If already sedated, continue current sedation: if only partial, increase medication to ensure fully unconscious.
- Have ready drawn morphine and midazolam syringes available throughout the procedure to give IV rapidly if sedation unexpectedly lightens/becomes distressed.
- Suction out the patient's mouth and suction down the ETT with a closed-circuit suction when fully sedated to reduce secretions and risk of dissemination/aerosolising on extubation.
- Consider giving IV buscopan and steroids one hour before extubation to reduce secretions, and post extubation spasm.
- Care should be made to avoid any ventilator disconnections.
- Turn off the ventilator BEFORE extubation to avoid the ventilator aerosolising secretions into the environment.
- Remove the endotracheal tube, wrap it in a green incontinence sheet and dispose of in a biohazard bag.

Non intubated patients

- Attention to privacy and dignity is paramount.
- Ensure consensus from medical staff (doctors and attending nursing) and full understanding of reason for removal of oxygen delivery devices or non-invasive ventilation. Document fully the reasoning.
- If conscious, ensure the patient is adequately sedated (midazolam) and opiated for dyspnoea/cough control BEFORE the removal of any oxygen delivering device: use PRN IV opioids/ benzodiazepines to titrate sedation and relief of symptoms. This titration should use drugs proportionately titrated against the relief of distress and sedation. The intent of using these drugs is not to cause death itself.
- Setting up a continuous opioid/benzodiazepine SC/IV infusion in advance of withdrawal of the oxygen delivery device is strongly recommended.
- If already sedated, continue current sedation: if only partial, increase medication to ensure fully unconscious.
- Have ready drawn morphine and midazolam syringes available throughout the procedure to give IV rapidly if sedation unexpectedly lightens/becomes distressed.

If the person does not die within a short time after invasive/non invasive ventilation stopped.

- As bed space is likely to be an issue in the ICU during a pandemic, arrangements to transfer to another ward should be made.
- Inform family if transfer off ICU is to occur, and reassure about ongoing compassionate care. Give contact details of new ward.
- Continue infusion of opioids/benzodiazepines. If on IV switch to SC if transfer ward not used to IV opioids/benzos. Contact pall care for advice if needed.
- Ensure SC PRN breakthrough medication is charted for the ward.
- Consider formulating a dedicated policy for transfer of dying patients with COVID off ICU so that there is clarity and a clear process to follow.

Handling of the deceased

Follow local hospital policy on the handling of the deceased with COVID19.

With thanks to Dr Colin Barnes SMO ICU CCDHB

Some principles of all COVID-19 guidelines produced by the Collaboration:

As with all guidelines, they are designed to support decision making and best practice alongside individual assessment and ongoing reassessment as possible.

No one size fits all, and the guideline recommendations should be tailored to individual circumstances. If local guidelines are available, these guidelines can be used in addition as appropriate. In some instances, these guidelines may not necessarily be appropriate or fitting.

Whilst these guidelines are aimed specifically for people with COVID-19, the principles may also apply to people who are dying of other conditions too during a crisis.

Please do not share these guidelines on social media: the information may be sensitive to the public if not given the appropriate context.

Please feedback with your experience, and what else needs to be added or changed, as we learn more about how best to help people needing palliative care in a COVID-19 pandemic. Please email rachel@hospice.org.nz