PALPRAC

The Association of Palliative Care Practitioners of SA
215-486 NPO
https://palprac.org/

Providing Palliative Care in South Africa During the COVID-19 Pandemic

Acknowledgements:

***PALPRAC writing team**:*

Dr Margie Venter, Dr Rene Krause, Dr Katya Evans, Dr Louise Walker, Dr Jayne Cunningham, Dr Clint Cupido, Dr Colleen Cox, Dr David Cameron, Dr Henriette Burger, Dr Patryk Szymanski, Dr Jennie Morgan, Dr John Turner, Dr Shelley Kibel.

***Social worker**:*

Rebecca Lazarus (The Wellbeing of Healthcare Professionals)

***Reviewers**:*

Prof Liz Gwyther, Dr Dalene van Jaarsveldt , Dr Charmaine de Blanchard, Prof Fiona Rawlinson

For more information please contact info@palprac.org
www.palprac.org

Version 2: 5 April 2020
Changes in "Hospital based …Pharmacological interventions" and EOL flow diagram
Additions to Communication section.

Table of Contents:

Palliative care for patients who are suspected of having COVID-19 or who are COVID-19 positive *4*

Patients with hypoxemic respiratory failure and ARDS failing ventilation support: *4*

Procedure for withdrawal of ventilatory support: 5

Death anticipated to occur rapidly after cessation of mechanical ventilation & inotropic support: 5

Not anticipating rapid death after withdrawal of ventilatory support: 6

Hospital-based care for patients with severe symptoms who are not candidates for critical care admission & ventilation if they deteriorate *6*

Oxygen therapy: 6

Pharmacological interventions: 7

Oral route: 7

IV or Continuous Subcutaneous infusion if patients are unable to swallow: 9

Subcutaneous bolus administration route (no syringe driver available) if patients are unable to swallow: 9

Non-pharmacological interventions: 10

End-of-Life Care *11*

Communication in the time of COVID-19 ..... *13*

End-of-life care for COVID-19 patients at home *18*

Management of COVID negative palliative care patients *19*

Advance care planning 20

Palliative care patients who develop symptoms of COVID-19 ..... *21*

Protection for healthcare providers in the community *23*

Long-term care facilities (LTCFs) *23*

Carer guidelines *24*

The Wellbeing of Healthcare Professionals *26*

Management of the deceased *30*

Addendums *30*

Addendum 1: PATIENT AND CARER INFORMATION SHEET FOR WHEN END-OF-LIFE CARE WILL TAKE PLACE AT HOME 30

Addendum 2: VIRTUAL SUPPORT 33

Addendum 3: MEET MY LOVED ONE 33

Addendum 4: DRUG CONVERSION TABLES 33

Addendum 5: ESSENTIAL EQUIPMENT 34

Introduction:

This is an evolving document created to provide guidance to health care workers (HCW) on the integration of palliative care (PC) into standard care in intensive care units, hospital wards, emergency departments, out-patient clinics, intermediate care facilities, care homes and private homes. It must be read in conjunction with, and aims to complement, the DOH Guidelines for the Clinical Management of Suspected or Confirmed COVID-19 Disease [link [1]]

[1] https://www.nicd.ac.za/wp-content/uploads/2020/03/Clinical_management_of_suspected_or_acute_COVID_V1.1_13.03.20_updated.pdf

It is aimed at ensuring that patients and families receive dignified, compassionate care during this pandemic. *Importantly, the term 'palliative care' does not only describe end-of-life care, but the relief of symptoms and suffering for all, whatever their COVID status or final health outcome.* Palliative care intends not to hasten or prolong death and must be provided alongside standard care.

It is acknowledged that all South Africans currently do not have access to formal PC services in their communities. However, this document aims to provide health care workers with the tools to limit the suffering of patients and their families during COVID-19, aligning treatment decisions with patient and family values whilst also ensuring that the community and health care workers are protected from infection. This type of care may require the same level of intensity as that which is required in an intensive care unit. Palliative care is best provided by interdisciplinary teams that may include palliative care physicians, as well as HCWs who usually focus on standard medical care and psycho-social and spiritual carers in hospitals and in the community.

The purpose of this document is to improve patient outcomes by guiding the care from health care workers in conjunction with mentorship from experienced palliative care providers. Patients with complex palliative care problems and situations are best managed within experienced palliative care teams. To find a palliative care provider close to you and access valuable resources for PC provision, follow this link to the PALPRAC website: [link [2]]

[2] https://palprac.org/palliative-care/find-a-provider/

This document covers the following topics:

- Ventilatory withdrawal
- Supportive care for patients suspected or diagnosed with COVID-19
- End-of-life care
- Communication at the time of COVID-19
- Hospital-based care for patients with severe symptoms who are not candidates for critical care admission & ventilation if they deteriorate
- Communication in the time of COVID-19
- Care suggestions for long-term care facilities
- Self-care and mental health for HCW

Palliative care for patients who are suspected of having COVID-19 or who are COVID-19 positive

South Africa is a country where resources need to be effectively and fairly allocated in order to provide the right care to the right patients and to ensure all patients receive compassionate and dignified care at all times. Palliative care is a fundamental part of the national response to COVID-19 and can be integrated into the severity scoring as follows, reassessing regularly as the colour code may change:

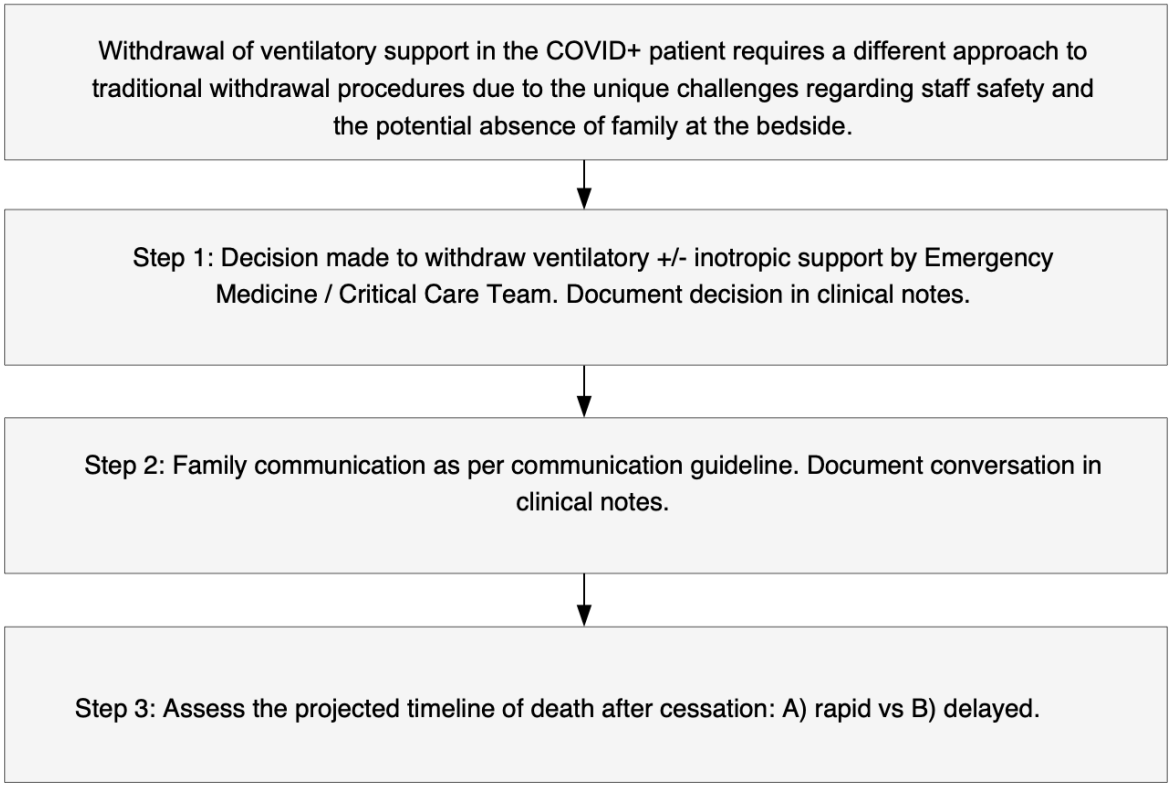
Mild to moderate COVID-19 cases	Less likely to need oxygen	Will need medical care and symptom control if required and psycho-social support.
Severe COVID-19 cases	Less likely to need mechanical ventilation. Likely needs oxygen	Symptom control and psycho-social support of patient and family are needed
Critical COVID-19 cases	Probably needs mechanical ventilation.	Palliative care should be integrated with life sustaining treatment. Psycho-social support of patient and family are needed
Expectant of not surviving COVID-19	Survival not possible with care available	Urgent palliative care is required

This document focuses on the care of patients where symptoms are significant and/or survival may not be possible with the available resources

Patients with hypoxemic respiratory failure and ARDS failing ventilation support:

Patients with hypoxemic respiratory failure and ARDS who were initiated on ventilatory support according to the DOH Guidelines for the clinical management of suspected or confirmed COVID-19 disease, but who fail to respond to intensive therapy may need to be considered for withdrawal of ventilatory support. The decision to withdraw ventilatory support is complex and emotive and must be done within the context of a team. Once the decision has been reached by the team, it must be clearly and compassionately communicated to the family. Psycho-social and spiritual support must be mobilised for the family and the HCW. It should be in place for the family and carers of all patients initiated on ventilation.

Procedure for withdrawal of ventilatory support:



Death anticipated to occur rapidly after cessation of mechanical ventilation & inotropic support:

Predictors - high PEEP & Fi02 or inotropic requirements or severe acidosis or obtunded.

Approach summary:

Gradual scaling down of ventilatory support over 10-30 minutes to allow for the titration of medications to adequately control dyspnoea and anxiety, but not to allow for hastening or prolonging of death. The patient should not be extubated for staff safety.

1. Ensure neuromuscular blockade agents have worn off.
2. Turn off the multiparameter bedside monitor. Further monitoring and management will be symptom-based and not based on vital sign measurement.
3. Stop inotropic infusions.
4. Decrease Pressure Support, PEEP, Fi02 every 5 minutes until at 0 & 21%.
5. If on an opiate infusion, continue the infusion to allow titration.
6. Reassess symptoms every 5 minutes whilst titrating down ventilatory setting and administer additional boluses of intravenous morphine; increase the infusion rate if showing signs of breathlessness.
7. Administer bolus of available benzodiazepine if the patient develops restlessness/anxiety.
8. The patient should not be extubated until after death.

Not anticipating rapid death after withdrawal of ventilatory support:

Approach summary:

1. Gradual scaling down of ventilatory support over 10-30 minutes to allow for the titration of medications to adequately control dyspnoea and anxiety, but not to allow for hastening or prolonging of death.
2. Once comfortable, the patient will require palliative extubation. As this is an airway procedure, this poses a significant risk to staff and the procedure needs to be performed wearing the same PPE as per the Provincial PPE Guideline section on intubation procedure.
3. Ensure neuromuscular blockade agents have worn off.
4. Turn off the multiparameter bedside monitor. Further monitoring and management will be symptom-based not based on vital sign measurement.
5. Stop inotropic infusions.
6. Administer Hyoscine Butylbromide (Buscopan) 20mg IV or Rubinol 200mcg IV.
7. Decrease Pressure Support, PEEP, Fi02 every 5 minutes until at 3 & 21%.
8. If on an opiate infusion, continue the infusion to allow for titration – to convert later to a subcutaneous infusion.
9. Reassess symptoms every 5 minutes whilst titrating down ventilatory setting and administer additional boluses of intravenous morphine; increase the infusion rate if showing signs of breathlessness.
10. Administer bolus of available benzodiazepine if the patient develops restlessness/anxiety.
11. Use patient head coverage at the hospital (same as per intubation procedure).
12. Suction airway using in-line closed suction if available; suction mouth; extubate the patient.
13. Convert to subcutaneous medication via bolus or infusion via syringe driver. See conversion in Addendum 2.
14. Provide oxygen via nasal cannula for comfort as required - patient to wear surgical mask over nasal cannula.
15. Move to the general ward or out of ICU/High Care.
16. Continue care as per detailed End-of-Life Guideline

Hospital-based care for patients with severe symptoms who are not candidates for critical care admission & ventilation if they deteriorate.

All patients with underlying chronic illnesses and severe COVID symptoms should be considered for early supportive therapy (supplemental oxygen with or without empiric antimicrobials) as per the COVID Clinical Guidelines section 4.2, unless resources do not allow for this or if the patient or their medical decision maker clearly states that they decline such therapy.

Oxygen therapy:

Oxygen therapy is likely to be the single most effective supportive measure in COVID-19 patients overall. Only a portion of patients with severe COVID symptoms may require critical care and ventilation. The patient should be reassessed daily and triage repeated if the condition and/or circumstances change. As per the COVID Clinical

Guidelines, any patient with hypoxaemia (saturation <90%) should be given supplemental oxygen to achieve O2 saturation >90% (aim for >92% in pregnant women).

- *Nasal cannula:*

21-40% oxygen (with surgical mask covering to prevent droplet spread); O2 dose 1-5L/min

- *Simple face mask:*

40-60% oxygen; O2 dose 6-10L/min

- *Non-rebreather facemask:*

60-95% oxygen; O2 dose 10-15L/min; ensure proper fit, to reduce risk of aerosol spread.

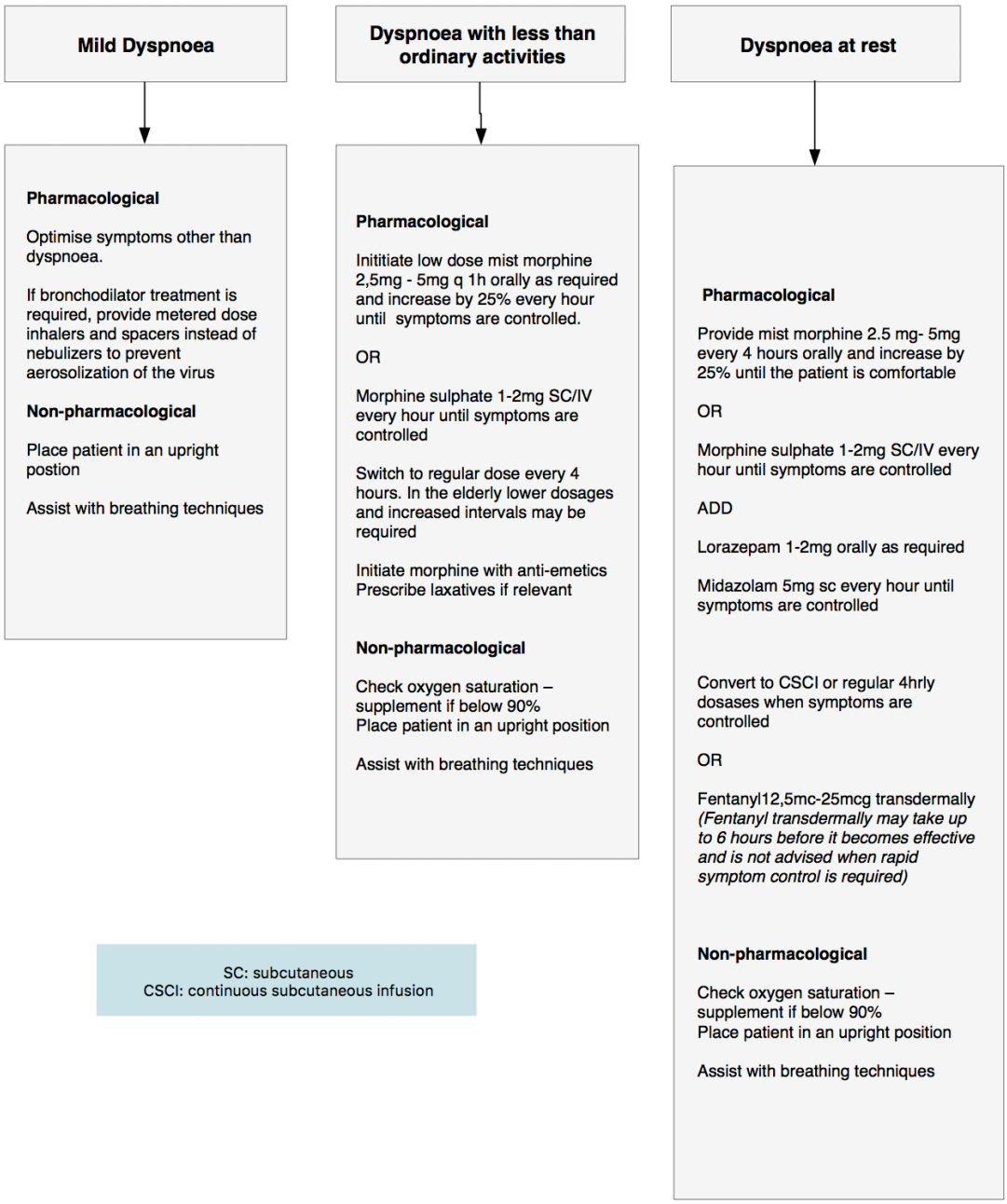
Pharmacological interventions:

Oral route:

This is the simplest and preferred route. Below are the starting doses for each symptom; COVID symptoms might advance rapidly, needing dose escalation.

- ***Fever:*** Paracetamol 1000mg 6hrly PO PRN
- ***Anxiety:*** Lorazepam 1mg-2mg s/l q2h prn until patient has settled, then 6-12 hourly PRN or alprazolam 0.5-1mg 8hrly PRN
- ***Dyspnoea:*** **Opioids** will assist in respiratory distress - Morphine syrup (Mist Morphine) 2.5-5mg PO 4hrly. Note: the amount of morphine syrup will vary depending on the strength at which it is mixed. This varies from pharmacy to pharmacy and region to region. Common strengths are 5mg/5mL (in which case give 2.5-5mL), 10mg/1mL (in which case give 0.25-0.5mL) or 20mg/5ml (in which case give 0.6-1.25ml). Specify strength in the script eg Mist morphine (20mg/5ml) 0.6ml 4 hrly.

Table: Flow diagram
Dyspnoea management



IV or Continuous Subcutaneous infusion if patients are unable to swallow:

Using an ambulatory syringe pump (syringe driver) to deliver a continuous subcutaneous infusion (CSCI) of medication is a very practical and safe way of administering drugs in the palliative care setting.
Below are the starting doses for each symptom; COVID symptoms might advance rapidly, needing dose escalation.

- ***Fever:*** Paracetamol 1000mg 6hrly IV may be given rather than oral (if available)
- ***Anxiety:*** Haloperidol 2-5mg SC stat and add 5mg over 24 hours CSCI (as alternative to Midazolam)
- ***Dyspnoea:*** Give Morphine Sulphate 1-2mg SC/IV and Midazolam 5mg stat SC. Then:
  - for CSCI with ASP: mix in a 20ml, 30ml or 50ml syringe
    - Morphine 15mg
    - Metoclopramide 30mg
    - Midazolam 10-15mg

    Fill up with 'water for injection', to a volume as determined by the device used, if needed. Set up to run over 24 hours OR
  - for IV infusion with infusion pump: mix in 200ml 0.9% sodium chloride
    - Morphine 15mg
    - Metoclopramide 30mg
    - Midazolam 10-15mg

    Run in over 24hours using an infusion pump.

Reassess and adjust rate if the patient is not comfortable or give additional breakthrough doses (2.5mg morphine and 5mg midazolam stat SC or IV).

If patient is already on morphine for pain control, increase the total 24-hour dose by 25% to add additional dyspnoea benefit

In the elderly and those with renal failure, start at lower doses.

Alternatives to morphine if available - Fentanyl patch 12mcg-25mcg/h every 72 hours Fentanyl patches may take up to 6-12 hours to be effective which requires additional subcutaneous Morphine boluses to be given 4hrly for the first 6-12hours.

Subcutaneous bolus administration route (no syringe driver available) if patients are unable to swallow:

Below are the starting doses for each symptom; COVID symptoms might advance rapidly, needing dose escalation.
Subcutaneous bolus doses of medication can be given via an indwelling butterfly/cannula. It will need to be flushed with 0,9% NaCl after each use.

- *Dyspnoea:* Morphine 1-2mg SC q1h; increase dose by 25% if symptoms are not controlled; once controlled switch to regular 4-hourly dosing (typically 1.5-2.5mg 4hrly SC)

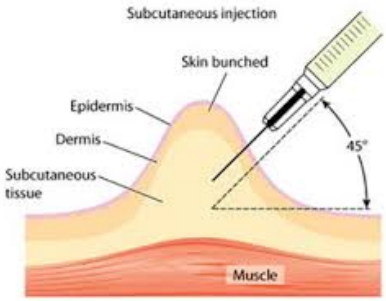
- *Anxiety:* Midazolam 5mg SC every hour until symptoms resolved
- *Nausea and vomiting:* Metoclopramide 10mg 8hrly PRN

Alternatives to morphine if available - Fentanyl patch 12mcg-25mcg/h every 72 hours
Fentanyl patches may take up to 6-12 hours to be effective which requires additional subcutaneous Morphine boluses to be given 4hrly for the first 6-12hours.
One can also slowly drip mist morphine into the side of the mouth as a last resort.

Note: Paracetamol cannot be given SC!
Morphine IMI injections not appropriate in this setting!

Securing subcutaneous access:

1. Obtain necessary supplies.
2. Ensure appropriate hygiene and PPE.
3. Explain the procedure to the patient.
4. Appropriate sites of placement: infraclavicular, lower abdominal wall, anterior thighs or outer aspect of the upper arm.
5. Site should be: easily accessible, free of lesions, away from large vessels, joints and bones, away from oedematous tissue that may alter medication/ fluid absorption.
6. Clean skin with an alcohol swab for 15 seconds and allow skin to dry.
7. Remove protective shield from needle.
8. Using thumb and index finger to create a roll of tissue of approximately 2.5 cm, bunch the skin around selected insertion site.
9. Insert the entire butterfly needle (23G) or yellow Jelco (24G), bevel side up, under the skin at an angle of 45 degrees.
10. Jelco: remove the needle and attach a short line; secure your cannula in place with Micropore.
11. Butterfly needle: secure needle in place with Micropore.
12. Attach a 3ml syringe and flush the tubing with normal saline.
13. Cover the insertion site, hub and wings with a transparent moisture-responsive dressing.



Non-pharmacological interventions:

- ***Restlessness:*** Consider polypharmacy - rationalize medication and discontinue all non-essential drugs; address factors that can agitate a patient (full bladders, constipation, noise, thirst, pain); nursing care; provide patient with sips of water; if mouth care is required, ensure appropriate PPE; keep the patient comfortable according to standard nursing care.

- ***Shortness of breath:*** Advise patients on breathing exercises and optimal positioning (https://www.youtube.com/watch?v=YmBanu2UHKk); relax shoulders, let them place a hand on their stomach and breathe from their abdomen to their

chest; focus on outbreath by controlling it with their hand; ask the patient to lean forward and to concentrate on the outbreath by pursing the lips and slowly breathing out; consider nursing the patient in a prone position for a part of the day if not contra-indicated or unnecessarily uncomfortable; stay calm with the patient and distract the patient with reassuring conversation; provide as much emotional and spiritual care as possible under the circumstances. See attached 'What to Say' guide for useful phrases when providing comfort.

Management of **other commonly experienced symptoms** (pain; nausea and vomiting)

See HPCA Clinical guideline [link [3]]

[3] https://hpca.co.za/Resources/clinical-guidelines/

End-of-Life Care

Patients can be defined as being terminal when there is irreversible decline in functional status prior to death. It is essential during this time to ensure the ethical management of the dying phase and to minimise distress for the patient, family and fellow health care professionals by using a bio-psycho-social and spiritual approach to care.

General measures:

Communication is at the centre of care. The following aspects should be addressed:

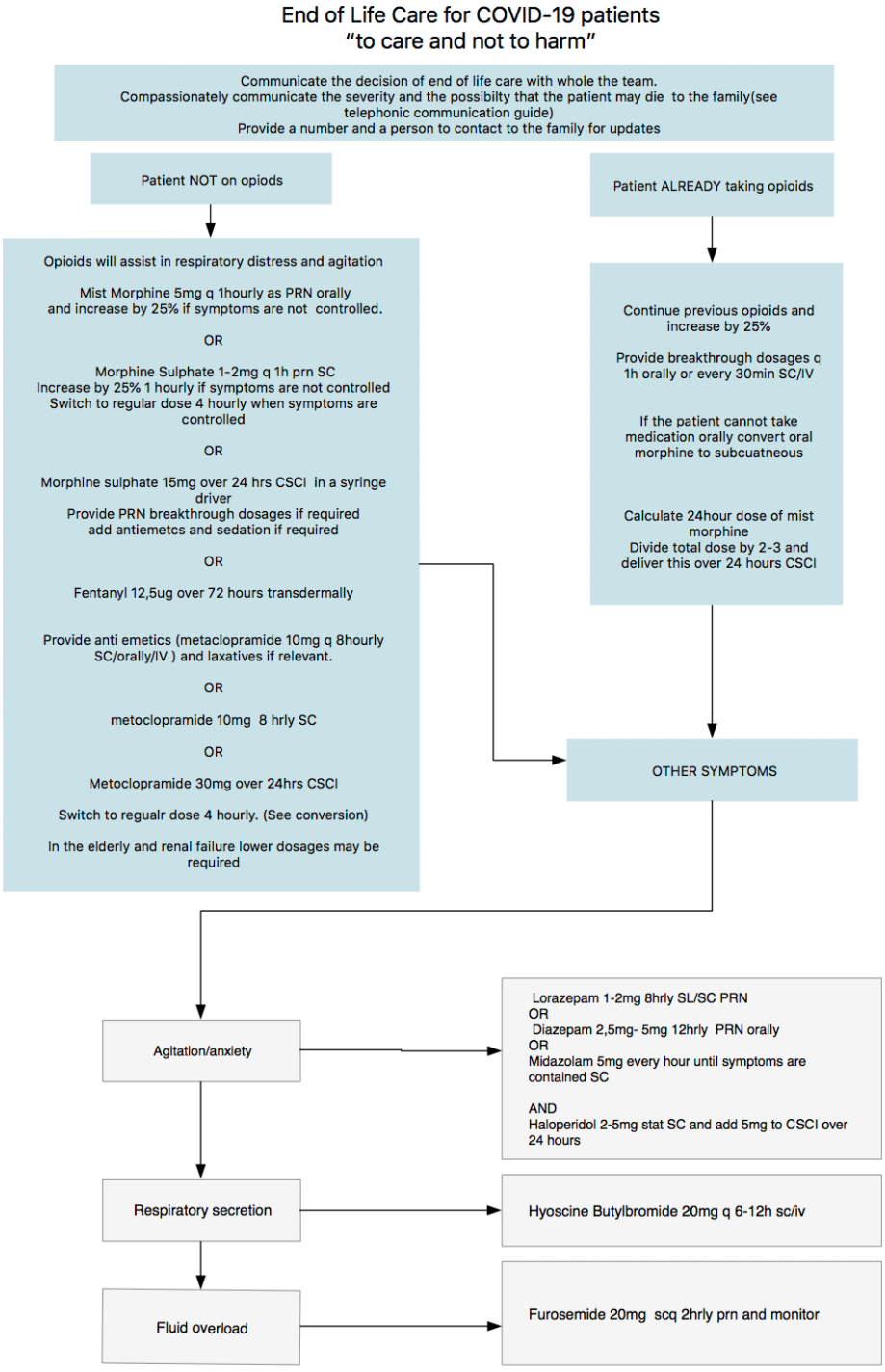
- Honest, direct, compassionate and culturally sensitive information about the prognosis (see Conversation Guide).
- Assessment of the patient and family resources and needs, especially spiritual needs.
- Place of death will be determined by the ability to maintain infection control.
- Emergency contact details, especially if the patient wants to go home.
- Compassionate information about symptoms that might develop and how to manage them (see Home Care Guide).
- Nutrition and hydration. Provide sips of water and comfort feeding.
- Discontinue all non-essential, non-beneficial procedures (which you will not act on) and medication, e.g. 4-hourly blood pressure measurements and vitamin tablets.
- Ensure medications are prescribed for symptom management and prescribe, when needed, medication to pre-empt common symptoms during the terminal phase using the appropriate route:
    - *Pain:* If the patient is on Morphine already, then continue; if the patient is unable to swallow, convert to Morphine Sulphate by dividing the total 24-hour dose by 3.
    - *Nausea and vomiting:* see table below
    - *Respiratory secretions:* see table below
    - *Agitation/restlessness/delirium*: see table below
- Feeding and hydration - discuss with the family. If the decision is to hydrate and/or feed, ensure gentle hydration and advise the family that hydration does not improve QOL, survival or symptom burden at the end of life and should not

be given as routine management. Rather offer sips of water if the patient is able to swallow.

- Ensure impeccable nursing care.

Source: NICD Environmental health guidelines: https://bit.ly/39vDWoS

Flow diagram of drug dosages for end-of-life care:



Communication in the time of COVID-19

Never more than in a time of high anxiety, great medical need and probable rationing of medical intervention, do we require skilled and compassionate communication with our patients, their families and each other.

Important *communication skills* to remember:

- Always start by checking the patient/family member's understanding of the situation and ask what they have been told before. There are often clues for you to use in order to take the conversation forward.
- Give information in small, digestible chunks, avoiding medical jargon.
- Use silence- this allows people to absorb what was said and show emotion.
- Acknowledge emotion: *NURSE* acronym
  - *N*ame emotion: 'You seem to be upset/worried?'
  - *U*nderstanding: 'Given what is going on, I can understand your concern.'
  - *R*especting: 'You have been really patient under difficult circumstances.'
  - *S*upporting: 'I understand that this is very hard. We will be here to help.'
  - *E*xploring: 'Tell me more, I would like to understand what you're thinking.'
- Never say**:** 'There is nothing more that we can do for you/your mother...'. Commit to excellent symptom management, compassionate communication and your presence.
- Consider linking family telephonically or online to say a final goodbye.
- Consider arranging a tablet or phone in a wipeable pouch for the unit for WhatsApp video calls or equivalent.

Below are a number of communication tips for specific scenarios, adapted for the South African setting from VitalTalk and made freely available during the COVID crisis. You can find more information, updated regularly including the full guide on their website [link [4]]

[4] https://www.vitaltalk.org/guides/covid-19-communication-skills/

Admitting: When your patient needs to be transferred to hospital or the ICU

What they say	What you say
[Patient] How bad is this?	From the information I have now and from my exam, your situation is serious enough that you should be in the hospital. We will know more in the next day, and we will update you.
[Family] Is my grandfather going to make it?	I imagine you are scared. Here's what I can say - because he is 90, and is already dealing with other illnesses, he is sick enough to die. Honestly, it is too soon to say for certain.

[Patient] Are you saying that no one can visit me?	I know it is hard to not have visitors. The risk of spreading the virus is so high that I am sorry to say we cannot allow visitors. They will be in more danger if they come into the hospital. I wish things were different. You can use your phone or request to use our portable phone, although I realize that is not quite the same.
[Family] How can you not let me in for a visit?	The risk of spreading the virus is so high that I am sorry to say we cannot allow visitors. We can help you be in contact electronically via video or phone call. I wish I could let you visit, because I know it's important. Sadly, it is not possible now.

Admitting: When emotions are running high

What they say	What you say
You people are incompetent!	I can see why you are not happy with things. I am willing to do what is in my power to improve things for you. What could I do that would help?
I want to talk to your boss.	I can see you are frustrated. I will ask my boss to come by as soon as they can. Please realize that they are juggling many things right now.
Do I need to say my good-byes?	I'm hoping that's not the case. And I worry time could indeed be short. What is most pressing on your mind?

Deciding: When things aren't going well; goals of care; when the patient is not for ICU or resuscitation

What they say	What you say
I want everything possible to be done. 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 stop 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?

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?

Resourcing: When limitations force you to choose, and even ration. (*NB: these are only to be used when our system goes into crisis mode)*

What they say	What you say
Why can't my 90-year-old grandmother go to the ICU?	This is an extraordinary time. We are trying to use resources in a way that is fair for everyone. Your grandmother's situation does not meet the criteria for the ICU today. I wish things were different.
Should I not be in the ICU?	Your situation does not meet criteria for the ICU right now. The hospital is using special rules about the ICU because we are trying to use our resources in a way that is fair for everyone. If this were a year ago, we might be making a different decision. This is an extraordinary time. I wish I had more resources.
My grandmother needs the ICU or she is going to die!	I know this is a scary situation, and I am worried for your grandmother myself. This virus is so deadly that even if we could transfer her to the ICU, I am not sure she would make it. So, we need to be prepared that she could die. We will do everything we can for her to make sure she is comfortable.
It sounds like you are rationing us.	What we are doing is trying to spread out our resources in the best way possible. This is a time where I wish we had more for every single person in this hospital.

How can you just take them off a ventilator when their life depends on it?	I'm so sorry that her condition has become worse, even though we are doing everything. Because we are in an extraordinary time, we are following special guidelines that apply to everyone here. We cannot continue to provide critical care to patients who are not getting better. This means that we need to accept that she will die, and that we need to take her off the ventilator. I wish things were different. We will make sure that she is comfortable, has no suffering and will make sure she is not alone.

Notifying: When you're telling someone over the phone

What they say	What you say
Yes, I'm his daughter. I am 5 hours away.	I have something serious to talk about with you. Are you in a place where you can talk?
What is going on? Has something happened?	I am calling about your mother. Are you in a place where you can talk? We are doing everything we can for her, and I am worried because she is getting worse.
What is going on? Has something happened?	I am calling about your mother. Are you in a place you can talk? We are caring for her in the best possible way and the breathing machine is not helping. (Silence) This is going to be hard to hear. We have to take her off the machine. (Pause) We are expecting that she might die within (insert timeline)… (Silence, then address emotion)
Crying	I can imagine not seeing her makes it so much worse. Even though she is not fully awake, would be helpful if I held the phone to her ear so that you can say a few words, or I can pass on a message to her?
I don't know what to say?	Well, may be one of these things will sound right for you: I forgive you; Please forgive me; I love you; Thank you; or Goodbye?
What is going on? Has something happened?	I am calling about your father. I am afraid I have bad news for you. He was admitted to hospital diagnosed with COVID19. I am sorry to tell you that he died a short time ago.

Crying	I am so sorry for your loss. (Silence) If you feel you must say something: Take your time. I am here.
I knew something was coming, but I didn't realize it would happen this fast.	I can only imagine how shocking this must be. It is sad. (Silence - wait for them to restart).

Anticipating: When you're worrying about what might happen

What you fear	What you can do
That patient's son is going to be very angry.	Before you go in the room, take a moment for one deep breath. What's the anger about? Love, responsibility, fear?
I don't know how to tell this adorable grandmother that I can't put her in the ICU and that she is going to die.	Remember what you can do: you can hear what she's concerned about, you can explain what's happening, you can help her prepare, you can be present. These are gifts.

Managing emotions in ourselves

What I am thinking	What you say
I should have been able to save that person.	Notice: *am I talking myself the way I would talk to a good friend?* Could I step back and just feel? Maybe it's sadness, or frustration, or just fatigue. Those feelings are normal. And these times are distinctly abnormal.
I cannot believe we don't have the right equipment/how mean that person was to me/how everything I do is blowing up in my face.	Notice: *am I letting everything get to me? Is all this analysing really about something else? Look how sad this is, how powerless I feel, how silly our efforts seem?* Under these conditions, such thoughts are to be expected. We don't have to let them drag us down. Can we just notice and feel/share them? Can I step into a less reactive, more balanced place as I move onto the next thing?

I am afraid of burnout, and of losing my heart.	Can you look for moments every day where you connect with someone, share something, enjoy something? It is possible to find little pockets of peace even in the middle of a maelstrom.

FOR CRISIS ONLY: use "SHARE" acronym
Talking About Resource Allocation (I.e. Rationing).

S- Show the Guideline
• "Here's what our institution / system / region is doing for patients with this condition."
• (Start the part directly relevant to that person.)

H- Headline what it Means for the Patient's Care
• "So for you, what this means is that we care for you in the ward and do everything we can to help you feel better and fight this illness. What we won't do is to transfer you to the ICU, or do CPR if your heart stops.
• (Note that you talk about what you *will* do first, then what you won't do)

A- Affirm the Care you will provide
• "We will be doing [the care plan], and we hope you will recover."

R- Respond to Emotion
• "I can see that you are concerned."

E- Emphasize that the Same Rules apply to Everyone
• "We are using the same rules with every other patient in this hospital / system / institution. We are not singling you out."

VITAL talk

VitalTalk is a 501c3 non-profit social impact organization dedicated to making communication skills for serious illness part of every clinician's toolbox.

<u>End-of-life care for COVID-19 patients at home</u>:

Patients with COVID-19 who have become severely, critically ill and who may not qualify for crisis triaging of ICU or hospital beds or ventilation may be directed to stay at home and be cared for in their home setting.

These difficult decisions must be conveyed to the patient and family members in a compassionate manner by a senior clinician with ongoing home support offered. Patients and their caregivers should be given contact details of a local palliative care provider who would be available to guide them through this time. Palliative care providers must be informed of the discharged patient immediately via email or WhatsApp.

These contact details are to be provided to the hospitals.

Local hospitals should liaise with the designated palliative care provider, informing them of:

1. the patient's COVID-19 status and laboratory results
2. their clinical condition
3. their medical information regarding relevant co-morbidities and ethical decision-making
4. the patient and carer's address and contact details
5. the patient's contact tracing list.

See discharge form required (COVID-19 patient home discharge and palliative care referral)
Supply the discharged patient with a tool kit for home:

- a care package with soap, masks, gloves, plastic refuse bags etc.
- an education pack to be given to the family regarding symptom control – available in all South African languages.
- all palliative medication must be sent from the discharging hospital or clinic; palliative care guidance to be given by the hospital doctor; script to include paracetamol, medication to manage symptoms and anticipatory symptoms.
- a phone number to contact if symptoms are not controlled.
- a home-based care referral.
- pre-bereavement counselling/contact with a social worker or psychologist on discharge from the hospital.
- guidance on financial matters e.g. a grant.
- guidance on childcare.
- guidance on wills.

Local epidemiology/ DOH authorities need to be informed of the patient returning to their community. At the same time, palliative care providers and home carers/nurses and family need to be adequately protected from contracting the virus.

Management of COVID negative palliative care patients:

COVID-19 has been shown to affect the elderly and frail, as well as patients with underlying chronic diseases more severely than others. This may include patients with advanced cancer, end-stage organ failure, AIDS and degenerative neurological diseases. Many of these patients may already be part of palliative care programs or are candidates for palliative care. See guidelines for identifying patients with deteriorating health https://www.spict.org.uk [link [5]].

[5] https://www.spict.org.uk

Unfortunately, in a severely resource limited setting like the current COVID pandemic, patients suffering from chronic diseases with no prospect of cure may not receive the care they deserve, due to patients with a better prognosis being prioritized above them. It is therefore imperative that we protect these vulnerable patients from being infected with COVID-19, whilst at the same time providing them with optimal symptom control for their existing conditions and ensuring ongoing palliative care according to their preferences and values.

Consider the following aspects of care:

- Be proactive (protect, plan and support).
- Encourage compliance with the strategies of hand hygiene and social distancing.
- Manage distressing symptoms of underlying disease as per the HPCA Clinical Guidelines [link [6]]

  [6] https://hpca.co.za/Resources/clinical-guidelines/
- Ensure more than one carer has been identified to help care for the patient and a chain of care has been developed to ensure ongoing care if the main carer becomes infected and needs to self-isolate or be hospitalized.
- All carers and family members should be asked to report if they develop a fever or cough or other symptoms suggestive of COVID-19. This should be done before coming to work or visiting.
- Discuss what the family should do if they observe symptoms suggestive of COVID-19.

Advance care planning:

Advance care planning (ACP) involves a dialogue between a healthcare provider and their patient about what might lie ahead with their illness and about how their personal goals, values and preferences can be respected and incorporated in the plan for their care. It is an integral part of caring for patients with serious illnesses or who are nearing the end of their lives, and healthcare providers should prioritize such discussions with their frail or chronically ill patients.

ACP has been shown to lead to care that is more aligned with patients' wishes, reduce the rate of futile, aggressive interventions at the end of life and reduce complicated bereavement in family members. It also provides healthcare providers and family with valuable information when having to make healthcare recommendations and decisions in the future.

In a time of limited healthcare resources like the COVID pandemic such decisions can be particularly difficult to make, so we recommend the urgent implementation of ACP for all patients with serious illnesses or who are nearing the end of their lives. Guidance on ACP can be found on the PALPRAC website by following this [link [7]]

[7] https://palprac.org/for-healthcare-providers/palprac-advance-care-planning/

It might be important to specifically discuss what they would prefer to do (remain at home or go to hospital) if they should develop symptoms of COVID-19. Make a note of the decision and the name of their designated healthcare proxy (decision maker).

Take note that a patient meeting the case definition for COVID-19, who chooses not to report to a healthcare facility or to get tested, is obliged to self-isolate and de-isolate strictly according to the clinical COVID guidelines. The same applies to their carers. If such a patient should die before de-isolation, the body should be regarded as a COVID infected body and be disposed of as per the COVID environmental health guidelines.

Medication, education and resources to ensure quality of life during isolation should be provided. Ensure patients have adequate medication at home to manage current symptoms, breakthrough symptoms and symptoms that might develop in the future

Educate patient and families on:

- Pharmacological and non-pharmacological symptom control for current and future symptoms.
- Hand washing and hygiene
- PPE (if needed)
- Symptoms and signs of COVID-19
- Basic nursing care, if families have to provide this.
- Resources - where to find help if symptoms are uncontrolled.
- Link the patient telephonically to local clinic or hospital unit.
- If possible, offer telemedicine. For basic advice on etiquette, follow this [link [8]]

  [8] https://www.capc.org/blog/telemedicine-virtual-connection-age-social-distancing/
- See the updated HPCSA guidelines on telemedicine during COVID [link [9]]

  [9] https://www.hpcsa.co.za/Uploads/Press%20Realeses/2020/Guidelines_to_telemedicine_in_South_Africa.pdf
- Provide patient and family with telephonic or online psycho-social and spiritual resources (it is best to link with local resources such as local churches and community organisations)

Palliative care patients who develop symptoms of COVID-19:

Testing of palliative patients who are bedbound/housebound with possible COVID-19 infection:
In patients with clinical suspicion and contact with a person either confirmed or under investigation for COVID, the NCID PUI form [link [10]] will need to be completed. However, many palliative care patients will not be able to visit testing sites. The need for further testing will need to be determined by health authorities.

These are some suggestions for managing *adult patients currently receiving palliative care outside of a hospital context* during the COVID-19 epidemic:

- Discuss what the family should do if they observe symptoms suggestive of COVID-19.
- Explain that 80% will develop a mild illness, 15% will develop severe disease and 5% become critically ill and may die.
- The severity of COVID-19 infection increases with age and with the severity of any underlying medical co-morbidity.
- Symptoms of COVID-19 infection can escalate quickly, and decisions regarding escalation of care must be discussed early and are best not made in the midst of an escalating crisis.

For those with mild symptoms:

- Start symptomatic treatment with paracetamol for pain and fever.
- Encourage appropriate fluid intake.

- Do not use Ibuprofen or NSAIDs as they have been implicated in aggravating the condition of some patients with COVID-19[1].
- Explain that your patient should remain in one room until better and have exclusive use of one bathroom, if possible. These rooms should be well ventilated (open windows and an open door). Limit the movement of the patient elsewhere in the house and ensure shared spaces e.g. kitchen and bathroom are well ventilated.
- Household members to maintain a distance of at least 1m (preferably 2m) from the ill patient. Limit the number of caregivers; ideally caregivers should be in good health with no underlying chronic or immunocompromising conditions. Non-essential visitors should not be allowed.
- Encourage hand washing, masks, appropriate disposal of tissues, dedicated crockery and cutlery, cleaning of surfaces with 0.1% hypochlorite or similar cleaning agent. Refer to the [link [11]]

  [11] WHO guideline "Home care for patients with suspected COVID-19 infection"
- Patients should be encouraged to wear a medical mask to contain respiratory secretions. If this is not feasible or not tolerated, cover the mouth and nose with disposable paper tissue when coughing or sneezing, and discard immediately after use. If handkerchiefs are used, wash after each use with soap and water.
- Arrange for a family member to report progress to you on a daily basis using WhatsApp.
- Warn of possible sudden deterioration.

For those with worsening symptoms:

- Refer to hospital if the patient and family request this. Notify the hospital and follow their protocol for triage and admission. Keep up to date with the availability of beds in your local hospital and their admission criteria.
- If the patient wishes to remain at home, continue supportive palliative care:
  - low dose (5ml) oral morphine 4-hourly for *dyspnoea,* if not already on opioids.
  - consider home oxygen if this is feasible and practical in the home environment.
  - consider an antibiotic if a secondary bacterial infection is suspected, but only where this meets the goals of care.
  - sublingual Lorazepam (Ativan, Tranqipam) 1-2mg as required if *restless*; repeat at 10-minute intervals until peaceful.
  - patients that are unable to swallow will need to be given medication via a *syringe driver* or, if that is not available, via *intermittent subcutaneous injection*.
  - Morphine and Midazolam should be given in appropriate doses, as discussed in the clinical management above.
- Refer for counselling and spiritual guidance if appropriate.

The dosages will vary depending on the patient's current prescription and needs and discretion of the clinician. Throughout this time, provide appropriate information regarding your assessment and the possible future scenarios. We are in a time of

great uncertainty and significant risk. Patients and families appreciate doctors who are willing to listen to their fears and provide adequate information and guidance.

- Download [link [12]] family guide to using oral morphine at home.
  [12] https://palprac.org/wp-content/uploads/2020/03/PALPRAC-A-guide-to-giving-oral-morphine-at-home-1.pdf
- Download [link [13]] PALPRAC Homebased Palliative Care guidelines_Covid-19
  [13] https://palprac.org/wp-content/uploads/2020/03/PALPRAC-Carers-Guideline.pdf

Protection for healthcare providers in the community

Refer to the WHO guideline [link [14]][14] https://apps.who.int/iris/handle/10665/331498 "Rational use of personal protective equipment for coronavirus disease (COVID-19)". The recommendations differ according to the setting, personnel and type of activity involved. It is important to note that basic protection and excellent hand hygiene is all that is required in day to day interactions with asymptomatic patients. Wear a medical mask if you have respiratory symptoms.

Here are some *guiding principles around PPE* for healthcare workers when caring for palliative patients in the home with known or suspected COVID-19:

1. Wear gloves, a surgical mask and perform hand hygiene after disposing of the mask.
2. Doctors and patients must stay at least 1m, and preferably 2m, apart except during examinations.
3. If tolerated, the patient needs to wear a surgical mask.

Note: N95 masks, face-protectors, goggles and gowns are reserved for procedures where respiratory secretions can be aerosolized such as intubation in known or suspected cases of COVID-19.

What if you have been in contact with an infected person:

Self-quarantine was advised in Hong Kong when contact was within 2m of a patient for >15 minutes; in Singapore that would be for >30 minutes. If exposure <15 minutes, but within 2m for >2 minutes, keep working but wear a surgical mask and have your temperature checked twice a day. If you have brief, incidental contact, you should monitor yourself.

Long-term care facilities (LTCFs)

Know your residents:

- Ensure all medical information is known to the staff and medical records are easily available.
- Ensure all residents have an advanced care plan in place.
- Ensure family contact details are correct and available.
- Ensure the highest standards of hygiene, sanitation, laundry and waste management are in place. See the WHO Infection Prevention and Control guidance for Long-Term Care Facilities in the context of COVID-19 (interim guidance document, 21 March 2020) [link [15]]
  [15] https://apps.who.int/iris/bitstream/handle/10665/331508/WHO-2019-nCoV-IPC_long_term_care-2020.1-eng.pdf

***Prospective surveillance for residents and staff**:*
Residents

- Assess each resident twice daily for fever >38C, cough and shortness of breath.
- Immediately report fever and respiratory symptoms to clinical staff.
- Staff
- Educate staff on signs and symptoms of COVID-19.
- Staff should stay at home if they had close contact with a COVID positive member.
- Staff should stay home if ill and symptomatic (response to COVID infection - see guideline above).

***General considerations for care**:*

- Older people, especially in isolation and those with cognitive decline, dementia, and those who are highly care-dependent, may become more anxious, angry, stressed, agitated and withdrawn during the outbreak or while in isolation.
- Provide practical and emotional support through informal networks (families) and health care providers.
- Regularly provide updated information about COVID-19 to residents, employees and staff.

***Support for healthcare workers and caregivers**:*

- As much as possible, protect staff from stress both physically and psychologically so they can fulfil their roles, in the context of a high workload and in case of any unfortunate experience as a result of stigma or fear in their family or community.
- Regularly and supportively monitor all staff for their wellbeing and foster an environment for timely communication and provision of care with accurate updates.
- Consider rest and recuperation and alternate arrangements as needed.
- Mental health and psychosocial support and psychological first aid training can benefit all staff in having the skills to provide the necessary support in the LTCFs.
- Staff need to ensure that safety measures are in place to prevent excessive worries or anxiety within the LTCFs.

Carer guidelines

COVID-19: GUIDANCE FOR CARE GIVERS
Your work is important and greatly appreciated! THANK YOU!

CORONA VIRUS (COVID-19) is mainly spread by droplets from the lungs of infected people who sneeze and cough. These droplets can land on the surfaces around us and infect others.

The most common symptoms are fever, tiredness, and dry cough. Some patients have aches and pains, nasal congestion, runny nose, sore throat or diarrhoea.

Although most people have mild infection and recover completely, it must be taken seriously as many people can catch it and some will die.

PROTECTING YOURSELF & YOUR FAMILY

HAND WASHING - frequent and thorough
Use soap and water for 20sec or certified hand sanitiser or hand wash.

COVER YOUR COUGH WITH TISSUE OR ELBOW
Dispose of tissues in closed plastic bag

KEEP AT LEAST 1.5m away from others who are coughing and sneezing

AVOID TOUCHING YOUR EYES, NOSE + MOUTH

CLEAN SURFACES FREQUENTLY using soap + water or Jik, Paper towels or cloths soaked in JIK, dried in the sun

AVOID CROWED PLACES

REDUCE TRAVEL – sleep in if possible

AVOID CROWDED MODES OF TRANSPORT/carry d-germ

PROTECTING YOUR PATIENT

STAY AT HOME IF YOU FEEL UNWELL

PERSONAL HYGIENE

WASH CLOTHES EVERY DAY

CHANGE CLOTHING ON ARRIVAL

HAND WASHING

CHECK YOUR TEMP

CLEAN SURFACES AROUND PATIENT

WEAR APRON when cleaning or turning patient

WASTE MANGEMENT - closed plastic bag

MASKS only needed if patient has infectious illness (check with Sister or Doctor)

Download [link [16]] "Carer Guidelines" brochure

[16] https://palprac.org/wp-content/uploads/2020/03/PALPRAC-Carers-Guideline.pdf

HAND WASHING ESSENTIALS

USE soap and water or d-germ (70% alcohol)

HOW**:** **Wet**, **apply soap**, **rub for 20 sec**, front and back, between fingers, under nails, **dry** with clean towel

WHEN:

Before, during and after preparing food or eating
Before and after caring for sick person or a wound
Before and after entering public place, taxi or bus
After using the toilet or changing nappy
After blowing your nose, coughing or sneezing
After touching and animal or animal food
After handling garbage

Also see these links for guidelines:

- WHO [link [17]] [17] https://www.who.int/publications-detail/infection-prevention-and-control-during-health-care-when-novel-coronavirus-(ncov)-infection-is-suspected-20200125

- Western Cape DOH [link [18]] [18] https://www.westerncape.gov.za/department-of-health/health-workers

The Wellbeing of Healthcare Professionals

When caring for patients with life-threatening illnesses or for those who are at the end-of-life, you as a health care practitioner are constantly faced with the suffering and distress that your patients and their families are experiencing. As members of a people-centred care profession we are constantly striving to reduce our patients' distress by giving them the best standard of health care that we can. Under normal circumstances we as healthcare professionals find that the demands of our work often exceed our inherent resources on the physical, emotional, psychological and spiritual levels.

In addition to this we have had limited formal training on how to practice self-awareness and to care for our own well-being. In fact, our training rewards characteristics like self-sacrifice, infallibility and not expressing our own emotions - be it anger, frustration or sadness. When pushed to the limits, these seemingly noble attributes can easily transform into feelings of resentment and deprivation. The consequences are self-entitlement, a conspiracy of silence around our shortcomings and errors and a sense of intense isolation and loneliness because our own emotions are never acknowledged.

Burnout is described as a 'mental state that arises from prolonged interaction with the unrelenting demands of one's work environment' and is characterized by:

1. exhaustion, where you find yourself depleted of physical energy, emotional strength and spiritual resources
2. feelings of cynicism, depersonalization and indifference towards others
3. a loss of purpose and a sense of failure as a professional and as a person

In healthcare practitioners, burnout has been linked to suboptimal patient care, medical error and reduced productivity, but more importantly it leads to reduced self-awareness, self-neglect, absence from work, depression and physicians leaving the profession. It is important to recognise that the presence of burnout itself is not a psychiatric disease. However, burnout may be associated with depression, substance abuse and suicidal ideation. *Make sure that you are able to recognize your own signs of burnout and act on them.*

Burnout in health care professionals can be caused by internal and external stressors as listed in the table below. It is possible to reduce some of our external stressors through careful analysis and re-organization of our workflow, work-environment and staff complement. Such changes require buy-in from employers and institutions and often take time to manifest. Some external and most internal risk factors for burnout can however only be mitigated through a personal commitment to self-awareness and self-care; *recognizing the aspects of your work that drain you, knowing how to reduce their draining effect and making time to do the things that replenish your resources.*

Internal	External
• Crossing of boundaries in doctor-patient relationships • Compassion fatigue • Cumulative grief (Multiple losses or deaths over a short time span) • Conversations that elicit emotion (Breaking bad news, Advance care planning, conflict resolution) • Countertransference • Lack of sense of control over events • Unable to access or utilize personal support structures (life-partner, family, friends) • Ethical dilemmas • Lack of sleep, exercise and a healthy diet • Lack of experience, skills, knowledge and mentorship • Attribution of achievement to chance or others rather than one's own abilities • Passive, defensive approach to stress and conflict • Lack of career fit or job dissatisfaction • High expectations of self to transform institutional, clinical and social culture • Inability to adapt to change	• Risk of personal physical harm • Change in work routine and setting • Ineffective leadership and supervision • Information overload • Rapid changes in policies and directives • Red tape/ paperwork • Shift-work • Staff shortages • Limited resources • Excessive overtime • Conflict between colleagues • Role blurring • Disorganized work environment • Abuse in the workplace • Inconsiderateness amongst colleagues • Inadequate remuneration • Workload

In the context of a global healthcare disaster like COVID-19, all these risk factors for burnout are amplified, but 3 of them bear special mention in the context of palliative care, namely cumulative grief, compassion fatigue and countertransference. Besides the medical care palliative care patients require, there is also a significant emotional component to their care – sometimes hidden and often disregarded in terms of its impact on the HCP.

Compassion fatigue:

A mental condition resulting from prolonged exposure to human suffering, particularly in persons working in people-orientated service professions who witness physical, emotional and mental pain on a daily basis as part of their job. It can manifest as exhaustion, irritability or emotional unavailability. In the setting of war and conflict, much like the current COVID pandemic, it is related to the witnessing of multiple deaths, senseless killing and seeing the devastating often long-term effects that war has on surviving individuals and societies. Compassion fatigue evolves specifically from the relationship between the practitioner and patient or family. It has been seen as the cost of caring for those in emotional pain and is also known as vicarious or secondary traumatization.

***Cumulative grief*:**

Defined as an intense form of grief resulting from experiencing multiple losses within a relatively short space of time without the opportunity to deal with each loss separately, thus leading to an individual suppressing their own grief response and simply carrying on. In the field of palliative medicine these losses are experienced at the death of a patient but also when children lose a parent, when we are unable to provide our patients with the kind of "good death" that they hoped for or when we see a family fall apart due to illness. And even though there may be recognition that we as doctors experience grief in response to these events, this is largely seen as an individual feeling which must be dealt with on a personal level. Not being afforded the time or space to express one's own grief can lead to feelings of numbness, dehumanization and guilt. This type of silent mourning can become a source of chronic stress that leads to burnout and decreased effectiveness.

***Countertransference*:**

Defined as the emotional reaction evoked in the carer, in response to the patient's disease, problems, behaviour or feelings. This is individually determined by your unique history, your sense of self as a person, your role in your family or society or perhaps by how you came to work in this field. Caring for patients with life-threatening illnesses can force us to face our own mortality, deal with unexamined regrets or unresolved feelings from a previous experience of loss. Every dying patient can represent an opportunity to make up for past failure where we might have been unable to provide compassionate care for someone who was dying.

It can also manifest as having the need to have patients understand and experience the situation exactly as you do. It is not 'wrong' or bad to feel these feelings, on the contrary, they represent a very normal response to bearing someone else's suffering. What is important is your awareness of the feelings, and the choices you have about what you do with them. If you are conscious of them, you will be less likely to feel guilty, criticize yourself, be angry or label the patient unnecessarily. Not recognizing these reactions as countertransference, will be unhelpful for the patient, and for yourself. Through self-awareness you can evaluate whether these reactions are your own uncomfortable feelings, or a clue to what the patient may be feeling.

We are unsure of the duration of the COVID-19 'season' and we need to ensure that we are going to be here at the start and the finish. We are expecting 20% of us to get infected and thus we are working on the premise that only 80% of staff will be at work. Below are a number of things that you can do today to stay healthy, both in body, mind and soul.

***Teamwork*:**

Working as part of a team can play a significant role in reducing the draining effect of these risk factors for burnout. The members of a team work together towards a common goal and each member, especially when the team consists of HCWs from different professional backgrounds, brings a different skill set to the table. These skills can be utilized to share the burden of decision-making, find creative solutions to complex patient and family problems and provide a safe space for confidential

debriefing after a particularly draining event. Successful teams prioritize communication between its members and between the team and the patients and families they care for. They ensure a pragmatic balance between clear role-definition and the flexibility to take over or share tasks and leadership roles if the need arises. Team members provide emotional and psychological support for each other and monitor each other for signs of stress and burnout.

***Learn to use the right words**:*

Difficult conversations that involve emotions can be extremely draining on health care professionals. By teaching yourself a few skills your interactions with patients in families can become less daunting and more gratifying for all involved. See section on Communication in the time of COVID-19.

***Self-care and mental health**:*

Physical Care:

- Eat a healthy diet (low in sugar) and drink sufficient fluids.
- Sleep between 6-8 hours per day.
- Exercise regularly.
- Practice good personal hygiene at work and don't forget on your way home and at home.
- Remove your second pair of clothes outside the house or in the garage, leaving shoes outside.
- Shower before spending time with your family.
- Ensure you protect those at home, who are high risk.

Mental Health:

- Many of us are already suffering with Anxiety and Depression - DO NOT STOP your chronic medication.
- Be aware of your own stress levels and know your limitations.
- Be aware of your own losses (of normality; loss of free time) and be aware of your own grief for patients.
- Acknowledge that you are human and your experience of this pandemic.
- Take breaks from the work by spending time with family; make time for relaxation.
- Identify things that give your strength and enjoyment.
- Seek help early if you need guidance or to talk to someone. There is the Metropolitan Employee Health and Wellness program (0800 611 093) and find out about other mental health services available at this time at your facility.
- Seek professional help if you need it.

Social Health:

- Do not emotionally isolate yourself during this time - communicate with colleagues, friends and family.
- Use WhatsApp, video calls and skype and check in on each other.
- Communication is critical.

Spiritual Health:
A pandemic like this often pushes one to the limits and we look within ourselves and search for meaning in all of this.

- Maintain your spirituality.
- Know your values - what gives you meaning, purpose and hope
- Practice gratitude and take time to reflect.
- Keep in contact with your religious and cultural groups.

See these links for further guidelines:

[link [19]] [19] https://www.who.int/docs/default-source/coronaviruse/mental-health-considerations.pdf
[link [20]] [20] https://www.facebook.com/northbrisbanepsychologist/videos/2962907510419354/

Management of the deceased:

Please see: Circular H 41 of 2020: COVID-19: Management of decedents in the Western Cape. Link will be provided

Addendums

Addendum 1: PATIENT AND CARER INFORMATION SHEET FOR WHEN END-OF-LIFE CARE WILL TAKE PLACE AT HOME

We would like to give you some information to help you during this very difficult time. Your ongoing support and care are very important to us.

You have been asked to care for someone who is very ill, but is also infected with a dangerous virus (Coronavirus) that could potentially cause you to become ill if safety precautions are not followed.

General Health and Safety Precautions:

- Wear a mask covering your mouth and nose. When your loved one coughs or sneezes, the virus particles can spread through the air and will infect you if you breathe them in.
- Wear gloves (if available) or cover your hands with plastic packets and then dispose of them. If the virus gets on to your hands and you touch your eyes, nose or mouth, you will become infected.
- Wash your hands thoroughly with soap and water for 20 seconds after touching or being in the same room with your loved one.
- Wipe down all hard surfaces with a cleaning agent several times a day. The virus particles can settle and stay on surfaces for up to 9 hours. Touching these surfaces and then your eyes, nose or mouth might spread the virus to you and your other family members.
- It is best for the ill person to stay in a room by him- or herself and not be allowed to move around the house. Visitors should be strictly limited – only the person/s caring directly for the ill person and those closest to him/her should be exposed.

- Keep crockery, cutlery, linen and clothing that your loved one uses separate from the rest of the household. Clean them thoroughly with soap and water.

What to expect from the Coronavirus:

There is still no known cure or vaccine for this virus. Thus, as the virus continues, your loved one will become more ill and may display the following symptoms:

- Ongoing high fevers with possible sweating and trembling.
- They may be very thirsty initially; but will not be able to tell you this as they become more unwell.
- Their mouth may become very dry, with their lips cracking, their tongue becoming fuzzy and their mouth smelling bad.
- Their cough may become more frequent and severe, preventing them from sleeping at night.
- They might cough up blood.
- Worsening tiredness with inability to walk to the bathroom, sit up or move around in bed.
- They may be very short of breath, even too breathless to speak. The slightest movement may make it worse, including going to the toilet or changing positions in bed.
- They are unlikely to be hungry and may refuse even small amounts of food and water.
- They will get thinner and weaker because the virus is attacking their bodies and also making them too sick to eat.
- They may develop constipation or even diarrhoea.
- Their circulation will become poor, so their hands and feet may feel colder and their skin will be more vulnerable to pressure sores. These will first appear as dark, pink to purplish areas and may form a blister. The skin will come off, leaving a moist yellowish area which will likely increase in size.

What you can do to Help:

- Try and rest when your loved one is sleeping, as their ongoing coughing is likely to keep you awake as well.
- Keep doing everything to prevent yourself from catching the virus. Follow the Health and Safety Precautions above carefully.
- If your loved one will tolerate wearing a mask/scarf/bandana please encourage it. However, when they become more breathless this will be too restrictive and should be removed.
- Make sure there is a breeze in their room, coming from behind you and away from you, to disperse any virus in the air. A flow of air will also ease the breathlessness that your loved one may be experiencing.

For high fever:
- ensure a breeze of fresh air
- use a moist facecloth or sponge to gently wash over the body
- take off unnecessary clothing or linen

- give medicine (Paracetamol 500mg tablets – 2 tablets by mouth every 6 hours)

For increasing shortness of breath, worsening cough or coughing up blood:
- while they are coughing, stay well clear - it is essential to wear something to cover your mouth and nose and even sunglasses over your eyes
- continue to talk calmly to your loved one – try and soothe their anxiety
- inform your palliative care provider who will organize Morphine syrup (a strong painkiller) for your loved one - this will help to ease the breathlessness and cough

For fear and anxiety:
- acknowledge their fears and reassure them that you will continue to support and care for them
- distract them with music or singing
- try and ask about what is causing them to feel this way
- contact people on the telephone if your loved one wants to talk to them – estranged family or friends, their pastor etc.
- if the breathlessness is causing anxiety, then more medication needs to be given - contact your palliative care provider who would be able to give you another tablet for this anxiety with directions for its safe use.

Tablets will become more difficult to swallow. Crush them between two spoons and mix with a small quantity of water or juice to make them easier to swallow.

What to expect towards the end:

If you are struggling to cope with keeping your loved one calm and you feel he/she is suffering, please contact your palliative care provider urgently.

Be prepared for your loved one's condition to worsen quickly and unexpectedly – have the contact numbers of support organisations and individuals that you can call close by. Try not to panic. You should not call an ambulance at this time as they won't be able to help.

If your loved one starts to show these signs, they may soon die:
- Extreme difficulty breathing or breathing that becomes irregular and has a rattling sound
- Persistent pain or pressure in the chest
- Increased confusion or sleepiness
- Bluish lips or face

What you can do:
- Continue to speak to your loved one - they can hear you, even if they do not respond
- Moisten their mouth with drops of water and try to position him/her comfortably
- Inform those that care about your loved one

Unfortunately, even after your loved one has died, you and everyone in your household will need to stay in quarantine for 14 days to prevent the virus from spreading to other people in your community.

Download information leaflet to hand to families [link [19]].

[19] https://palprac.org/wp-content/uploads/2020/04/PALPRAC-A-guide-to-caring-for-someone-who-is-in-their-last-days_hours-of-life-1.pdf

Addendum 2: VIRTUAL SUPPORT

Offering know patients support via teleconference or telephone is encouraged during the COVID crises.

- For advise on virtual consult etiquette [link [21]]
  [21] https://www.capc.org/blog/telemedicine-virtual-connection-age-social-distancing/
- See the updated HPCSA guidelines on telemedicine during COVID [link [22]]
  [22] https://www.hpcsa.co.za/Uploads/Press%20Realeses/2020/Guidelines_to_telemedicine_in_South_Africa.pdf

Addendum 3: MEET MY LOVED ONE

During the COVID crises families are unlikely to visit their loved ones in hospital or a care facility. This flyer allows families to tell health care providers something of their loved ones as well as confirming relevant contact details.

[link [23]] [23] https://palprac.org/wp-content/uploads/2020/04/PALPRAC_MEET-MY-LOVED-ONE_BW.pdf [black and white]

[link [24]] [24] https://palprac.org/wp-content/uploads/2020/04/PALPRAC_MEET-MY-LOVED-ONE.pdf [colour]

Addendum 4: DRUG CONVERSION TABLES

Drug	Conversion ratio from oral morphine	Equianalgesic dose to 30mg of oral morphine
Mist Morphine (Morphine syrup)	1	30mg
Morphine sulphate (SC)	2 to 1	15 mg
Morphine sulphate (IV)	3 to 1	10 mg

Example: To convert oral Mist Morphine 60mg in 24 hours to subcutaneous Morphine, divide 24-hour oral dose by 2 to give 30mg over 24hours. If the patient is in renal failure, use lower dosages.

Syringe driver prescription for a patient who has **not** been on opioids:
Morphine 15mg
Metoclopramide 30mg
Midazolam 10-15mg
0.9% sodium chloride or 'water for injection' to fill up the 20-50ml syringe
Infusion rate settings
For 20ml syringe: run @ 0.8ml/h continuously over 24 hours
For 50ml syringe: run @ 2ml/h continuously over 24 hours

Addendum 5: ESSENTIAL EQUIPMENT

- Ambulatory syringe pumps (syringe drivers) OR infusion pumps
- Butterfly needles (23G) / blue yellow IV cannula (Jelcos®) (22G or 24G)
- Alcohol cleaning swabs (Webcols™)
- Dressing tape (Micropore™)
- 50ml, 20ml and 3ml syringes
- Short IV infusion sets
- Normal Saline unit dose vials (UDVs) for flushing lines
- Nasal cannula/ prongs OR simple oxygen face masks