GUIDELINES FOR PALLIATIVE HOME CARE DURING THE COVID-19 PANDEMIC
A South African Context
August 2020

A guide for health professionals and families of COVID-19 positive patients requiring palliative care at home.
Acknowledgements

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Introduction

This document is an evolving document that has been created during the COVID-19 pandemic to support health professionals facing decisions around discharging COVID-19 positive patients' home for palliative or end of life care, and the families of those patients onto whom the care burden will fall. Although difficult decisions will need to be made regarding the distribution of resources and patients' access to these resources' care should not be compromised.

We, alongside the WHO, strongly advocate for all COVID-19 patients to have access to palliative care support and resources, for symptom control, psychosocial and spiritual care and where needed, for end of life care, no matter where they receive their care. The focus of these guidelines is the support and care in the community or home environment. Furthermore, we urge that the family members/informal carers of patients who do not have easy access to healthcare systems due to their geographical location be supported in providing adequate home care should the patient choose to stay at home or be unable to be transported to hospital. There needs to be support in place for these patients, and their families, accessible in the home environment to manage symptoms and prevent further infection and spread of the virus into the community.

The proposed guidelines aim to support health professionals when making difficult ethical decisions as well as address the practical needs of these patients and their families should they be discharged home for palliative or end-of life care; and will also include considerations around infection control if patients are discharged home COVID-19 positive or after recovering from COVID-19 infection. Due to the pandemic patients currently receiving palliative care support at home may find it challenging to access ongoing support and these guidelines can also help assist those patients and their families in the home environment.

The guidelines will have two sections, one aimed at health-care professionals and the other aimed at the families/primary caregiver who will be looking after the patients in the home environment.
The provision of palliative care and end of life care at home during COVID-19 will almost exclusively fall on household members, as existing palliative care services such as hospice and home-based care are unlikely to be able to offer support to many of these households due to:

- Already supporting high numbers of terminal non-COVID patients in the communities
- Stretched resources (equipment and staff)
- Not enough staff trained formally in palliative care
- Employees falling sick themselves and needing to self-isolate
- Lack the funding needed to increase their capacity to take on large numbers of extra patients

*(For more information on the healthcare challenges during COVID-19 please see Appendix A)*

Household members will need to be empowered to be able to deal with the challenges that this will bring, and palliative care services should aim for what is realistically achievable with the resources available.
UNDERSTANDING REFERRALS FOR PALLIATIVE CARE IN COVID-19

It is often the perception of those within the health professions, as well as the public, that palliative care is only necessary for those at the end of their life e.g.: hospice care. Although a large focus of palliative care is the terminally ill and the dying, the principles of palliative care can be implemented at all levels of healthcare to improve a patient’s quality of life, while living with illness.

During this COVID-19 pandemic it is important to integrate palliative care into the management of all patients to control symptoms, especially the symptom of breathlessness which can be very distressing for patients and their families to experience. Palliative Care is considered the active and total care of patients with life threatening or life-limiting disease, is given alongside curative care, and encompasses care for physical symptoms and psychosocial and spiritual burdens.

There is concern that during COVID-19 palliative care is seen to be offered as a result of an overburdened and under-resourced health care system, as a last resort or default method for patients. However, this should not be the case:

• In some situations, patients are offered palliative care and not intensive treatment because this is an appropriate choice of management, and one which will respect the patient’s wishes and needs, improve their quality of life and uphold their dignity.

• In other situations, patients may choose to remain at home for treatment and this is their personal wish, not a compromise due to lack of resources, and this should be respected (see the section on Ethical Decision-Making)

• All patients with COVID-19, not only “end-of-life” patients, should receive palliative care input to best manage their symptoms whether in hospital or the home environment.

• In cases where health systems may be overburdened and under-resourced it is even more important for patients and their families to have access to palliative care support and resources so they can be cared for in the home environment, safely and comfortably.

• All patients recovering from COVID-19 and COVID-19 complications or post-ICU syndrome (if they were ventilated) will also require Palliative Care and support during this longer road to recovery.

Through appropriate training, good education of health professionals, patients and their families and increasing awareness about palliative care and what it can offer patients, we hope to change these misconceptions surrounding palliative care and make it accessible to all.
Consultation with and teamwork between and within the department of health. CBOs/Hospices will be important in supporting patients and families. The WHO has released a helpful guide for CBOs to utilize during COVID-19- “Community-based health care, including outreach and campaigns, in the context of the COVID-19 pandemic, May 2020” which can be found at: https://www.who.int/publications/i/item/WHO-2019-nCoV-Comm_health_care-2020.1

**ETHICAL DECISION-MAKING CONSIDERATIONS DURING THE COVID-19 PANDEMIC IN SOUTH AFRICA**

“The greatest moral challenge posed by a pandemic is how to respect commitments to social justice in the face of the overwhelming and entrenched inequalities in health, well-being, and resources that will constitute the backdrop for, and the harsh realities of, any global outbreak of devastating disease” Ruth Faden (John Hopkins University)

Ethical dilemmas may arise when duties (e.g.: to the state, health care system, professional, personal), obligations and values conflict. Our efforts are to prepare and equip healthcare providers, families and patients to deal with foreseeable ethical dilemmas during this public health emergency, thereby promoting patient’s human rights, the integrity of health care workers and safe-guarding the short- and long-term capacity and functioning of the South African health care system, cognizant of the limitations of resources in the South African context.

Within the ethical framework, triage can be considered as an example of distributive justice as the intention is to facilitate fair healthcare burdens and benefits within a population. However, it is not infrequent for a conflict to arise in terms of balancing the clinical ethical considerations of utilitarianism, non-maleficence, beneficence and individual autonomy. While the objective of triage protocols may be to prioritise care and resource allocation to maximise population survival, this may not always be the case in practice. As such, in order to claim ethical legitimacy, the process of developing triage protocols must be transparent, inclusive (allowing for participation of all those who may be affected by decisions resulting from the process), evidence-based, and subject to critical review as new information becomes available. Additionally, one must remain aware that triage protocols during the COVID-19 pandemic are created as public health policies and therefore focus primarily on population-level health outcomes which in some instances, appear to undermine the interests and rights of individuals to the common good.

The Critical Care Society of South Africa (CCSSA) provide guidance for the triage of critically ill patients in the event that a public health emergency creates demand for critical care resources (e.g., ventilators, critical care beds) that outstrips the supply. It is expressly stated that “this allocation framework is grounded in ethical obligations that include duty to care, duty to steward resources to optimize population health, distributive and procedural justice, and transparency. It is consistent with existing recommendations for how to allocate scarce critical care resources during a public health emergency.”

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GUIDELINES FOR PALLIATIVE HOME CARE DURING THE COVID-19 PANDEMIC

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Decisions to transfer patients depend more on the resources available and likelihood of escalation of care being successful, than on whether the patient requests escalation of care. Thus, large proportions of the decision to escalate and de-escalate care during the crisis and surge phase will not be a strictly collaborative decision with the patient and their families. The availability of resources (and the replenishment of resources) will vary between regions as well as during different phases of the pandemic (surge or critical phases being the most constrained).

With the above in mind we propose the below flow diagram to guide and support Healthcare practitioners in different clinical settings when faced with Ethical decisions during the COVID-19 pandemic.

**Figure 1.** A triage (prioritisation) decision is a complex clinical decision made when ICU beds are limited.

The CCSSA recommends that triaging decisions be made by a triage team – and not the treating clinical team to ensure objectivity, conflicts of commitments and minimize moral distress. This requires then that each health care facility designate a triage officer or team. Decisions to transfer patients depend more on the resources available and likelihood of escalation of care being successful, than on whether the patient requests escalation of care. Thus, large proportions of the decision to escalate and de-escalate care during the crisis and surge phase will not be a strictly collaborative decision with the patient and their families. The availability of resources (and the replenishment of resources) will vary between regions as well as during different phases of the pandemic (surge or critical phases being the most constrained).
The following section is based on the flow diagram below.

**PROPOSED ETHICAL FLOW DIAGRAM**

**Figure 2:** Proposed Ethical flow diagram. Each pathway within the diagram is numbered and correlates to a full explanation which can be found under Appendix B. It is recommended that the flow diagram and the explanation are read in unison.
Never more than in this time of high anxiety and uncertainty, 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 when discussing the patient’s prognosis and advised care-plan:

- Always start by checking the patient/family member’s understanding of the situation and ask what they have been told before. Build upon their knowledge from that starting point. 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. Anticipate strong emotions such as: anger (due to sense of helplessness, paternalism, social injustice, nihilism), disappointment, fear and a sense of abandonment from the patient, their family.
  - Do not fear difficult emotions; allow them to be voiced.
  - Remember that these emotions are not directed at you but at the situation.
  - Try and have more than one team-member present for these difficult conversations, as support.
- Acknowledge emotion: NURSE acronym
  - Name emotion: ‘You seem to be upset/worried?’
  - Understanding: ‘Given what is going on, I can understand your concern.’
  - Respecting: ‘You have been really patient under difficult circumstances.’
  - Supporting: ‘I understand that this is very hard. We will be here to help.’
  - Exploring: ‘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…’. Rather focus on what you can do for the patient and commit to excellent symptom management, support referral and compassionate communication.
- Consider linking family telephonically or online to say a final goodbye.
MAINTAINING CONTINUITY OF CARE AND CO-ORDINATING DISCHARGES HOME

Patients that are receiving care in hospital for the treatment of COVID-19, will be discharged home back into the community. For most patients this will be a relatively easy process as they recover and go from strength to strength. However, for others such as: those who are already very ill with other health issues or terminal illness, those who suffer complications from COVID-19 or those who have had to undergo intubation in the ICU, the journey back to recovery may be a slow process and the reality is that some of these patients may even die at home. It is vital that these patients have access to palliative care support for symptom management at the very least and if required, end-of-life care that will be needed at home. Therefore, these patients need to be identified in hospital/in the community and, appropriate care support at home needs to be arranged.

PATIENTS THAT COULD NEED ONGOING AND INTENSIVE PALLIATIVE CARE SUPPORT AT HOME

- Patients with a life-threatening illness (not necessarily COVID-positive) who make the decision to be cared for at home without hospital admission.
- Patients who are cared for in frail care homes who become hypoxic but choose not to go to hospital and can be managed in their current care facility with oxygen.
- Patients with chronic health conditions who fall ill with COVID-19, are treated and are successfully discharged, but struggle with added symptom burden post infection (see the section on Ethical Decision-Making)
- Patients that suffer complications from COVID-19, such as strokes, heart-attacks.
- Patients with COVID-19 who have been intubated and successfully extubated in the ICU and then discharged from hospital but are needing supportive care and rehabilitation for ongoing symptoms at home.

IMPORTANT FACTORS FOR THE HEALTHCARE PROFESSIONAL TO CONSIDER AND ARRANGE WHEN DISCHARGING/CONTINUING CARE OF PATIENT’S AT HOME

- What home environment is the patient being discharged home to? This will influence how much extra support and resources are needed.
- Assess if the family understand the level of care needed for the patient in their current state and if they potentially worsen.
- What support does the patient have at home? Is there someone who will be able to take on the role of ‘carer’ at home. Provide the family with the appropriate health education and information needed for them to safely care for their loved one at home during COVID-19.
- Are there any other vulnerable family members in the household? Family will need to be educated on how to prevent the spread of COVID-19 to these vulnerable family members.
- Does the patient need input from a home-based care organization? And if so, ensure the family has the details for organizations in their area and send a referral letter for the patient to be registered with the organization.

- Is there a hospice organization or palliative care network that could provide home support? And if so, arrange an adequate discharge letter the patient can present to them. Most hospices will require a discharge letter or referral from the doctor involved with the patient.

- Is there a primary health care clinic that they could access for medical support and rehabilitation? And if so, ensure that the patient has the clinic’s contact details to request further assistance AND an adequate discharge summary from the referring hospital to present to the clinic.

- In order to prevent unnecessary hospital/clinic visits consider if the patient will need extra medication when going home, or if there is someone in their support system who will be able to fetch medication for them. And provide the patient with the enough stock of medication to take home/a script for enough stock to be collected at their nearest clinic. It is important to be aware of medications that might be unavailable due to demand and provide alternative medications in their place, so patients symptoms can be managed at home. (see the section on Palliative Care Homecare Symptom Management Guide).

- Ensure that if there is any emergency medicine that might be required by the patient/family at home, such as morphine for breathlessness, that the patient goes home with some stock or knows where to access these medications if they are needing them.

**CO-ORDINATING CARE**

When these patients are discharged into the community/choose to remain in the community for home care it is vital that the families are informed on how to provide this care safely at home. These patients should also be referred, where possible, to support organizations in the community.

- Contact the family prior to patient being discharged, this will happen telephonically. It is important that the family understands what will be required for the patient to be cared for at home, a main caregiver needs to be identified for the home care (see the section on infection control), therefore family “buy-in” is important for the process to work well.

- Making contact with the family allows us to give them vital information regarding infection control and symptom management at home, as well as address any anxiety they may have about taking their loved-one home, by answering their questions and explaining where to access support during this time. They can also be screened for symptoms of COVID-19 at this point.

- Ensure the patient goes home with the necessary medication to manage symptoms at home (see the section on: Palliative Care Homecare Symptom Management Guide for Health professionals)

- Send with the patient a clear discharge letter that the family can take to their local clinic for support with ongoing medication and advice if needed.
• Where possible refer the patient and family to home-based care support (NGO or hospice-based organizations)

• The idea of a ‘care bucket’ has been proposed by PALPRAC9 in their guidelines. These buckets would assist the families in maintaining infection control at home. (see Palprac guidelines at https://palprac.org/wp-content/uploads/2020/04/PALPRAC_Providing-Palliative-Care-in-South-Africa-during-COVID-19-Update-23-April-2020-1.pdf)

• Explore linking with known palliative care providers to set up a network of telephonic support for patients and families at home during the COVID-19 pandemic.
  » E.g.: In the Western Cape a network of volunteer palliative care providers has been identified and are making themselves available to assist doctors, patients and their families telephonically with palliative care advice.
  » And an online platform known as Vula is being used to make the referral of palliative care patients into the community more streamlined. Vula is an online service which, offers a secure format to discuss individual patient concerns. It is used throughout the country and requires less data than whatsapp and is more secure. The site can be accessed here: https://www.vulamobile.com/.

(See Appendix A for more information on Vula)
PALLIATIVE CARE HOMECARE SYMPTOM MANAGEMENT GUIDELINES FOR HEALTH PROFESSIONALS

This section will focus on the management of specific symptoms that could occur at home both in the COVID-19 positive patient and the dying patient. The following section is largely based on the PALPRAC guidelines “Providing Palliative Care in South Africa During the COVID-19 Pandemic” which can be accessed at: https://palprac.org/wp-content/uploads/2020/04/PALPRAC_Providing-Palliative-Care-in-South-Africa-during-COVID-19-Update-5-April-2020-3.pdf

ADVANCE CARE PLANNING

Every patient being cared for at home with a high risk for poor Covid19 outcomes should have had some form of an Advanced Care Planning (ACP) conversation with their health care team. 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.

As part of palliative care 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.

Guidance on ACP for health care providers can be found on the PALPRAC website by following this: https://palprac.org/for-healthcare-providers/palprac-advance-care-planning/

For a detailed preparatory document about advance care planning and guidance on how to start these conversations at home please see the following link to the Hospice Palliative Care Association of South Africa (HPCA) website: https://hpca.co.za/living-matters/

CHALLENGES IN THE COVID-19 PANDEMIC

• In a pandemic situation time for discussion with patients and families may be limited.

• Limited health care resources in the pandemic may impact decisions around escalating care and make triage decisions about what level to seek care at even more important.

• Clinical Deterioration may be rapid and unexpected
RECOMMENDATIONS DURING THE COVID-19 PANDEMIC

• The urgent implementation of ACP at diagnosis of COVID-19, or ideally even before for all patients with co-morbidities or who are nearing the end of their lives.

• If it is not possible to do a full advanced care plan at a minimum discuss what patients would prefer to do should they develop symptoms of moderate or severe COVID-19 infection (e.g. remain at home with supportive care or go to hospital, specific wishes around ventilation if patient has strong preferences etc.). Make a clear note of the decision and the name of their designated health care proxy (decision maker).

• These conversations may need to be revisited at critical points in the illness trajectory (e.g.: shifting from mild to moderate or severe infection) for example, when considering the escalation of care to ICU or intubation, before these changes are made to management.

• Sharing the following information regarding COVID-19 infection with patients and families to help inform ACP:

1. 80% will develop a mild illness, 15% will develop severe disease and 5% become critically ill and may die.

2. The severity of COVID-19 infection increases with age and with the severity of any underlying medical co-morbidity.

3. If appropriate, discuss the realities of CPR, ventilation and the possibility of a low chance of successfully being taken off ventilation and even after successful ICU treatment there is a likelihood of a long road of rehabilitation. (See the section on Ethical Decision-Making)

4. If admitted to hospital, patients will not have access to their loved ones and might even die without being able to physically say goodbye

5. 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.

6. Any up to date information about what the local inpatient services are able to offer in terms of capacity (available beds) and supportive care (e.g. oxygen/ventilation) may help inform decisions.
MANAGING SYMPTOMS AT HOME TO ENSURE PATIENT COMFORT

*Note: This guide addresses symptom management only, not the acute pharmacological management of Covid19 infections.

The most common distressing symptoms that patients could experience are fever, breathlessness, anxiety and agitation. If patients are being cared for at home the families need to be educated on how to manage these symptoms in the home environment, which will include pharmacological and non-pharmacological management of these symptoms.

The family will need support and advice from health care professionals; a hospice or home care service can provide this advice or a general practitioner. In some cases, health care professionals who have recovered from COVID-19 themselves are available to go into the home to provide hands on assistance or otherwise, the home care service can assist when wearing full PPE (Hospice, HBC organisation, GP) may provide telephonic advice. Section 2 of these guidelines are aimed at families and primary caregivers and describes advice for family members/primary caregivers providing care in the home environment during COVID-19.

NON-PHARMACOLOGICAL INTERVENTIONS

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Intervention</th>
</tr>
</thead>
</table>
| **Fever**     | Remove excess bedding/cover  
                 Tepid sponging or cool cloth to forehead and back of neck               |
| **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.  
                 Self awake proning has been shown to be helpful in those who are able to turn (https://youtu.be/f-AkBQ9CvGA) |
| **Agitation/delirium** | 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: calm communication; provide patient with sips of water; check if mouth care is required; keep the patient comfortable according to standard nursing care. |
PHARMACOLOGICAL INTERVENTIONS

In the home environment there are three main ways that medication can be administered to the patient:

1. The oral route is the easiest and preferred route if the patient can swallow, and the family can also administer.

2. Continuous Subcutaneous medication via a syringe driver, if patient unable to swallow. It needs to be commenced by a doctor or nurse, and the family needs to be educated on how to monitor the machine. Syringe drivers are currently in short supply in the community.

3. Subcutaneous doses of medication given as a bolus via a butterfly needle. The butterfly needle can remain in-situ for up to 10 days, as long as the area of insertion is checked daily. It needs to be commenced and managed by a doctor or nurse. A family member could be trained in how to give bolus doses periodically, provided they receive the appropriate training and demonstrate competency.

1. Oral medication

Below are the starting doses for each symptom; COVID-19 symptoms might advance rapidly, needing dose escalation.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fever</td>
<td>• Paracetamol 1000mg 6hrly PO PRN OR</td>
</tr>
<tr>
<td></td>
<td>• If patient is unable to swallow: Paracetamol 500-1000mg PR 6hrly (available as paediatric 250mg suppositories).</td>
</tr>
<tr>
<td>Anxiety</td>
<td>• Preferred: Lorazepam 1mg-2mg s/l q2h prn until patient has settled then 6-12 hourly PRN OR</td>
</tr>
<tr>
<td></td>
<td>• Alprazolam 0.5-1mg 8hrly prn OR</td>
</tr>
<tr>
<td></td>
<td>• Diazepam 2.5mg-5mg PO until settled, then 12 hourly OR</td>
</tr>
<tr>
<td></td>
<td>• Clonazepam 0.5mg po 8hrly prn</td>
</tr>
<tr>
<td>Breathlessness</td>
<td>• Low dose opioids are the mainstay in managing the symptom of breathlessness</td>
</tr>
<tr>
<td>(dyspnoea)</td>
<td>• Morphine syrup (Mist Morphine) 2.5-5mg PO hourly until symptoms settle and then 4hrly ongoing. Doses as low as 1mg has been shown to be effective.</td>
</tr>
<tr>
<td></td>
<td>• Alternative: low dose fentanyl, starting at 12mcg/h every 72hours (note: only starts working after 8-12hours – start with bolus morphine)</td>
</tr>
<tr>
<td></td>
<td>• Scripting oral morphine:</td>
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<tr>
<td></td>
<td>» The amount of morphine syrup will vary depending on the strength/concentration at which it is mixed: 5mg/5mL (give 1-5mL), 10mg/5mL (give 0.5-2.5ml).</td>
</tr>
<tr>
<td></td>
<td>» Specify concentration and volume to be administered and dispensed e.g. Mist Morphine 10mg/5mL: give 0.5 ml PO 4 hourly. Dose can be increased to a maximum of 2.5ml PO 4 hourly. Issue 100ml (hundred millilitres).</td>
</tr>
<tr>
<td></td>
<td>• Possible side effects:</td>
</tr>
<tr>
<td></td>
<td>» Nausea: metoclopramide 10mg 8h po</td>
</tr>
</tbody>
</table>
**Constipation:** When patients are more bed bound and are taking any form of pain medication including panado and morphine, constipation is one of the unfortunate side effects that does not resolve and requires constant monitoring and management. Patients should be having a bowel movement every 3 days at least, even if **ONLY** taking in fluids and softer foods. The result of constipation can be increased pain, nausea and confusion with abdominal discomfort. It is, therefore, standard practice to **ALWAYS** prescribe a stool softener with a stimulant laxative to be taken daily, when commencing a patient on morphine:

- Stool softener: lactulose 15ml bd po/30mg d po, Sorbitol 15ml bd po/30mg d po
- Stimulant laxative: Senna 2-4 tabs nocte po, Bisacodyl 2 tabs nocte po
- If a patient is unable to swallow/if a patient has had no bowel movement after 3-4days suppositories can be used to help stimulate the bowels: Glycerine x1 suppository per rectum (softener) with Dulcolax x1 (stimulant) suppository per rectum (given one after the other).
- Patients can also be encouraged to increase water intake if possible, add some fruit to their diet such as stewed prunes, and where possible try to mobilize in and out of bed to help stimulate the bowels.
- If the patient is dying, their oral intake will naturally decrease, and they will naturally need less laxation and so this will decrease the need for the laxatives during the dying phase.

**Home oxygen** is the main supportive treatment of Covid19 when hypoxia (sats <95%) is present. In and off itself, it will not improve the sensation of breathlessness unless hypoxia is severe.

Escalate according to need
- Nasal cannula administration is first line (2-6L/min).
- Face mask 40% (6-8L/min)
- Reservoir mask (flow to fill reservoir bag)

In the unresponsive dying patient, titrate oxygen down with intention to stop, while still managing breathlessness.

Home oxygen is available privately through medical aid schemes and in many of the frail care homes and from some hospices (PMB, no blood gasses needed, only saturation measurement). However, in poorer resourced areas obtaining home oxygen will be a challenge.

**Agitation or delirium**

Use medication only if the patient is distressed, hallucinating or danger to self or others.

**Haloperidol** 0.5mg po q1h until settled; then q4h prn (or SC bolus) (preferred; often unavailable) OR

**Risperidone** 0.25mg-0.5mg po bd OR

**Olanzapine** 2.5mg-5mg po bd (or SC bolus) OR

**Quetiapine** 12.5mg-50mg po bd OR

**Ziprasidone** 10mg IMI
2. 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 home setting when the patient is unable to swallow oral medication. These battery-operated machines are set up in the home environment by a community GP or hospice nursing sister who are trained in how to operate and monitor them in the home environment.

Before commencing the syringe driver, a stat dose of medication would need to be given to begin managing the symptoms while the syringe driver takes effect:

- **Dyspnoea**: Morphine Sulphate 1-2mg SC stat
- **Anxiety**: Midazolam 2.5mg-5mg SC stat
- **Agitation**: Haloperidol 2.5mg- 5mg SC stat
- **Nausea**: Metoclopramide 10mg SC stat

Then for a 24-hour subcutaneous infusion, using a syringe driver at home, combine the following for symptom control:

- Morphine 15mg **with**
- Metoclopramide 30mg (to counter any nausea due to morphine) **with**
- Midazolam 10-15mg

**And/or** Haloperidol 2.5mg-5mg

*Haloperidol can be used for nausea as well as restlessness and can replace metoclopramide for nausea, if available.*

**Note:**
- Follow instructions of specific device
- Reassess and adjust rate if the patient is not comfortable or give additional breakthrough doses (1- 2.5mg morphine and 2.5mg midazolam stat SC)
- 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 start at a lower dose and in those with complete renal failure PRN medication may be indicated.
- **Alternatives to morphine if available** - Fentanyl transdermal patch 12mcg-25mcg/h change every 72 hours. Dose calculations need to be carefully made as per SAMF, remembering that Fentanyl is 100-150 times the potency of oral morphine. It may take up to 8-12 hours to be effective which requires additional subcutaneous Morphine boluses to be given 4hrly for the first 6-12hours.
3. **Subcutaneous bolus administration route when no syringe driver available and patients are unable to swallow**

If a patient is unable to swallow and no syringe driver is available, they may need to receive their medication via a subcutaneous butterfly needle, left in place, to give bolus doses of medication. In this case it would be best to contact the clinic Dr or hospice nurse if available to commence these medications at home and assess if there is a family member able to assist with the administration of these medicines.

Below are the starting doses for each symptom; COVID-19 symptoms might advance rapidly, needing dose escalation.

Subcutaneous bolus doses of medication are given over 30s-1min (depending on volume administered) via an indwelling butterfly/cannula and then flushed with 0.5-1ml of 0.9% NaCl after each use.

### Bolus dosing of medication to control symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Dosing Protocol</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dyspnoea</strong></td>
<td>Morphine 1-2mg SC q1h until symptoms are controlled; once controlled switch to regular 4-hourly dosing (typically 1.0 - 2.5mg 4hrly SC) increase dose by 25% once per 24 hours, if symptoms are not controlled.</td>
</tr>
<tr>
<td><strong>Agitation/restlessness</strong></td>
<td>Haloperidol 2.5mg over 24hrs via CSCI/SC, doses may need to be repeated according to symptoms.</td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td>Midazolam 2.5-5mg SC every hour until symptoms resolved/patient is settled, regular dosing may be required for ongoing severe dyspnoea causing anxiety/panic.</td>
</tr>
<tr>
<td><strong>Nausea and vomiting</strong></td>
<td>Metoclopramide 10mg 8hrly SC or PRN, depending on symptom assessment</td>
</tr>
</tbody>
</table>

**Note:**

- Alternatives to morphine if available - Fentanyl patch 12mcg-25mcg/h change patch 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, if there is no-one available to commence a syringe driver or give bolus doses of medication.**
- Morphine IMI injections are not appropriate in this setting! Subcutaneous infusions or injections are less painful and more steadily and reliably absorbed.

**Equipment required for subcutaneous therapy**

- Ambulatory syringe pumps (syringe drivers) OR infusion pumps AND/OR
- Butterfly needles (23G) / blue yellow IV cannula (Jelcos®) (22G or 24G)
- Short IV infusion sets (perfusor lines) for syringe pump use (can use butterfly alone if unavailable)
- Alcohol cleaning swabs (Webcols™)
- Dressing tape (Micropore™) and (if available) see-through dressing such as Hydrofilm to secure butterfly needle
- 60ml, 20ml, 10ml and 3ml syringes (the syringe size used for the infusion will depend on the type of syringe-driver pump being used, as well as the volume needing to be infused)
- Normal Saline unit dose vials (UDVs) for flushing lines
- Nasal cannula/ prongs OR simple oxygen face masks (if oxygen in use)

**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. If the patient is confused, the upper back area over the scapula can also work.
5. The 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.
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.
### Drug conversion tables

<table>
<thead>
<tr>
<th>Drug</th>
<th>Conversion ratio from oral morphine</th>
<th>Equianalgesic dose to 30mg of oral morphine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mist Morphine (Morphine syrup)</td>
<td>1:1</td>
<td>30mg</td>
</tr>
<tr>
<td>Morphine sulphate (SC)</td>
<td>2:1</td>
<td>15 mg</td>
</tr>
<tr>
<td>Morphine sulphate (IV)</td>
<td>3:1</td>
<td>10 mg</td>
</tr>
</tbody>
</table>

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

Management of **other commonly experienced symptoms** (pain; nausea and vomiting) See HPCA Clinical guideline

### End-of-life signs and symptoms: Normalizing signs of death

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 in PALPRAC guidelines, link provided above).
- Assessment of the patient and family resources and needs, especially spiritual needs.
- Provide appropriate care in accordance with patient preferences and facility/home resources to provide care.
- Compassionate information about symptoms that might develop and how to manage them (see the information leaflet for family and primary care givers under section 2: End of Life: Changes to expect).
- Discontinue all non-essential, non-beneficial procedures 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 subcutaneous Morphine Sulphate by dividing the total 24-hour dose by 2 and administer in divided regular bolus doses or as a continuous infusion (see detailed notes above on subcutaneous medication for symptom control).
  - **Nausea and vomiting:** Metoclopramide 10mg 8hrly SC/PO or Metoclopramide 30mg over 24hrs via CSCl
  - **Respiratory secretions:** Hyoscine Butylbromide 20-40mg SC every 4 hours or via CSCl over 24hrs.
» *Agitation/restlessness/delirium:*  
  a) Lorazepam 1-2mg 8hrly/PRN via SL/SC **OR**  
  b) Diazepam 2.5mg-5mg PO 12 hrly **OR**  
  c) Midazolam 5mg every hour SC until symptoms settled **AND**  
  d) Haloperidol 2.5mg added to CSCI over 24hours.

- Feeding and hydration - Advise the family that in the last few days/weeks food and fluids do not improve quality of life, survival or symptom burden at the end of life and should not be given as routine management. Rather offer soft food if the patient wants this and sips of water if the patient is able to swallow. If the patient is not able to swallow moisten the lips and mouth with sips of water or ice chips and use petroleum jelly on the lips.

- Nursing care: encourage position change every 4-6 hours to prevent discomfort in areas of pressure. Gentle bed washing care as required. Oral care - remove secretions using a soft moist cloth or mouth swabs if available.

- These principles are appropriate whether in hospital, in a care facility or at home.

**Social issues:**

Patients may have social issues/concerns that could impact their care at home and their end of life journey if left unsupported. These could take the form of:

- Social grant issues
- Guardianship of children
- Wills not yet finalized
- Substance abuse in the household
- Conflicted relationships
- Limited family support.
- Power of Attorney for financial matters
- Stigmatization *(Please see appendix C: Acknowledging the impact of stigma during the COVID-19 pandemic)*

These need to be explored with the patient so there can be an attempt to resolve/improve them while there is still time to do so. Patients should be referred to social workers in the community or linked to the hospitals/clinics who can try and assist patients and families.

In the resources section below there is a list of contact numbers that families can access for additional support.

**Patients must be encouraged to:**

Acknowledge their experience with COVID-19, and the impact it is having on their health. Seek counselling and support where they can for extra support through a difficult time.

**Spiritual and Emotional distress:**

Many families have existing spiritual support structures such as religious/faith community leaders, family members or friends who play a mentorship role or who share religious/spiritual beliefs or outlooks.

Local resources such as hospices and primary health care or social service facilities may be able to provide access to spiritual and psychosocial counselling for patients and families.

Families should be encouraged to seek support that is culturally acceptable to them, this may be restricted to their existing faith-based support structures.

In the context of COVID-19 infection control and isolation measures will present additional obstacles to accessing support BUT telephonic or online counselling can be accessed. Simple practical options such as having a conversation outdoors with appropriate social
distancing for patients who are able to manage that or for family members. 

**Medical care providers can refer to:**

COVID-19 Palliative Care Counsellor’s Database by emailing
Welly den Hollander (secretary: S A Oncology and Social Workers’ Forum)

wellydenholl@gmail.com
+27-798726408

Link to PALPRAC webinar on Providing Spiritual support during COVID-19

https://vimeo.com/412017507/0f4b8169e2
DEATH IN THE HOME: WHAT TO DO DURING COVID-19

*This information is based on current South African Government Regulations \(^{16,17,18}\) and information from the WHO \(^{19}\)

It is important to respect the dignity and sacredness of the deceased, their cultural and religious traditions, as well as their families.

However, given the pandemic’s threat to public health, the desired burial norms of the deceased and their families’ may be curtailed and restricted. It has been cautioned that the deceased’s body may still be a source of COVID-19 infection and the strictest infection control measures should continue to be observed by the relatives having cared for the patient, and all involved in handling of the deceased’s body thereafter. This section has been included here so that HCPs are equipped in how to support family members at such a time.

Once the family members recognize that their loved one has died, they should:

- Respectfully cover the face and body of the deceased at home – with a sheet or other suitable covering, wearing a mask and gloves if possible and wash hands thoroughly afterwards
- Maintain strict infection control
- Limit access to the room housing the deceased
- Be discouraged from touching or moving the deceased’s body – wait for the undertakers
- Be discouraged from allowing extended family or friends from visiting the deceased’s home even in paying their respects.
- Be discouraged from washing or preparing the body for burial due to the risk of infection (If a family member would like to be involved in the washing of the deceased prior to the burial then this must be done under the guidance of the religious/cultural group that has been trained on the correct use of PPE for the procedure.)
- Not delay in contacting the following agencies (and inform them that the patient has been confirmed to be COVID-19 + or was suspected of having COVID-19):
  1. Emergency Medical Services (EMS) - to complete the death notification form (which will be left with the family)
  2. South African Police Service (SAPS) – to complete the SAPS 180 form – this is necessary to have the body removed. (This form will also be left with the family)
  3. Undertaker of choice – to facilitate the appropriate wrapping of the deceased, collection of the body and documentation, and transfer to the appropriate mortuary. The undertaker should be trained in managing COVID-19 decedents and should wear the appropriate PPE. Undertakers will double bag and decontaminate the outer bag for the safe transportation of the human remains. Deceased will be transported in the undertaker’s vehicle.
- If the deceased’s cause of death was likely due to COVID-19 however formal testing had not been carried out, then the local clinic should arrange to perform a nasopharyngeal swab post-mortem on the deceased with the family’s consent. This can occur up to 3 days post-mortem
- Explain the death of a loved one to children affected (request assistance from local clinic or social worker if required)
Once the deceased’s body has been collected from the home:

- Belongings of the deceased and all surfaces that the deceased was in contact with must be thoroughly disinfected: washed with a chloride solution such as 0.5% bleach or a solution containing at least 70% alcohol. The deceased’s clothing should be washed with warm water (60-90°C).

**THE BURIAL CEREMONY/ FUNERAL**

- A funeral is not considered a prohibited gathering
- Embalming is not recommended to avoid excessive manipulation of the body.
- The deceased’s body is not to be touched even though in plastic. A mask must be worn if in close contact with deceased or if viewing the body. People viewing body to wash hands with soap and water and disinfect hands with 70% alcohol following the viewing.
- The holding of night vigils is prohibited.
- Burial or cremation should take place within 3 days
- To avoid bottlenecks in scheduling funerals, family members are urged to consider weekday services
- Limits have been placed on the duration of the service (1 hour) and attendee numbers (50 only)
- It is recommended that only immediate family of the deceased attend the service. Those older than 60 years, immunosuppressed or with respiratory diseases should not have contact with the deceased to reduce their risk of contracting coronavirus. Any mourner who is showing COVID-19 symptoms should not attend the funeral as they pose a risk to others - remote participation (live streaming) should be considered
- Social distancing (>1.5m) needs to be observed – which affects seating arrangements and embracing of fellow mourners. Furthermore, social gatherings/cleansing ceremonies/ traditional feasts after the burial service are not allowed.
- Gloves and masks to be worn when coffin is placed in the grave. The gloves and masks are to be disposed of in a sealed bag or dustbin. Hands must be washed with soap and water thereafter.

**IMPORT AND EXPORT OF HUMAN REMAINS WHO DIED OF COVID-19**

It is preferable for the human remains to be cremated. Repatriation of confirmed or suspected COVID-19-19 human remains must be in line with the Regulations relating to the management of human remains (Regulation 363 off 22 May 2013). The human remains can only be imported/exported following a permit from the Director-General: Health made by Department of International Relations and Co-operation (DIRCO). Permit, death certificate and declaration stating that human remains is not a health hazard must accompany the human remains.

*Export of human remains who died of COVID-19*

The undertaker will transport the human remains from the mortuary. AN environmental health practitioner (EHP) will monitor the handling and removal of human remains by the undertaker.

*Import of human remains who died of COVID-19*

EHP to inform undertaker upon arrival of human remains. EHP to monitor removal and handling of human remains.
These guidelines serve as a basic guide for bereavement care of family members who have lost a loved one due to COVID-19 and should be introduced within the framework of existing bereavement theories and models.

**UNDERSTANDING THE CONCEPTS**

- Bereavement is the response to a loss.
- Grief is the interpersonal expression of the bereavement. Grief is the result of loss.
- Anticipatory grief is the grief we experience in anticipation of death. It is also grieving the secondary losses associated with the pending death.
- Complicated grief is when a person is stuck in grief and unable to perform as close as possible to his/her pre-death psychosocial functioning. The challenges experienced by a COVID-19 death have the potential to lead to complicated grief which should be addressed by an experienced therapist.

**COVID-19 BEREAVEMENT CARE CHALLENGES**

The challenges that have to be faced when living in the midst of the COVID-19 pandemic has at its core the reality that death is or could be possible, and thus requires HCP’s to be prepared to face the challenge of having to be more willing and prepared to have difficult conversations, where loss and grief will form the core themes of the narrative that has to be shared. This is indeed challenging at the best of times and now even more so in itself in this time. Dealing with loss and grief is a complicated matter especially when deaths are perceived as being “bad deaths”: patients have pain, the death is sudden, the family feel things could have been done differently etc. COVID-19 deaths are likely to be perceived as “bad deaths” due to the patient dying in hospital (often suddenly), isolated, without family contact, with breathlessness and pain, and often with invasive treatments in place, e.g.: mechanical ventilation. The stress and trauma around these deaths for families means that the death is perceived as “bad” and the patient perceived as suffering and therefore managing loss and grief in the face of a COVID-19 death can even be more complicated. Added to that are the challenges, listed below, in providing ongoing bereavement support during the current COVID-19 pandemic:

- The need for self-isolation (and quarantine if indicated) lead to breakdown or potential breakdown of family household relationships.
- Regular/familiar support structures (e.g. family, friends etc.) are not available to patients.
- Regular access to support activities (e.g.: sport, worship) are not available to patients/families.
- Travel restrictions and limitations on funerals/memorials/mass gatherings mean that people have limited access to their usual ways of processing loss and grieving for loved ones.
- Possible multiple deaths in a household/community create trauma and anxiety and can complicate the grieving process.
- Feelings of guilt, anger and blame could surface if a household member was seen to be the one “brining COVID-19” into the house (stigma).
- Financial constraints and other personal stressors families are experiencing during this time mean that they might not be able to grieve the death as they usually would.
• Counselling (if needed) will have to be done remotely and this can challenge the establishment of supportive relationships. It would be good to take note of some of the challenges of digital counselling should you have to counsel remotely:
  » Ethical considerations, such as confidentiality.
  » Access to digital resources, specifically in remote/rural areas.
  » Financial constraints.
  » Challenges in observing non-verbal communication.

MANIFESTATIONS OF GRIEF

Grieving the death of a person due to COVID-19 does not differ from what is regarded as normal grief. The bereaved person reacts to his/her grief in many ways:

• Physically: People who grieve may experience the following physical symptoms: Dry mouth, tightness in the chest and throat, butterflies or the feeling of a "hole" in the tummy, loss of energy, loss of appetite, loss of sexual drive, change in sleeping patterns

• Emotionally: Numbness, yearning, sadness, anger, guilt, anxiety, loneliness, and a feeling of relief are some of the expected emotions that the bereaved person can experience.

• Behaviour is often the way a person expresses his/her emotions. A person may be passive or overly active, crying and sighing, indecisiveness, lack of concentration, mood swings, and sometimes increased use of substances.

• The cognitive ability of the bereaved person could also be affected. It manifests in the following: denial, disbelief, shock, confusion, sensing the presence of the deceased, and sometimes a preoccupation with the deceased.

• A bereaved person’s spiritual well-being can also be affected by the bereavement. Loss of faith, finding comfort in faith, a search for meaning, and alienation are some of the ways that grief can manifest.

BEREAVEMENT IN COVID-19

Due to the infectious nature of COVID-19 families may not be able to mourn their loved ones as they usually would. Below are some suggested bereavement care guidelines that can help you support the family after a COVID-19 death:

• Families will not be allowed to touch the body of the deceased as we often want to do in times of death. Speaking to the deceased is one of the limited means to say goodbye. Support the family in writing a goodbye letter to the deceased which can then be placed in the coffin. This can help to ease the pain of unfinished business between the deceased and the bereaved person.

• If the patient has passed away in hospital and if appropriate, the staff could take a photo of the deceased which could be shown to the family, to verify the death as well as give the family some closure.

• Normalize their grief but be careful not to downplay their complicated experience.

• Allow them to acknowledge their feelings, as you would in non-COVID-19 deaths.

• The relationship between the deceased and the bereaved person is of importance. Using the empty chair technique to encourage the family to stay connected to the wisdom and wishes of the deceased by using words like: “If we had Martha sitting in this chair now what do you think she would say to you now in this situation?” This can remind them of the fact that death does not separate them from the relationship...
they had with their loved one.

- Reflect with them on some of the memories and thoughts they have about the deceased person, that they honour and value. This can help to encourage a new but different relationship with their loved one. They can “check in” with the memory of their loved one when they need to and be sustained by it, while remembering the values, ideas and lessons learned from the deceased over time.

- Respect the cultural rites of the family members as far as possible within the COVID-19 regulations.

- Link the family members with undertakers who are skilled in the funeral procedures and who will provide support with the practical aspects of these processes such as funeral/cremation arrangements.

- Familiarize yourself with the national guidelines for undertakers if you are uncertain of what to do.

- Consult with faith leaders and funeral directors about the live streaming or video recording of memorial services and burials to include as many family and friends as possible.

- Always adhere to the national COVID-19 funeral regulations

- Link the family with financial resources, where to find food, and how to access emotional support. Remember that the community who is usually a strong support during a time of death, will be restricted in the support that they can provide.

- Encourage the close family members to accept help from other family and friends to assist with the practical aspects of the funeral/cremation. For example, ask a family member or a friend to assist with a list of potential people to invite to the funeral, ask someone to arrange the flowers, and call on community members to provide food for those attending the funeral – always within the funeral regulations for the duration of COVID-19.

- Link the family with bereavement support in their community.

- Create a “memory corner” or set up a “mourning corner” in the house with a picture of the deceased person where members of the household can have time to grieve on their own or together.

- Discuss options for tele/web-based counselling, while isolation regulations are in place. E.g.: Fellow bereaved may be able to support others telephonically, and elderly people especially (who may not have access to/understand how to use web-based programs) could be linked to a “telephone support buddy” during this time.

- Encourage “shared rituals” which could be implemented across households that may be far apart, to help the grieving process and so the loved ones feel connect to each other e.g.: each household light a candle at supper time and remember the deceased.
RESOURCES THAT CAN BE ACCESSED BY PEOPLE IN THE HOME ENVIRONMENT FOR BEREAVEMENT SUPPORT

You are encouraged to seek support during your bereavement. The following organisations and individuals may be able to provide a service.

- HPCA Psychosocial App (in development at this stage)
- Psychologists
- Counsellors
- Church communities
- Hospices: Refer to the HPCA website or the resources guide at the end of these guidelines for contact details of Hospices and their location. [www.hpca.co.za](http://www.hpca.co.za)
- Link for the PALPRAC video webinar on grief and bereavement during COVID-19: [https://vimeo.com/412017196/45349c8f7e](https://vimeo.com/412017196/45349c8f7e)
<table>
<thead>
<tr>
<th>FOR FAMILIES/PRIMARY CAREGIVERS</th>
<th>SECTION 2</th>
</tr>
</thead>
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**INFECTION CONTROL IN THE HOME ENVIRONMENT**

*This information, on how to maintain infection control and prevent the spread of COVID-19 within communities, is based on guidance from the WHO\textsuperscript{24,25,26} as well as the Department of Health\textsuperscript{27} and adapted for the South African Context.

This section will cover the important aspects of infection control at home and can be given to the families as a guide to take home.

**HOUSEHOLD MEMBERS**

**The patient**

The patient must be included in all health decisions and guidance taken from them regarding their care at home.

**The caregiver**

The caregiver is defined as the person who will be designated to look after the patient at home (family member, carer, community support) for the majority of the time, until they recover or pass away. They will be the one who attends to the patient’s daily needs and assists them with all tasks. The number of caregivers that attend to the patient should be as few as possible to reduce the risk of exposure and spread of COVID-19. To limit this risk, the caregiver should:

- Be younger than 55yrs old.
- Have no other health issues to put them at risk (e.g.: uncontrolled high blood pressure, diabetes, HIV positive not on ARVs, on steroids long-term)
- Be available at home to assist the patient when needed during the day and night.
- Restrict mixing with others socially, at shops or using public transport.

**The vulnerable family members**

These are family members staying in the same house as the patient that are going to be at risk of contracting COVID-19. They are:

- Anyone 55yrs and older.
- Anyone of any age with pre-existing health conditions such as: high blood pressure, diabetes, COPD, TB or HIV, cancer patients on active treatment and any uncontrolled chronic medical condition.
- Pregnant women

These family members should seek advice from their clinic or healthcare provider regarding their respective risk and will need to adhere strictly to the recommended infectious precautions of wearing their masks, socially distancing and handwashing and sanitizing in the house.
**Items needed to maintain infection control while performing care at home**

The following will need to be available at home for the caregiver to be able to care for the patient:

**Essential items**

- Masks: cloth fabric masks made of 3 layers, if surgical masks not available
- Refuse bags/buckets with a sealable lid for waste
- Access to clean water—this can also be from communal water taps or even homemade water stations ("Tippy Taps") which can provide running water (see this video by UNICEF for guidance on how to make your own "Tippy Tap": [https://www.youtube.com/watch?v=6F9jcA8ZAI0](https://www.youtube.com/watch?v=6F9jcA8ZAI0))
- Access to bleach for sanitizing

**If possible**

- Face shield to protect the eyes (see resources section for information on how to create your own homemade face-shield)
- Gloves: Medical gloves may be expensive to buy ongoing and if you are performing handwashing then it is not essential to have gloves, but plastic kitchen gloves could be used and washed and dried after each use. **However, it is important to remember that gloves do not replace handwashing.** So, hands must be washed thoroughly after gloves have been removed. And if gloves are discarded at any point they will need to be put into a sealed bag and disposed of as described below.
- Protective Apron:
  - Any dress, gown or designated outfit that can be washed and will protect other clothing and cover your arms and legs. To be used ONLY when caring for the patient and to be removed and washed daily (it might be an idea to have two sets of protective wear so one can be used and the other washed)
  - Or a black refuse bag, cut at the top for the face and sides for the arms (see resources section for tips on how to make).

**WASTE/GARBAGE MANAGEMENT**

- Gloves, masks, and other waste generated during home care should be placed into a waste bin lined with a bag and closed with a lid in the patient’s room.
- All waste generated must be put in double plastic bag. As per government regulations and recommendations, the bag is left outside for 5 days and can then be discarded with the other household waste.
- Where waste collection is difficult it is important that the waste is kept in sealed bags, double bagged and away/separate from other household waste, to prevent the virus spreading.
- Or if hospice is visiting, they can collect the waste and dispose of it in their waste containers, removed by the designated waste removal company

**ALWAYS WASH HANDS AFTER HANDLING THE WASTE**
PROTECTING AND SCREENING THE DESIGNATED CAREGIVER

The caregiver at home will need to be protected from getting the virus and screened regularly according to most recent screening criteria, to assess if they have the virus.

- Two main forms of protection will be handwashing and wearing of a mask.
- The caregiver can screen themselves for signs and symptoms of COVID-19: sore throat, coughing and fever (temperature 38 and over) are a few of the common symptoms one might experience. If any of these symptoms are present it is likely COVID-19 and they would need to self-isolate.
- If the caregiver showed any signs of difficulty breathing, chest pain or confusion they would need to go to their nearest clinic for assessment and advice. In that case a new caregiver would need to be identified for the very ill patient at home.

READYING THE HOME ENVIRONMENT FOR THE ILL COVID-19 POSITIVE PATIENT

The room

- The patient should be in a room alone wherever possible. Household members should stay in a different room or, if that is not possible, maintain a distance of at least 1 metre from the ill person (e.g. sleep on a bed on the floor/in another room if possible).
- Place the patient in a well-ventilated single room (i.e. with open windows and an open door), in winter, open windows 10 minutes every hour to air the room.
- Limit the movement of the patient in the house and minimize shared space. Ensure that shared spaces (e.g. kitchen, bathroom) are well ventilated (keep windows open).
- Caregiver should minimize the time in the room with the patient, not more than 15 minutes at a time if practical.
- Perform hand hygiene after any type of contact with patients or their immediate environment. A wash station can be created using a bowl of water with soap, placed outside the room to prevent the caregiver touching other items along the way to the bathroom/taps. Sanitizer can be placed in the patient’s room, to be used before the caregiver leaves the room, before washing hands outside the room.
- Clean and sanitize surfaces regularly (at least four times a day) that are frequently touched in the room where the patient is being cared for, such as bedside tables, bedframes, and other bedroom furniture, daily. Regular household soap or detergent should be used first for cleaning, and then, after rinsing, regular household disinfectant such as bleach or jik or any cleaning product containing 0.1% sodium hypochlorite (i.e. equivalent to 1000 ppm) should be used, you can use six (6) tablespoons of bleach mixed with four (4) cups of water.
- Avoid other types of exposure to contaminated items from the patient’s immediate environment (e.g. do not share toothbrushes, cigarettes, towels, washcloths, or bed linen).
The bathroom

- **Shared outdoor communal bathrooms**
  » If these need to be used then the patient needs to wear a face mask at all times, keep a 1-meter distance from those around them and the bathroom preferably needs to be cleaned before the next person uses it. Alternatively, if the patient was unable to mobilize to the outdoor communal bathroom a bucket/basin could be provided for them to use. The contents would need to be discarded down a sewerage drain away from the house. The family member/caregiver emptying the bucket will need to wear a mask and apron when doing so, and the bucket will need to be cleaned with soapy water and the sanitized and dried before used again. **Strict handwashing must be adhered to during and after this process.**

- **Shared bathroom within the household**
  » Given the enclosed space within a bathroom, the patient should occupy the bathroom privately if practical.
  » Once they have used the bathroom, the surfaces they have had contact with should be cleaned with soap and water, and then sanitized with the bleach and water recipe mentioned above.

- **The bed-bound patient**
  » These patients will need assistance with all daily needs from their bed. They will need their own bucket/basin for washing and this should NOT be shared with ANYONE else in the house.
  » *(See the section on supporting the carer at home for more information on how to wash the patient in bed.)*
Basic Hygiene Practices:

• If the patient is coughing, the caregiver must wear a 3-layer mask for protection. These are masks that are either:
  » Made up of special material to protect against droplets such as the blue medical/surgical masks worn by healthcare professionals OR
  » A cloth mask made up of three layers of fabric.
• Both types of masks are appropriate at home when directly looking after a patient diagnosed as COVID-19 positive. However, for most South Africans cloth masks might be the more affordable option.
  • The patient must cover their mouth and nose with a disposable paper tissue when coughing or sneezing or cough or sneeze into their elbow.
  • If tissues are not available, the patient can use a cloth or other materials, but these materials used to cover the mouth and nose should be discarded into a closed plastic lined bin which is cleaned with soap and warm water when refuse is removed.
  • Avoid direct contact with body fluids, particularly oral or respiratory secretions, and stool.
  • Wash hands and wear a mask when providing care and when handling stool, urine, and other waste.

Mask education:

• The caregiver should wear a mask at all times while working with the patient, 3-layer cloth mask acceptable, but should be washed and ironed daily. It may help to have two masks so while one is in the wash the other can be used.
• Place the mask on carefully, ensuring it covers the MOUTH and NOSE, and tie it securely to minimize any gaps between the face and the mask.
  • DO NOT touch the outside of the mask while wearing it.
  • If the mask is touched, hands need to be sanitized.
• Remove the mask using without touching the front. Discard the mask immediately after use and perform hand hygiene.

• Cloth masks can be washed at the end of each day and re-used the next day. Wash in hot water (60-90 degrees best) with soap, rinse and let dry (in the sun if possible). Once dried, iron the mask and it can then be re-used.

• If you are going to be using the mask again in the same day, you can take it off carefully WITHOUT touching the front of the mask and place it in a brown bag, Ziploc packet or plastic container (Tupperware) to keep it from touching other surfaces and spreading the virus. (See Appendix E for examples of how to store masks at home).

• Perform hand hygiene before and after removing the mask.

• Replace masks as soon as they become damp, with a new clean, dry mask.

• If patient is not too breathless, encourage the wearing of a mask while the caregiver is in the room.

**CARING FOR THE PATIENT’S PERSONAL BELONGINGS**

**Utensils**

• Identify a set of utensils (knives, forks and spoons), dishes (plates and bowls) and cups/glasses that the patient will use. These must NOT be used by anyone else in the house and must be washed separately. If possible, these can be washed in the patient’s room in a bowl and kept in their room to prevent the spread of COVID-19.

• These items should be cleaned with soap and hot water after use and may be re-used instead of being discarded.
Laundry: Clothes/Linen

- Identify a set of linen and towels for the patient and DO NOT use them for anyone else in the house. They can be washed and re-used for the patient.
- Place contaminated linen into a designated laundry bag/bucket, so it does not mix with regular linen.
- Wash the patients clothing, linen, and towels separately from the rest of the household washing so they do not mix in the water.
- Do not shake soiled laundry and avoid contaminated materials coming into contact with skin and clothes.

- Mask and plastic apron/black bag should be worn when cleaning surfaces or handling clothing or linen soiled with body fluids.
- If needing to wash the patient’s clothes, bed linen, and bath and hand towels use either regular laundry soap and water (hot if possible) for handwashing or if possible, machine wash at 60–90 °C (140–194 °F) with common household detergent. Dry thoroughly, in the sun if possible.
- If handwashing, remember once the clothes have been washed, discard the water safely down a drain. Rinse the clothes under running water if possible, if not rinse and discard the water as before. DO NOT TOUCH YOUR FACE (NOSE, EYES AND MOUTH) WHILE WORKING WITH THE WASHING and WASH HANDS WELL AFTERWARDS.
The main symptoms that people with COVID-19 experience are:

- fever
- body aches and pains
- difficulty breathing or feeling short of breath - this can often cause anxiety/worry

Your nurse/doctor/community health worker will explain how to treat these symptoms. Medicines taken by mouth will be used as much as possible. Even if patients are unable to swallow, medicines can be given in other simple ways at home. This will be explained if needed.

Below are some simple things you can do to keep your loved one comfortable at home.

### For pain and fever:

- Paracetamol (this is dispensed under various trade names such as panado, acetonapamol, dolorol, painamol, painblok, paramed) can be used. Give 2 x 500mg tablets every 6 hours day and night.
- If patient is feverish remove extra blankets/coverings until they cool down.
- You can also put a cool cloth on the forehead or the back of the neck.
- If fever is very high you can sponge or wipe down the face and upper body using cool (not cold or icy) water until they cool down.
- If you are worried phone your GP, palliative care nursing sister or clinic for advice.

### For difficulty breathing or shortness of breath

- Open windows and doors and allow fresh air to move across the patient’s face if possible. This is VERY helpful.
- Speak in calm and reassuring tones. Try not to add to their worry/anxiety.
- Encourage them to try to breathe out through pursed lips. They should pucker or partly close their lips firmly (as though they are going to blow out a candle) leaving just enough space for air to escape and blow air out against the resistance until it feels as though all the air is out of their lungs before taking a next breath in. Do this for a few breaths then breath normally again. Repeat as need be.
- Use extra pillows, or any kind of support, to prop the patient up so that the upper body is elevated to help the patient breathe easier.
- If you are worried phone your GP, palliative care nursing sister or clinic for advice.

### For anxiety/agitation/worry

- Family should be as calm and reassuring as possible.
- Address factors that can agitate a patient
  - Full bladders: assist to use the bathroom at regular intervals to empty the bladder.
  - Constipation: use of oral laxatives as mentioned above, encourage fluids, encourage mobilization if possible.
  - Noise: try to ensure a quiet and calm environment for the patient.
  - Thirst: small sips of water throughout the day, ice-chips in a cup next to the bed, wet cloth to suck if swallowing difficult.
  - Pain: manage pain with medication as prescribed by the healthcare team
- Create a relaxing environment for the patient (decrease noise)
- Make contact with any community members who usually provide religious/spiritual/emotional support if possible, in a way that is safe and does not put them at risk of COVID-19 infection.
- If you are worried phone your GP, palliative care nursing sister or clinic for advice.
SUPPORTING THE CAREGIVER: PRACTICAL TIPS FOR CARING FOR YOUR LOVED ONE AT HOME DURING COVID-19

*This information has been adapted for use in the home environment in the South African context, during COVID-19.

If your loved one is bed-bound (lying in bed more than half the day), they will need extra care at home. During COVID-19, due to the healthcare systems being overwhelmed, the care of the patient will likely fall to the family to carry out. This section covers what you need to know to care for a bed-bound patient at home.

Bed-bound patients have daily needs that they cannot carry out themselves and will need assistance with, these are:

- Washing
- Dressing
- Changing Linen
- Pressure Care
- Mouth Care
- Toileting
- Eating and Drinking
- Taking Medication

**WASHING A BED-BOUND PATIENT**

Patients can be washed sitting at the bedside or lying in bed. The method used will depend on the energy levels and physical capabilities of the patient. *Remember to wear your mask and apron (gown/homemade black-bag apron*) when working with your COVID-19-positive loved one.

You will need:

- A bucket/basin with warm water
- A towel
- A cloth/sponge for washing
- Soap (bar or liquid)
- Clean clothes
- Cream for skin (e.g.: PREP, Aqueous cream)

Before starting, wash your hands with soap and water. Keep the items you will need in the patient’s room, so you do not need to go in and out of the room. Try and limit your time in the room to 15 minutes at a time.

- Try and warm the room for washing so the patient does not get cold; if there is no heater or water bottle available, try wash the patient later in the morning when it is not so cold outside.
• At all times during the wash make sure that the parts of the body not being washed are covered by a sheet, blanket or extra towel.
• Remove the patient’s clothes, if very cold you can remove the clothing one section at a time as you wash that section of the body.
• If washing the patient in the bed, remove all pillows and blankets from the bed to make moving easier, except for a pillow beneath the patient’s head if needed. **Leave the pillows behind a patient if the patient is very short of breath and struggles to lie flat, or rather wash them in an upright position.**
• Start by washing the face, ears and neck. As you wash each section of the body dry it immediately after with a towel, so they do not get cold.
• Next wash the arms, chest and abdomen.
• While washing, to protect the linen, place the towel under the section of body being washed, e.g.: when washing the arms place the towel under the arm on the bed, once washed use the towel to dry the arm and swap to the other side.
• Next move onto the legs and feet. Washing one at a time and drying in between.
• Cream can be applied to the feet, especially the heels which can be red from lying against the bed. Massage the feet well, this helps improve blood flow and stop pressure sores forming.
• Next wash the back. If the patient is lying in the bed you will need to roll the patient onto their side. To do this: bend the patients knee on the leg closest to you, and ask the patient to wrap their arm (closest to you) around their stomach as if they are giving themselves a ‘hug’, once they are in this position gently place your one hand on their hip and your other hand on their shoulder and roll them away from you, onto their side in the bed. Now you can place the towel on the bed under their back and wash their back and hip area. While washing rub in circular motions to massage the skin and help get the blood flowing. Apply cream once you have dried this area. If sitting on the side of the bed simply wash their back while they are sitting. When needing to wash the buttocks and genitalia, ask the patient to stand, while at the same time they can support themselves by holding onto the back of a chair, so they do not fall.
• If the patient is lying on their side in bed, you can move the towel down slightly and wash their buttocks. Wash from the front to the back. Rinse the cloth in between. Check the buttocks for redness, this area often develops pressure sores first. Apply cream to the area once dry, rubbing in circular motions.
• Once finished roll the patient onto their back again and wash the genitals. Again, wash from the front to the back, to prevent infection.
• Once finished and the patient is dry. Re-dress the patient in clean clothes. Deodorant can be applied for a fresh smell.
• Cover the patient in a blanket and re-adjust their pillows for comfort.
• **Wash your hands after you have finished washing the patient.**
Dressing a Bed-Bound Patient

Dressing a patient in bed can be difficult. It is recommended that where possible, loose fitting clothes be used, as these are easier to get on and off.

- Tops with buttons down the front are easier to slide on the arms, while washing the patient and rolling them from side to side, than a t-shirt or top that needs to go over the head.
- Loose fitting pants with elastic are easiest to slide over the hips and buttocks.
- Warm socks can be worn in bed, just watch out that they are not too tight. If socks leave marks around the legs, then they are too tight, and this will stop blood flow to the feet and cause pressure sores. You can make a 2cm cut down the top of the sock to loosen the elastic so they can still be used but do not stop blood flow.

Changing the Linen with a Patient in the Bed

If your loved one is bedbound and unable to mobilize to a chair, then the linen will need to be changed while they are still in the bed. It is best to do this with the morning wash as you will be moving the patient at that time and you need to limit your time in the room if your loved one is COVID-19-positive.

*If the patient has severe pain, it is IMPORTANT to give them a dose of pain medication before 30 MINUTES before attempting to move or wash them (a breakthrough dose of medication)-see the section on symptom management at home or contact your clinic/homecare sister if you are unsure which medication you can use for breakthrough pain*

- Start by removing all pillows and extra blankets from the bed (except the pillow under their heads).
- Untuck the sides of the dirty sheet and loosen from the bed.
- Roll the patient onto their side (if you are washing them then you will add this in when they are already on their backs, once you have finished washing them). To roll the patient, always ensure that you bend the opposite leg of the side you are rolling the patient to, and ensure the arm on the same side as the bent leg is over the chest ‘hugging’ the body, then gently place your hands on their hip and shoulder and turn them away from you onto their side. You can slide your hands under their bottom once they are on their side and ‘pull out’ their bottom so they remain on their side and do not roll back onto their back. *If you are worried that the patient will roll onto the floor, place a chair next to the bed on the opposite side of where you are standing so they can hold onto the chair for support.*
- Once on their side you can roll the dirty sheet and mattress protector (if there is one) as far as possible underneath the patient’s back. *A black bag can be cut open into a big rectangle and placed under the sheet, on top of the mattress, to protect the mattress from getting soiled.*
- Then take the new sheet and lay it out on the half of the bed that is uncovered. Tuck in the two corners to secure the sheet in place, then roll up the extra remaining sheet lengthwise along the patients back, right against the dirty linen that has been rolled underneath the patient. Warn the patient they may feel a ‘lump’ underneath them.
• Roll the patient onto their back and then their opposite side and pull out the dirty linen and discard into a designated bucket/bag.
• Next pull the new sheet through, under the patient and straighten and tuck in the remaining two corners of the sheet. *Ensure there are no wrinkles or creases as these can cause pressure sores and be uncomfortable for the patient.*
• Ensure the patient is comfortable and replace the pillows and blankets.

**Pressure Care**

When someone is very ill and spends a lot of their time in bed, they are at risk of developing pressure sores or “bed sores” from lack of movement and therefore persistent pressure on certain areas. These are sores that often develop on the “bony areas” of the body as they lie against the bed. Once they are there, they are very difficult to treat to get better, so it is VERY important to do what you can to prevent them starting. Here is more information on this.

The common areas that are affected are:

- Heels
- Elbows
- Sacral area (bottom)
- Lower Back
- Hips
- Ears (if lying on their side mostly)

You will first notice that the skin becomes red in that area, once red the skin is at risk of breaking down and forming open sores. These sores will usually have a red border and yellow in the middle, (like an ulcer you would find in the mouth). It is important to do proper pressure care, regularly to prevent these sores from developing. Once they develop they will increase patient pain and discomfort and can lead to infection.

The following tips can be used to prevent these sores from occurring in a bed bound patient:

• Make sure the patient is turning regularly. Every 2-4 hours they need to change position. Turn them from their back onto their side and then keep rotating between the back and their sides.
• When changing the patient’s position, use some cream (non-fragranced) such as: prep or aqueous cream) to rub the back, hips, legs and heels. This helps to move the blood around the body and prevent the sores from forming. *Do not use Vaseline on the skin as the skin can sweat underneath and this can cause pressure sores.*
• When doing the morning wash, use circular motions to wash the body, back, arms and legs to improve the circulation in the body.

• For the heels, elevate the feet off the bed by putting a pillow or soft blanket underneath the feet, let the heels hang off the end of the pillow, so they are not touching the bed or the pillow.

• Encourage the patient to move their legs, arms and feet by themselves if they can. These are called passive exercises and can be done in bed. Ask them to bend their arms and legs and rotate their wrists and ankles as much as they are able. If they cannot do it themselves, you can gently do it for them from time to time when in the room.

• Ensure if they are in nappies that their nappy is checked and changed as soon as dirty with urine or stool. *If soiled nappies are left on, the skin will break down.

• Make sure when changing the linen that there are no wrinkles, as wrinkles will push against the skin and cause the skin to breakdown.

• When moving/turning the patient, the easiest way is to use a draw-sheet. A draw-sheet can be created using a big towel, blanket or single sheet. It must be folded into a rectangle shape and must fit from above the patients shoulders to underneath their bottom, including the back of their upper thigh. This sheet is placed underneath the patient and can then be used to pull the patient up in the bed or roll them onto their sides. When moving the patient, you will pull on the sheet and not on the patient’s skin. The draw-sheet also prevents your back from being injured when trying to move a patient.

  » If you are on your own, you will stand behind the head of the bed and pull the sheet from both sides to move the patient up in the bed.

  » If there are two of you one can stand each side of the bed and hold the sheet at the top and bottom ends and move the patient up the bed (one...two....three...move)

  » If you want to roll the patient to the side from their back or opposite side, you will stand on the side they are rolling to and hold the sheet on the opposite side top and bottom and pull the sheet over towards you (you would be standing in front of them so they do not fall off the bed). Once on their side, you can move around the bed to the other side, where their back is now facing you and gently slide your hands under their bottom to pull it back slightly so they are comfortable, you can then put a pillow behind their back to prevent them from rolling back onto their backs.

• When a patient is lying on their side ensure you put a pillow or soft blanket (folded up) between their legs to prevent the knees from pushing against each other and developing sores.

• A pillow can be placed underneath the calves of the legs to lift the heels off the bed, reducing pressure.

*if the patient develops bed sores contact your home care sister or clinic to get advice on how to dress the sores to promote healing.
MOUTH CARE

Often patients who are very ill are unable to brush their teeth or may be unable to take sips of water to keep their mouths moist. They will need help to keep their mouth clean, moist and fresh. This will prevent sores and infection from developing that can cause pain, and difficulty with eating and swallowing. Mouth care should be done at least twice a day. While performing mouth care be aware that coronavirus can spread through droplets in the air, so ensure you are wearing your mask throughout the procedure. Wash your hands before starting and after finishing.

Brushing the teeth:

• Place the patient in an upright position as far as possible (sitting in the bedside or propped up with pillows).
• Place a towel or some paper under the chin in case any water spills and have a bowl ready to catch water from the mouth.
• Dip the brush in water and add toothpaste onto the brush, give the patient a sip of water to wet the mouth before starting.
• Brush the teeth using a gentle circular/back and forth motion.
• Remember to brush the tongue as well, but do not push the brush too far back into the throat as this will cause gagging.
• Once done give the patient sips of water to rinse their mouth, the patient must NOT swallow the water, but rather spit it into the bowl.
• Dry the mouth and clean the toothbrush and discard the water.
• Wash your hands when finished.
• If the patient is unconscious/unresponsive/ unable to spit out the water used to rinse the mouth out after brushing, then DO NOT brush with toothpaste. Rather use a brush dipped in a mouth solution (see below for recipe) and use this to gently brush the teeth.
• DO NOT put your fingers into the patient's mouth, as they may bite.

Rinsing the mouth:

• Help the patient rinse the mouth after brushing to freshen the mouth.
• Avoid alcohol-based rinses as they can be painful if the mouth is sore, dry or cracked.
• Rather try the following that can be made at home:
• Mix baking soda (1 teaspoon) and cooled, boiled water (2 cups) or
• Mix salt (1/2 teaspoon), baking soda (1 teaspoon) and cooled boiled water (4 cups)
• ALWAYS ensure that the patient is sitting in an upright position when rinsing the mouth, so they DO NOT choke.
• If a patient cannot sit upright but are responsive and alert, you can lie them on the side and give small sips of mouth rinse which they can then spit out of the mouth onto a towel, placed under the head.
• If a patient is unresponsive, it is best to brush the teeth using a toothbrush dipped into one of the cleaning solutions suggested above.
Dry Lips and Mouth:

- Lips can become very dry and cracked/chapped, especially if patients are not taking in a lot of fluid.
- Use lip-balm, glycerine or Vaseline to keep the lips moist and prevent them from drying out.
- To keep the mouth moist, you can try the following:
  » Encourage small sips of water throughout the day.
  » Add a few drops of lemon juice to the water, this can help to stimulate saliva to be produced.
  » Ice can be crushed to form ‘ice-chips’, which can be placed in a cup next to the bedside and the patient can put one ‘ice-chip’ into their mouth at a time throughout the day.
  » A clean cloth can be dipped into cool, boiled water and the patient can suck on the cloth.
- If you notice sores inside the mouth or if the mouth, gums or throat become covered in a thick white or yellow coating, contact the clinic/homecare sister for advice. Continue with mouth care and rinsing.

TOILETING

- While bed bound, and if still taking in fluids and solid food, the patient will still need to pass urine and stools. They will need assistance with this. If your loved-one is COVID-19-positive they will need to use either a separate bathroom or if a shared bathroom, the bathroom will need to be cleaned down after they have been in, to prevent infection to other family members.
- There are a few options that can be used to assist toileting:
  - Nappies which can be changed in the bed and are easiest for patients who are bed bound.
  - If nappies are unavailable, then towels can be used and folded around the patient and secured in place with safety-pins.
  - Commodes/toilet next to the bed, if the patient can move from the bed to the commode and if commode is available.
  - Urinal bottle, for males in bed, can be created from any bottle that has been washed and sterilized, or a bucket can also be used.

FEEDING PATIENTS

Your family member may not be able to feed/drink themselves and may require assistance to do this at home. There are a few points to remember when helping a patient feed/drink:

- Sit the patient as upright as possible for easier swallowing and to prevent choking. You can use pillows behind the head if needed.
- If the patient can sit on the side of the bed to eat this is ideal, but then the patient needs to be watched so that they do not fall over.
• Use a spoon to feed the patient, as a fork could cause injury to the mouth as it is sharper.
• If the food is solid make sure it is cut up into small pieces before feeding the patient.
• Use a towel to cover them from under the chin to the chest, in case they spill.
• Allow time for them to chew and swallow between bites.
• Do not force food in. This can make the patient feel nauseous and they could vomit.
• Rather offer smaller meals more frequently through the day, as their appetite may be decreased, which is normal during illness and after recovery from hospital.
• Encourage small sips of water through the day, leaving a bottle they can reach and use easily by the bedside is a good idea.
• If you have access to supplement drinks e.g.: Ensure (powder you mix with water/milk), this can help boost the patient’s intake during the day.
• Eating patterns will change when a patient is dying refer to the end-of-life information for feeding changes you can expect when your loved one is dying.
• If the patient is very nauseous or vomiting a lot and unable to eat or drink, contact your local clinic or home care sister for advice.

**TAKING MEDICATION**

Most patients will need to take medication at home to manage the symptoms of COVID-19 and for any other medical conditions they already have e.g.: High blood pressure, diabetes, heart failure etc. In a bed-bound/very ill patient sometimes medication can be difficult for the patient to take. The following are some tips you can try:

• Ensure the patient is sitting upright, they cannot swallow medication lying down flat on their back, they will choke.
• Try and space out the medication if possible, so they do not take too many tablets at once.
• If they are struggling with tablets, the tablets can be crushed and mixed into yoghurt to make it easier to swallow them. Do not add the tablets into a large portion of yoghurt as the patient may not finish it all and then you will not know if the tablets are finished or not, rather mix small amounts of the crushed tablets onto the spoon with the yoghurt as you give it to the patient.

• *Note some tablets cannot be crushed so before crushing tablets check with your local clinic if they can be crushed, or if they need to be reviewed and changed.
• If the patient refuses the medication, take a break and try again later. Do not get anxious and angry; fighting with the patient can make the situation worse.
• If using a syringe for giving the medication, place the syringe in the side of the mouth by the check and slowly push the medication into the mouth, watching that the patient swallows from time to time.
**Acknowledgement: the below section is based on information sheets developed for families from Stepping Stone Hospice and Care Services and can be found in more detail at [https://www.steppingstonehospice.co.za/](https://www.steppingstonehospice.co.za/)**

When patients near the end of life, there are some normal signs and symptoms that show that their body is getting weaker and death is near. It is helpful to know what these are to reduce anxiety around the normal process of dying. The table below details the normal signs and symptoms to expect and what can be done to manage them in the home environment.

| Decrease in appetite and fluid intake | Offer softer foods and sips of water. If jaw is closed and clenched the patient is indicating that they do not want food. Use a syringe/teaspoon to provide drops of water into the side of the mouth to keep the mouth moist. A spray bottle filled with water can be used to spray water onto the inside of the mouth from time to time to keep the mouth moist. Ice-chips can be used to keep the mouth moist. **DO NOT FORCE FOOD AND WATER IN TO THE MOUTH, THE PATIENT COULD CHOKE AND VOMIT.** |
| Urine output and bowels decrease | It is normal for the patient to have less urine output and less frequent bowel movements. No intervention required unless there is severe amounts of abdominal pain and an urge to pass urine. (retention of urine-call for advice in this case.) |
| Increased sleep | Patients will sleep more and more and seem to withdrawal from the world around them. Let them sleep. Spend time with them. |
| Increased confusion As oxygen to the brain decreases the patient can become confused | When they wake reassure them and remind them the day, time and where they are. Allow them to talk, even if what they say makes no sense to you at that moment. |
| Decreased ability to speak/communicate and hear | Speak slowly and clearly. Use yes/no questions. Keep the room calm and quiet. Patients can hear us, talk as if they can still hear you even if not responsive. |
| Increased secretions There may be a build-up of secretions in the back of the throat that may rattle/gurgle when the patient breathes. | If loud, keep the patient on their side so the secretions can come out. Treat the patient’s anxiety if there is, ask for advice re: medications to use. Small sips of water can help with phlegm build-up. |
| Breathing changes Breathing may become irregular, with long gaps between, or speed up faster. It may seem like hard work for the patient. There may be some normal moaning and groaning at this time. | Prop the patient up in bed slightly, to make breathing easier. The moaning and sounds are normal, it is families who become distressed rather than the patients, who are usually unaware at this point. |
### Restlessness

**Decreased oxygen the brain can cause restlessness.** Patients may try to get up out of bed, and may pull bedclothes on and off repeatedly, or “pick” in the air with their hands.

- Reassure the patient in a calm voice.
- Use chairs next to the bed to prevent them falling out, or cushions on the floor.
- Use anti-anxiety medication to help relax and calm the patient during this time, ask Dr or hospice sister for advice on this.
- Soft music/back rub can help settle them.
- Limit visitors into the room, this can cause agitation. **(IN COVID-19 VISITORS WILL NOT BE ALLOWED).**

### Temperature changes

**As the circulation slows people will get hot and cold.** They may also present with blue/cold hands, feet, elbows and knees, known as “mottling”. This is not reversible.

- Use blankets, warm bean bags and beanies to keep patient warm if cold.
- Massage the hands and feet to promote circulation and heat.
- Sponge bath using luke-warm water if patient sweating.
- Keep linen dry and clean.

### Symbolic language/visions

- Sometimes as people near death they will see people that have passed before them or have visits from loved ones who are dead.
- They may also talk about packing their bags, catching a train, taxi or aeroplane etc.
- Take note of this, it can indicate that they are getting ready to ‘depart’ from this life.
- No intervention is necessary unless the visions cause the patient extreme distress, contact your clinic for advice on sedating the patient.

### At death

**The patient is unresponsive.** Bowels and urine may release. Eyes will become fixed (not moving) and stare. Breathing will cease. No pulse will be felt. Jaw may relax and drop open.

- Put a plastic bag under/on top of the sheet beforehand to prevent mattress and linen being soiled.
- If open, gently push the eyelids down and hold them for a few seconds, to close them.
- A towel can be placed under the jaw, around the neck to close the mouth.
- Lay their legs out straight and arms down by the sides or across the chest.
- Cover them with a sheet.

**ALWAYS REMEMBER TO WASH YOUR HANDS AND SANITIZE AFTER TOUCHING THE PATIENT.**

The focus as patients enter this terminal phase of life is comfort care. All actions taken at this point are to minimize discomfort and promote comfort for the patient. Remember, at this point it is important to “just be there” and reassure the patient, by doing and gently saying, that you are fulfilling all their needs at this point. There are 6 important things to say to someone at this time, which can make it easier for them to gently “let go”

- I’m sorry
- I forgive you
- Thank you
- I love you
- It’s ok to die, we will be ok
- Goodbye
WHAT TO DO IF YOUR LOVED ONE DIES AT HOME DURING THE COVID-19 PANDEMIC

Your loved one has passed at home with COVID-19 or during the COVID-19 pandemic. Unfortunately, due to the way the disease is spread there are limitations on what you can and cannot do with the body of a loved one, once they have passed. And there are certain steps that must be followed after death. Below is a list of these “do’s and don’ts” and the next steps to take.

AFTER DEATH

- Respectfully lay out the body with legs straight, arms at the side or crossed over the chest and cover the face and body of the deceased at home – with a sheet or other suitable covering, wearing a mask at all times while working with the body and washing hands thoroughly afterwards.
- Limit the time you spend in the room and limit access to the room housing the deceased.
- Ensure strict handwashing and sanitizing for anyone who comes into contact with the body.
- As far as possible try not to touch or move the body-wait for the undertakers.
- Do not allow extended family or friends from visiting your house at this time, as difficult as this may be, it is to protect those you love and prevent the spread of the virus to them.
- If the body must be washed and prepared for burial, this must be done under the guidance of the religious/cultural group that has been trained on the correct use of PPE for the procedure.
- As soon as possible after death contact the following agencies and inform them that the patient has been confirmed to be COVID-19 + or was suspected of having COVID-19:

1. Emergency Medical Services (EMS) – to complete the death notification form which will be left with you for the undertakers.

2. South African Police Service (SAPS) – to complete the SAPS 180 form – this is also necessary for the undertakers to have to be able to move the body.

3. Undertaker of choice – to facilitate the appropriate wrapping of the deceased, collection of the body and documentation, and transfer to the appropriate mortuary.

Note:

- If your loved one was suspected COVID-19 positive but not yet tested, you may be asked to give consent for a COVID-19 test to be done post-death. This is done by taking a ‘swab’ (like a bigger cotton earbud) and gently inserting it into the nose. This swab is then sent to the labs for testing.

AFTER THE UNDERTAKERS HAVE BEEN

- You will need to clean and sterilize the room where your loved one was cared for.
- All surfaces that were touched by your loved one (the bed, bedside tables, lamps, the floor etc.) need to be sanitized by washing with a bleach/JIK solution diluted in water.
(six (6) tablespoons of bleach mixed with four (4) cups of water).

- Their belongings will also need to be sterilized with the disinfectant solution.
- Clothing that was used by the deceased as well as the linen need to be washed either in a machine or handwashed with soap and hot water to sterilize and prevent the spread of the virus.
- Open any windows to air the room once cleaned and allow to dry.
- Any waste needs to be double bagged and left outside for 5 days before adding to the garbage to be removed by the municipality.

THE BURIAL CEREMONY/ FUNERAL

- You can still have a funeral/memorial service for your loved one however limits have been placed on the duration of the service (1 hour) and attendee numbers (50 only) for current lockdown level 3.
- It is recommended that only immediate family of the deceased attend the service. Those older than 60 years, immunosuppressed or with respiratory diseases should not have contact with the deceased to reduce their risk of contracting coronavirus. Any mourner who is showing COVID-19 symptoms should not attend the funeral as they pose a risk to others - remote participation (live streaming) should be considered
- Social distancing (>1.5m) needs to be observed at the funeral/memorial – which affects seating arrangements and embracing of fellow mourners. Furthermore, social gatherings/cleansing ceremonies/ traditional feasts after the burial service are not allowed.
- It is recommended that the burial or cremation should take place within 3 days of the person passing
- If a viewing is preferred, people may not touch the body and they will have to wash and sanitize their hands (with 70% alcohol solution) straight away after the viewing. A mask will need to be worn at all times.
- Night vigils are not allowed at this time.
- Families are asked to consider holding weekday services to accommodate the increased demand for funerals/memorials during this time of COVID-19, so mourners arriving and leaving gatherings do not overlap, which would increase the risk of exposure to COVID-19.
- When the coffin is being placed in the ground gloves and masks are to be worn. The gloves and masks will then need to be disposed of in a sealed bag or dustbin. Hands must be washed with soap and water thereafter.
TRAVEL TO THE BURIAL CEREMONY OR FUNERAL

- Please consult https://www.gov.za/coronavirus/guidelines for up to date information

- Under Lockdown level 3, movement between provinces, metropolitan areas or districts by a person intending to attend a funeral is only permitted if the person is a -
  (a) spouse or partner of the deceased;
  (b) child or grandchild of the deceased, whether biological, adopted, stepchild, or a foster child;
  (c) child-in-law of the deceased;
  (d) parent of the deceased whether biological, adopted or stepparent;
  (e) sibling, whether biological, adopted or stepbrother or sister of the deceased; or
  (f) grandparent of the deceased
  (g) persons closely affiliated to the deceased

- Each person, whether traveling alone or not, wishing to attend a funeral and who has to travel between metropolitan areas, districts, or between provinces must obtain a permit, from his or her nearest magistrate’s office or police station to travel to the funeral and back.

- The head of court, or a person designated by him or her, or a station commander of a police station or a person designated by him or her, may issue the permit to travel to a funeral.

- Upon a request for a permit to attend a funeral, a person requesting a permit must produce a death certificate or a certified copy of the death certificate to the head of court, or a person designated by him or her, or a station commander of a police station or a person designated by him or her: Provided that where a death certificate is not yet available, and the funeral must be held within 24 hours in keeping with cultural or religious practices, the person requesting the permit must make a sworn affidavit at a police station, together with a letter from a cultural or religious leader confirming the need for the funeral to take place within 24 hours.

- After the funeral, a deferred celebration or memorial service, which could be considered and held after the social restrictions are lifted and at a time when attendance and shared mourning can safely take place
APPENDIX A: HEALTHCARE SERVICE CHALLENGES

HEALTHCARE SERVICE CHALLENGES

We are aware that our already overburdened Healthcare system will be struggling with known and unknown challenges in the face of COVID-19. These will impact the quality of homecare support and guidance that will be able to be provided at this time. Some examples of these challenges are listed below:

- Limited resources across South Africa
- Limited access to healthcare by some populations
- An already overburdened health system being increasingly stretched
- Risk of health care workers being exposed to COVID-19
- Increased financial burden
- Difficult decision making and allocation of limited resources

Limited Resources

Human, infrastructure, equipment and medical resources are already constrained in the South African environment. The majority of those with severe COVID-19 will only require oxygen and supportive measures in hospital and are likely to make a full recovery, but as many people are falling ill at the same time, there is potential that resources may become limited. Early initiation of oxygen has proven to decrease mortality in COVID-19. With little to no home oxygen available, it is unlikely that patients who present to health care facilities with breathlessness will be discharged home. Even in hospital settings where there is no oxygen available, it may not be practical to transport these patients’ home and so end of life care would need to be provided where these patients present. There may be very difficult decisions as to whether patients in the terminal phase of the illness should be transported from home, particularly where certain health facilities may lack the necessary resources or already be overburdened and unable to provide the necessary care. Even where oxygenators are available for use at home, the re-introduction of load shedding reduces its usage, as it needs electricity to deliver oxygen to the patient.

Limited Access to Healthcare Services

Access to healthcare services, including home-based palliative services, may be limited in LMICs due to geography, infrastructure and socioeconomics. Geographically there are many outlying towns and villages where physical access to healthcare is difficult. In terms of infrastructure, there are a limited number of healthcare facilities and available beds in many areas. Access includes the ability to afford healthcare services and/or transport to healthcare facilities. Not only are these challenges problematic for day to day home-based patient management, but also in cases of emergencies and progression towards end-of-life.

Trying to facilitate the safe and appropriate care of COVID-19 patients at home is complex as there is limited ability to prognosticate and with rapid deterioration and limited access there is increased risk of dying at home.
System Challenges

The healthcare system is complex with many stakeholders and processes. There is concern that poor co-ordination, communication and logistics will hamper efforts to effectively respond to the Pandemic.

There is limited surge capacity in an already overburdened system. As well as already limited means in some places to transport patients between home and hospital/clinics. This brings with it the risk, that in some areas for a period of time, healthcare may be disrupted and unable to offer medical care to those who need it. This will have knock-on effects. The ideal scenario would be to plan ahead effectively for how these surge periods may be best managed and the system supported, alongside patients, families and communities, so that the knock-on-effects are as limited as possible and the health system can remain as responsive as possible.

Risks to healthcare workers

Health care workers are at high risk of becoming infected and taking the disease back to their homes and communities. This not only poses a health risk to the individual but the home and community too. When a healthcare worker dies this is a significant loss to their families and community.

For small CBOs and Hospices, if the professional nurse is infected due to patient exposure, it means shutting down the organisation and those non-COVID-19 patients will not receive palliative care services at home.

In some communities where many people are dying as a result of already existing community spread, healthcare workers may be blamed for bringing the infection into the community. They may also be blamed for not doing enough. This may cause fear amongst healthcare workers and there is potential for further stigmatisation in the community.

Difficult Decision-Making

Decision making with limited resources is always a challenge. In addition, disease progression may be rapid and the time interval to provide the necessary care short. We advocate for clear pathways and guidelines for all facilities and also effective and responsive communication channels, so that the health system can be as responsive as necessary and supportive of the health care workers on the frontline who are needing to make challenging decisions, whether they be home care workers, HCWs in clinics, EMS, hospitals or field hospitals.

Examples include scenarios, where patients deteriorate at home and are deemed to have critical disease - difficult decisions as to whether to transport to a facility or to palliate the patient at home may need to be made. Equally it is difficult to decide who can be safely discharged from hospital and be cared for at home. The section on ethical decision-making aims to guide the HCW through potential scenarios and the important ethical aspects to consider.

Limited Scopes of Practice

Even when there is the ability to assist those at home, the healthcare workers (nurses and paramedics) who are able to assist with this care are not able to prescribe necessary
medications, due to limits within their current scope of practice. For palliative care, this specifically relates to the utilization of low dose opioids for symptom management e.g.: pain and breathlessness.

**CHALLENGES THAT MAY BE FACED WHEN DISCHARGING A PATIENT HOME FROM HOSPITAL INTO THE COMMUNITY**

In South Africa there are many challenges to home care already existing in our communities. During COVID-19 these challenges will be aggravated and will impact the patient’s quality of life if they are discharged home/choose to go home/choose to stay in the community setting for care at home during COVID-19. Therefore, we advocate strongly for PC training to be implemented/offered to all home-based care community workers/organizations. Some of these challenges are listed below and are important to consider when a patient is going to be cared for in the home setting:

- Lack of care support at home
- Other vulnerable/ high-risk family members living in the household will influence who can look after the patient at home.
- No access to medication
- Lack of palliative care medical advice and support
- Families ill-equipped to look after these patients
- No health professional ‘point of contact person’ to oversee the patient at home so the family feel unsupported
- Stigma within the community of COVID-19 patients
- Patient’s fear and anxiety
- Necessary PPE for patient or family
- Adequate quarantining facilities
- Limited or no water access for large segments of the population
- Deteriorating sanitation and hygiene infrastructure

The notion of “Ubuntu” and “communalism” is of great importance and a common thread in South Africa and the rest of the continent. Through its emphasis on humanity, compassion and social responsibility, “Ubuntu” (“I am because we are”) has the potential to facilitate solutions to and avert conflicts between individual rights and public health.

During the current COVID-19 pandemic health workers, communities and essential staff and services, have shown great courage, compassion and dedication, with people standing together to support each other during these difficult times. Communities are coming together to overcome many of the challenges they are facing. Food campaigns and community networks such as Community Action Networks (CAN) are assisting vulnerable members in the community. Personal Protective Equipment (PPE) drives are assisting healthcare workers with access to much needed PPE and running water stations are being created in rural areas to facilitate access to running water for hand washing. Through these innovative and creative ideas South Africans are overcoming some of their daily challenges while living with the reality of COVID-19.
An online platform known as Vula is being used to make the referral of palliative care patients into the community more streamlined. Vula is an online service which offers a secure format to discuss individual patient concerns. It is used throughout the country and requires less data than whatsapp and is more secure. It allows photos and vital patient information to be shared between users. It is easy to use and needs no training, if one already has basic computer literacy skills. All health care workers can get access to Vula and have a profile. To be on the page to receive referrals, the individual needs to contact Vula support and ask to be able to receive referrals for their facility on the Palliative Care page. Vula allows for zoom calls between clinicians too. Vula is open to doctors, nurses and allied health workers. One only needs a registration number, to log in and get a password. The site can be accessed here: https://www.vulamobile.com/. Patients from hospital can then be referred easily across to Primary Health Care clinicians who will then have access to patient notes and current treatment plans and if the patient contacts the clinic they can be assisted more easily.
APPENDIX B: ETHICAL DECISION-MAKING CONSIDERATIONS
DURING THE COVID-19 PANDEMIC IN SOUTH AFRICA

“The greatest moral challenge posed by a pandemic is how to respect commitments to social justice in the face of the overwhelming and entrenched inequalities in health, well-being, and resources that will constitute the backdrop for, and the harsh realities of, any global outbreak of devastating disease” Ruth Faden (John Hopkins University)

We propose the ethics flow diagram as specifically relating to patients who have moderate to severe COVID-19, with or without co-morbidities, who are at risk of dying. We acknowledge that death occurring due to coronavirus occurs in a limited percentage of those infected and emphasize that the diagram considers the worst-case scenarios and highlights vulnerabilities within our national health system. We do not adopt a nihilistic approach but encourage the highest standard of care be afforded each member of society.

We also acknowledge that this ethics flow diagram is generalized and might not be relevant to each patient or clinic scenario – and thus encourage that decisions still be considered on an individual basis with goals of care in mind and documentation in place to justify decisions. Care pathways may change and thus are open to being discussed and revised – within a sound ethical framework.

Ethical dilemmas may arise when duties (e.g.: to the state, health care system, professional, personal), obligations and values conflict. Our efforts are to prepare and equip healthcare providers, families and patients to deal with foreseeable ethical dilemmas during this public health emergency, thereby promoting patient’s human rights, the integrity of health care workers and safe-guarding the short- and long-term capacity and functioning of the South African health care system, cognizant of the limitations of resources in the South African context.


CORE CLINICAL ETHICAL PRINCIPLES

The core clinical ethical principles (of Beauchamp and Childress) that are most frequently described37:

Autonomy

The understanding that each person in South Africa (whether citizens or not) has the right to be fully informed of the reasonable health care choices available to them – and this is communicated to them or their family in such a way to be well understood and uncoerced and preferably in their own language. South Africa is a place of great diversity and patients are encouraged to make an individualized decision regarding their care or
their preferred place of care. The patient’s dignity, values and preferences during care and death are respected and honoured as far as is possible. The patients specific cultural and religious/spiritual practices should also be taken into account. Ideally, the patients and their families’ contributions to the planning and implementation of the care pathway should be included.

**Beneficence**

The principle of acting for the benefit of patients and their families, society or the health care system. This implies defending patients’ rights to care, preventing harm done to others and acting in their best interests given the available resources.

**Non-maleficence**

This refers to taking due care to minimize harm and intentionally avoiding doing harm to others. It is also being aware of possible unintended consequences of decisions that may impact patients, families, societies and the healthcare system in the future.

**Justice**

This principle promotes the fair and equitable treatment for each member of society in a consistent and appropriate manner. This pertains to access to health care and information regarding the Coronavirus pandemic, the application of admission criteria, criteria for escalation of care and distribution of scarce resources. Importantly, being aware of the existing socio-economic disparities in the delivery of health care and endeavouring to reduce further likelihood of widening these disparities – by acknowledging that the burden of the pandemic should be shared equitably, and that universal health coverage remains our national goal. Our response efforts should display reciprocity in trying to lessen the socio-economic disparities.

In deliberating ethical dilemmas:

1. Define the issue
2. Clarify the facts as much as possible
3. Identify stakeholders and their perspectives
4. Identify and analyze the principles and values
5. Identify alternative courses of action in light of these values
6. Make a decision and document the decision
7. Implement the decision
8. Review and document any revised decision

**PUBLIC HEALTH ETHICS**

In contrast to clinical ethics, Public health ethics purport rather to promote the health and interests of the wider population by “minimizing morbidity and mortality through the prudent use of resources and strategies”^{38} In a public health emergency, when the population may be at risk, individual’s rights and preferences assume a lower priority in order to best serve the needs and greater good of the wider population. In other words, the need to protect and serve the community may outweigh the needs of the individual
during this coronavirus pandemic and that resources (such as staffing, PPE) would be allocated to maximize their effectiveness.

The respect and sanctity of each person's life matters equally, however, during a crisis in which resources are scarce, every person is not able to receive the same management. In some circumstances, trade-offs will need to be made when it is not possible to uphold all values\(^{39}\).

The current pandemic has again highlighted the need for Palliative Care principles to be implemented and integrated into our health systems across South Africa. Where this is not happening it remains our responsibility as health care professionals to a) report the flaws in the system as responsibly as we can through the various channels that are created and b) to inform patients of their right to care - which include palliative care support and medications for symptom control e.g.: morphine if needed for pain and breathlessness. Citizens have the right to demand/insist on appropriate access to care.

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**PUBLIC HEALTH PRINCIPLES**

**Equality**

Persons should have equal access to health care resources

**Equity**

Those who might benefit the most from the available resources should be offered these resources preferentially

**Efficiency/Utility**

Decisions and actions ought to promote the greatest good and produce the least harm in serving the greatest number of patients, as well as being as efficient as possible.

**Rationing**

This describes the allocation of scarce resources and the decisions involved in the dividing

We have attempted to be rational, reasonable and practical in discussing these ethical situations that arise in the depicted flow diagram.

*Despite the many challenges we face in South Africa, and given all the ethical considerations, we must always strive to provide care with compassion and transparency.*
The Ethical flow diagram below is suggested as a support to health care professionals having to make difficult ethical decisions during the current COVID-19 pandemic. An explanation for each number indicated on the Ethical flow diagram can be found on the next few pages.
(1) Pt unwell at home (breathless/ agitated) Presumed COVID+

The state has a responsibility of ensuring that rural communities are educated regarding the symptoms of coronavirus infection, what to expect, what to do if symptoms worsen, infection precautions, quarantining and how best to access health care and advice. (Justice, Human rights, transparency, Section 27 of the Bill of Rights mandates the right to access healthcare services; the National Health Act and the Patients’ Rights Charter). Persons should have equal access to health care resources (equality)

The ill patient ideally should be isolated to prevent possible spread of the coronavirus. The location of isolation will depend on the established COVID-19 care pathway and can be done at a health facility, community facility or at home. The decision of location should be made on a case-by-case basis and will depend on the clinical presentation, requirement for supportive care, potential risk factors for severe disease, and conditions at home, including the presence of vulnerable persons in the household. For patients at high risk for deterioration, isolation in hospital is preferred.

Some patients will be looked after at home by families/community members and need to be supported as best as possible. Ongoing additional resources need to be deployed to service the most rural communities for patients to trust the health care system (beneficence/non-maleficence/transparency/autonomy/justice)

Even in the most rural areas, Palliative Care provision is imperative in caring for a very unwell COVID+ patient and for supporting their family during quarantine. If such a patient is unable or unwilling to attend their local clinic or request emergency services, and the patient continues to deteriorate, then the index patient may die at home.

(2) Patient dies at home

Where death has occurred in the home, families will need information and practical support in being able to manage the body and the practical arrangements that follow. Justice, beneficence and non-maleficence all advocate for easily accessible information, clear communication channels, with telephone calls readily answered and responders able to give clear and compassionate advice and support to families. (See the section: Death in the home-what to do during COVID-19). In addition to this, bereavement support for families, during their quarantine period and beyond, will be required, so as to ensure beneficent care and support is provided beyond the patient’s death for all family members. The arising need in many communities may be great and this needs to be considered in planning, so that resources can be maximized and equitably utilized to ensure universal health coverage for any potential mental health impact.

(3) Patient attends local clinic

Should the patient have access to transportation or be in close proximity, he or she may present to the local clinic or local district hospital.

The Department of Health (DoH) is responsible for the pandemic preparedness for the clinic and its staff. The DoH is responsible for ensuring adequate resources for the clinic with respect to staffing, testing, PPE, medical supplies, communication networks and education regarding symptomatic management of most frequent coronavirus symptoms,
infection precautions in the home and palliative care.

Triage will happen at every level of patient contact with a health facility as a standard of care and is not a unique practice during COVID. The Triage system used in South Africa is the South African Triage System (SATS). However, specifically during the pandemic, COVID+ patients' clinical severity is determined based on the WHO COVID-19 Severity Classification which also informs the level of care required.

The National Policy Framework and Strategy on Palliative Care 2017 – 2022 lays the foundation for the provision of palliative care at all levels in the public health service. According to this policy, palliative care resources including medication and trained health care professionals should be available at all levels of care, however this is not yet a reality or uniformly instituted. Due to the nature of COVID-19, the recommendation of this guideline is that the palliative care preparedness of all clinics, hospitals and all facilities should be addressed. This should include the provision of oral morphine solution for symptom control at clinics.

(4) Patient discharged home

There may be a number of scenarios where patients with moderate to severe disease may be managed at home:

i. An informed and competent patient, with an enabled and willing family, may choose not to be admitted and to receive palliative care at home (autonomy, beneficence, non-maleficence, justice, with equality and equity)

ii. Thinking of a potential worst case scenario of overwhelmed facilities, care may have to continue at home for a sub-set of patients in this scenario, and here we strongly advocate for clear palliative care plans and appropriate resources and support for patients and families in the home setting (beneficence, non-maleficence, justice, with equality, equity, utility and rationing).

iii. The patient who has had COVID-19, has been treated, is discharged home and is now on the road to recovery; they will also need supportive care at home whilst recovering from post-ICU syndrome or complications which arose from COVID-19.

Palliative care is an essential component in the integrated public health response to this pandemic, as it enables the public health ethical principles of equality, equity, efficiency/utility and rationing, for health care in any setting.

For patients who have accessed the health care system and have been discharged home for palliative care at home, there is a responsibility of the health system not to abandon these patients and their families. The necessary symptom relief should be provided adequately and with no undue burden and ongoing support and care for the patient and their families be continued. This may require the dispensing of medication, the arrangement of home oxygen, the education of family caregivers and the psycho-social and spiritual support of families. This also includes the referral to local home care or palliative care organizations to facilitate support for patients and families (Beneficence, non-maleficence, justice, respect for persons).

It behooves the national health department to consider how these barriers to effective provision of care can be minimized and indeed overcome. It is also important that
the relevant care pathways are clear and decision-making pathways and processes are transparent.

According to the WHO, supportive and palliative care should be provided to persons unable to access lifesaving resources. Efforts should be made to ensure that no patients are abandoned\(^4\). The WHO also remark that efforts should be made to allow for palliative care interventions, including medicines and access to health care professionals, to be available to patients in their homes\(^3\). We would advocate for virtual palliative care advisory teams in each province as potential new interventions so that areas with limited numbers of palliative care trained HCPs can receive such support for HCPs and even for families, as required.

(5) Clinic team able to engage with local district hospital, regional hospital, tertiary hospital OR dedicated COVID critical care unit

Should the clinic ascertain that the patient’s condition warrants transfer from the local clinic (due to worsening clinical status, inability of the clinic staff to provide adequate symptom relief or inadequate home circumstances to care for the patient) the clinic team is required to initiate discussions to escalate ongoing management to an appropriate level of care (according to Department of Health directives for each clinic).

(6) Up-to-date information gathered to present to patient or family regarding management options

The clinic team should be able to access communication pathways easily with referral hospital and with EMS (\textit{justice/beneficence/non-maleficence/transparency})

It is critical for the clinic team to have current information regarding bed-status and resource availability - to be truthful in presenting options to the patient and family. Further management options will depend on resources available within the healthcare system—such as ambulance services, PPE, oxygen, mechanical ventilation and ICU beds.

It is equally important that the referral hospital receive accurate information about the patient – particularly when triaging for the appropriate allocation of scarce resources.

(7) Collaborative and collective discussion between clinic team, patient and their family – considering management options and reaching decision consensus

The information regarding the patient’s management options and resource availability needs to be conveyed to the patient and their family. The clinical team must be able to engage with the patient regarding his/her choices, so that the patient can take part fully in the informed decision-making process (\textit{justice, beneficence, non-maleficence, respect for persons}). The clinical team should ideally be skilled in appropriate communication techniques to provide appropriate care – (\textit{beneficence, non-maleficence and justice}). (For more advice on communication skills please see the PALPRAC guidelines “Providing Palliative Care in South Africa During the COVID-19 Pandemic\(^9\) which can be accessed at: \texttt{https://palprac.org/wp-content/uploads/2020/04/PALPRAC_Providing-Palliative-Care-in-South-Africa-during-COVID-19-Update-5-April-2020-3.pdf}

While autonomy may be limited due to the public health imperative to contain the spread of the infection, respect for persons is a foundational principle and should be held in the forefront of all patient interactions and decision-making.
**Patient declines escalation of care**

If the patient is able to make an informed decision after being given the options available in a transparent and honest manner – and decides against being transferred onwards or for escalation of care – that decision should be respected (autonomy should be facilitated, but not at the expense of beneficence or the public good, in terms of infection control). The patient (and family) must be guaranteed of ongoing care and support (non-abandonment, reciprocity, non-maleficence). Please see the clinical guidance section of this guideline.

Given that mortality is high (~86%) if ventilated, many elderly and chronically ill patients may choose to forgo escalation of care. Such vulnerable patients must not be coerced into these decisions (non-maleficence; equality).

**Escalation of care/ transfer not possible or not advised**

If after discussion with the referral hospital’s team and EMS, transfer of the very unwell patient is not advisable or not possible due to resource constraints, then discussion with the patient, their family or health care proxy is very important to:

- Explain the reasons for transfer/ escalation of care not being possible (transparency; respect; justified decision-making/ rationale)
- Offer appropriate alternatives for ongoing care – remain at clinic, hospice, home (non-abandonment, beneficence, non-maleficence; duty to care, transparency, justice)
- Allow opportunity to respond to the decision. If disagreement by the patient or family, then a formal review to the clinical management team should be requested and escalated through the higher management structures from there
- Institute appropriate palliative care measures with support (psychosocial and spiritual)
- Provide adequate education and infectious precaution resources needed to nurse the patient at home if necessary
- Document discussion and consensus on management in patient’s records

Given the gravity of this discussion, every effort must be made to contact the patient’s family or healthcare proxy (if not accompanying the patient) telephonically and with an interpreter if needs be.

Anger (due to sense of helplessness, paternalism, social injustice, nihilism), disappointment, fear and a sense of abandonment are to be anticipated from the patient, their family and their community. The managing care team must be able to contain this situation. Palliative care support and expertise must be available to provide relief from suffering (physical, psychological, social and spiritual).

At this point, the patient might be too unwell to be transferred back home and would remain in hospital. This is an unwanted situation for many as there is likely to be no family present. The psycho-socio-spiritual suffering is immense, and we advocate for the appropriate care and follow up of all such patients and families, according to palliative care principles (justice, beneficence, non-maleficence).
(10) Decision to escalate care and transfer to referral hospital

The clinical team must be able to educate and engage with the patient regarding escalation of care and ICU care (respect for autonomy)

To transfer the patient to the COVID critical care center/ hospital requires:

- established communication networks,
- patient’s consent (respect for autonomy and respect for persons),
- availability of EMS personnel and ambulance or transport;
- infectious precautions available for EMS (adequate supply of PPE) and
- the assurance that further care is possible at the referral hospital and that the hospital has capacity to accept and care for the patient. (beneficence; non-maleficence; efficiency; utility; thus, justified call-out for EMS)

(11) The patient dies in transit and presents to the referral hospital “Dead on arrival” (DOA)

The rapid deterioration of COVID+ patients during transport (by EMS or with family from clinic/ district hospital or from home) can result in patients being found to be already deceased when arriving at a health care facility.

It would be important that each facility have a clear pathway of what actions to take and who will take on the necessary responsibilities (such as post-mortem COVID-19 swabbing, informing next-of-kin). These pathways and responsibilities can be amended for the COVID-19 situation, from the existing protocols. The ethical principle of respect for persons should be applied to the body of the deceased, ensuring that all handling of the body, including the post-mortem diagnostic swab, is dignified, while ensuring that all infection control procedures followed.

It is important that families are informed of their loved ones passing and questions and fears they may have explored and explained as best is possible. Professionals need to be compassionate and respectful in their communication with family members. The manner in which this news is shared should follow the principles of respect for persons, beneficence and also maintain appropriate confidentiality for the deceased person.

If the patient who has died was transported by family members, there will be additional ethical concerns and practical matters to consider. The duty to safeguard family members from infection and maintaining infection control should always be applied. It will be important to be able to ensure the physical and emotional safety of any lay person/family member who arrives at a facility with a deceased patient – adhering to the principles of beneficence and non-maleficence and respect for persons. In the light of restricted visiting and access to facilities, families will need access to information on what procedures will be followed regarding the body of their loved one and how they can plan a burial appropriate to their cultural or religious affiliations – adhering to the principle of respect for persons and ensuring protection of the community. To consider the principle of non-abandonment, pathways for referral to support services should be clear and be explained to family members, with facilitation of referral for any pressing psycho-social or spiritual need in the family.
(12) The patient is triaged again on arrival at the referral hospital

Each province in South Africa has such a center. Usually, the Triage system used in South Africa is the South African Triage System (SATS). During the pandemic, the WHO classification for disease severity ("mild", "moderate", "severe" and "critical") disease are used. If a patient is critically ill, he or she will be triaged for ICU using the CCSSA guidelines. The patient will also be screened for COVID if not already done so.

(13) Patient is unwell but escalation of care (e.g. ICU admission) deemed futile

"Futile" refers to ongoing or further care being deemed medically inappropriate. Should the patient after triaging be considered “critical”, and the clinical impression being that the likelihood of improved survival with quality of life is deemed unlikely AND the use of scarce resources during the pandemic needs to be used judiciously, then the patient’s care is not escalated as such. This type of decision may erroneously be interpreted as paternalistic or showing favouritism, but in order to preserve resources for a patient more likely to recover (end points to be determined) difficult decisions such as these need to be made. (utility) It is paramount that consensus is reached in management decisions after honest disclosure to the patient, their health care proxy or family (transparency).

(14) Collaborative and collective discussion between clinic team, patient and their family - decision consensus

If it is deemed by the clinic team, the patient and their family that the benefits to the patient’s well-being outweigh the possible risks to the patient and the concomitant use of resources – then the patient is transferred to a dedicated COVID critical center. Note, that the patients’ wish or preference (autonomy) is insufficient alone in a public health emergency to make the determination of transfer or escalation of care. Reaching a decision consensus may involve triaging and rationing of resources. The clinical team must be able to educate and engage with patient regarding potential patient choices, so that patient is part of the decision-making process and where appropriate can make a truly informed decision – justice, beneficence, non-maleficence, respect for persons. Similarly, the clinical team should be adequately skilled in appropriate communication techniques to provide appropriate care – beneficence, non-maleficence and justice.

(15) Patient wishes to return home with knowledge of likely death

If the patient expressly wishes to return home having been fully counselled that death would be likely at home (respecting patient’s autonomy) AND that discharge palliative medicine is available AND that there is family unit to receive and care for the patient AND they have been fully informed regarding the patient’s poor clinical status and infection control procedures AND what to do in the event of the patient passing away at home AND sufficient PPE is provided for the family’s safety in caring for the patient AND there is availability of transportation (reciprocity) then it could be conceived as ethically justifiable. It would be unacceptably unethical to discharge a vulnerable patient home without providing adequate medical supplies and palliative care support to them and their family.

(16) Escalation of care deemed medically appropriate

In this scenario, the patient is unwell (has Moderate to severe disease) but given appropriate escalation of care their prognosis is deemed fairly good.
While transfer is awaited, the patient must receive appropriate clinical care and psychosocial support – *beneficence and non-maleficence*. The patient’s family needs to be kept informed of the patient’s clinical status and proposed referral and receive clear information on the visiting protocols telephone numbers of the receiving hospital (*respect for persons, beneficence, non-maleficence, continuity of care*)

**(17) Resources for escalation of care unavailable**

This would include an ICU bed, or even high flow nasal oxygen being unavailable. In this scenario, moral distress for the healthcare team would be high as there is the possibility of not being able to provide life-saving care for a patient, who under “normal circumstances” would have survived if such necessary care was rendered. Palliative care is imperative in this scenario when the very unwell patient is then transferred to a general or palliative care ward for end-of-life care. See the section on Palliative Care Homecare Symptom Management Guide, for the healthcare professional, in these guidelines.

**(18) Collaborative and collective discussion between clinic team, patient and their family - decision consensus**

**(19) Patient transferred to general or palliative care ward**

See relevant sections of this guideline: Palliative Care Symptom Management, for the healthcare professional.

**(20) Resources for escalation of care available**

In this scenario, if the patient’s triage score is such that they qualify for ICU and there are such resources available AND it would be in the patient’s best-interests to mechanically ventilate with the hope of a good outcome then it would be unethical not to admit to ICU. (*non-maleficence*)

This is the ideal situation where the resources match the demand or need for care delivery. The patient receives care proportionate to his or her need with the hope of a favourable outcome (*beneficence*). This pathway is labour and resource intensive and needs to be reviewed frequently to assess that ongoing benefit is foreseen and that costs and risks are warranted.

**(21) Patient’s condition deteriorates OR a more appropriate patient requires the ICU bed**

In this case one would need to follow the hospital’s protocol as to how to navigate this situation.

This decision however must not appear paternalistic and needs to involve intensive collaboration and discussion with the care team (including palliative care), patient and their family to reach an informed consensus. Should the patient no longer be an ICU candidate, he or she would be transferred to a palliative care/ general ward with palliative care provision. The hospital is mandated to provide adequate palliative care – which requires the planning and implementation of palliative care pathways beforehand.

**(22) The patient recovers and discharged home**

Ideally, the patient’s condition might improve, and the patient recovers well enough to be discharged home. The patient’s mental health and rehabilitative needs should be screened for – being aware of Post-intensive care syndrome and deconditioning. Ongoing
appropriate care needs to be arranged prior to discharge (beneficence, and duty of care) with referral to local home-based care organizations and hospices. For patients who have accessed the health care system and been discharged home for palliative care – in terms of at home, there is a responsibility of the health system not to abandon patients and families, and to provide the necessary symptom relief for as long as this is required, and to support the care of patients and support for patients and families. This may require the dispensing of medication, the arrangement of home oxygen (if available), the education of family caregivers and the psycho-social and spiritual support of families, through the involvement of an interdisciplinary team. (Beneficence, non-maleficence, justice, respect for persons) Please see the clinical guidance section of this guideline.

The clinic is responsible for follow up of patients sent back home and wherever possible, referrals should be made timeously to the local home care organizations and hospice for follow up, palliative care training for existing staff, palliative care consultants, ample essential medication for the relief of symptoms and support of patients and families being cared for at home – respect for persons, non-abandonment, beneficence, non-maleficence and justice.

Adequate discharge summaries and communication needs to be provided. Further quarantine and isolation might be imposed on the patient and family should recovery period be <14 days. Despite this being an imposition on autonomy for the greater good of the community this needs to be adhered to (duty of the individual to society) – particularly in the light of having expended the health systems resources and the knowledge of the constraints on resources (reciprocity).

(23) Ethical justification on the quarantining of contacts and the isolation of symptomatic contacts

The COVID-19 virus is highly infectious. This has significantly curtailed the freedom of movement of individuals, in order to protect the community at large, and particularly the members of the community who are vulnerable to severe COVID-19 disease. The ethical principle of utility applies here, as the freedoms of individuals are temporarily and reasonably curtailed in order to protect the vulnerable and assist in the benefit of the greater good in minimizing the spread of the virus as far as is possible. Where contacts can appropriately and safely quarantine in their own home, this should be facilitated with dignity, ensuring that beneficence and non-maleficence are applied. In these instances, the assistance of communities to support quarantining individuals and families for provisions of food and other essential supplies needs to be supported. Where contacts are not able to quarantine in their own home, the provision of safe and appropriate quarantine facilities is the responsibility of the state. These facilities need to provide beneficent care and safety for all quarantined persons, always respecting persons and ensuring justice.
APPENDIX C: ACKNOWLEDGING THE IMPACT OF STIGMA DURING THE COVID-19 PANDEMIC

Stigma occurs when people negatively associate an infectious disease with a specific group of people, resulting in fear, anger, blame and even acts of violence towards those people perceived to have “started/spread” the disease. Stigmatization is not a new concept with regards to infectious illnesses; the bubonic plague, typhus, cholera, TB and HIV/AIDS pandemics all resulted in the stigmatization of specific groups of people.\(^47\)

Stigma occurs as a result of the uncertainty and misunderstanding around the disease which results in fear and anxiety that influences people’s behaviour. People need to understand where a disease comes from, how a disease is spread and how they can protect themselves against the disease.

Stigma can have a negative impact on a patient’s experience of the disease, their recovery from the disease and their mental health by:

- Discouraging people from seeking help for fear of being positive and having people find out and therefore exacerbate the spread and negative health outcomes of COVID-19.
- Creating fear of being “blamed” for spreading the virus and infecting others
- Creating barriers for governments and health professionals to control and assist in managing the outbreak e.g.: people not reporting symptoms and avoiding clinics for fear of being stigmatized.
- Decreases community compliance to the recommended behaviour changes required to control the spread of the disease.
- Destabilizing communities and isolating certain groups of people from their community, affecting not only those who may be ill but their friends, family, and the larger community too.

COVID-19 is no different from other diseases, and instances of stigma towards COVID-19 positive patients and the exposed healthcare workers on the frontline has already been reported\(^47,48,49\). In some countries the disease has been labelled a “Chinese disease” already causing groups of people to be ostracized and unfairly treated due to their heritage\(^50\). And due to the nature of COVID-19 one of the recommendations for controlling the spread of the disease is social distancing and isolating. Unfortunately, this recommendation may result in the further isolation and stigmatization of vulnerable populations such as the elderly and the immunocompromised\(^47\).

COVID-19 is a new disease, and it is understandable that its emergence and spread has caused confusion, anxiety and fear among the general public. It is important to acknowledge the impact that stigma can have on the preventative measures put in place to curb the spread of the disease, and strategies are needed to deal with these challenges. How and what we communicate about COVID-19 is critical in supporting people to take effective action to avoid fuelling fear and stigma. An environment needs to be created in which the disease and its impact can be discussed and addressed openly, honestly and in a culturally appropriate way.
Some examples of stigma during the COVID-19 pandemic that could occur include:

- **Language**: The language used by the government, social media and other channels can sometimes influence which group of people end up being blamed in a situation. For example, in COVID-19 it is the Healthcare workers who may be stigmatized as they are seen as being responsible for spreading the disease to their families and therefore into the communities.

- **Visual portrayals**: showing certain groups of people or professions associated with COVID-19

- **Physical attacks**: escalation to xenophobia where attacks are perpetrated on groups of people believed to be the cause of COVID-19, or that these groups will minimise their right to access health and/or that these groups are not entitled to equal access to health under the South African constitution.

**ADDRESSING STIGMA**

It is important that stigma is acknowledged and addressed early on. Communication, engagement with communities and identifying health advocates are vital steps to prevent the spread of fear and anxiety causing stigma, when a new disease arises.

**Communication**: Therefore, in order to prevent misunderstanding and miscommunication around COVID-19, it is vital to package communication around the disease that is appropriate and understandable for patients and communities, to help prevent them from panicking and help them to understand the disease better. The language used by the media and on social media must be carefully considered when creating educational messages regarding COVID-19 to create a positive message and perception of the disease amongst people. Social media plays a big role in everyday life and the perceptions on social media regarding COVID-19 need to be monitored and tailored to encourage compassion, care and understanding rather than fear and anxiety.

**Community engagement**: Community “buy-in” is important to ensure that the correct information and messages are spread through community networks. Communities need to be approached and organizations and prominent individuals in those communities engaged with to create a cohesive response to COVID-19. An example of this in South Africa are the CANs (Community Action Networks) that have been created across a variety of communities, to assist vulnerable communities with food, clothing and basic hygiene products etc. in response to the COVID-19 pandemic. It is also critical that in the midst of the COVID-19 pandemic it is ensured that other health programs or services continue to run in the different communities by supporting the health of program staff, providers, and beneficiaries through preventing COVID-19 infection, supporting links to COVID-19 related screening and care, and addressing the holistic well-being of HCWs and beneficiaries.

Identifying Health Advocates: Well-known and respected public figures could be identified and approached to help spread the correct information and attitude around COVID-19 to the public through social media and educational programs.
## APPENDIX D: LIST OF CONTACT NUMBERS FOR SUPPORT AT HOME

### COVID-19 HELPLINES

<table>
<thead>
<tr>
<th>Description</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>CORONA VIRUS (COVID-19) 24-HOUR HOTLINE NUMBER</td>
<td>0800 029 999</td>
</tr>
</tbody>
</table>
| CORONA VIRUS (COVID-19) WhatsApp Number | 0600 12 3456  
Step 1: Save The Number To Your Contacts On Your Cellphone.  
Step 2: In Send The Word "Hi" To Covid-19 Connect And Start Chatting. |
| COVID-19 Clinicians Hotline | 082 8839920 |
| National Institute for Communicable Diseases | 0800 029 999 |

### FOR EMERGENCIES NATION WIDE ACROSS SOUTH AFRICA

<table>
<thead>
<tr>
<th>Description</th>
<th>Number</th>
</tr>
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</table>
| Nation Wide Emergency number | 10111  
Calls to 10111 made on a landline are free. Calls made from a cell phone are charged at the normal cell phone rates. |
| Cell phone emergency | 112  
A call to 112 on a cell phone is free and is even possible on a cell phone that does not have airtime. |
| Ambulance response | 10177 |

### HOSPITALS DESIGNATED TO MANAGE COVID-19

<table>
<thead>
<tr>
<th>Province</th>
<th>Designated Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limpopo</td>
<td>Polokwane Hospital</td>
</tr>
<tr>
<td>Mpumalanga</td>
<td>Rob Ferreira Hospital</td>
</tr>
</tbody>
</table>
| Gauteng | Charlotte Maxeke Hospital  
Steve Biko Hospital  
Thembisa Hospital  
Designated Referral Hospital: Charlotte Maxeke Hospital |
| KwaZulu-Natal | Greys Hospital |
| North West | Klerksdorp Hospital |
| Free State | Pelonomi Hospital |
| Northern Cape | Kimberley Hospital |
| Eastern Cape | Livingston Hospital |
| Western Cape | Tygerberg Hospital  
Designated Referral Hospital Tygerberg Hospital |
<table>
<thead>
<tr>
<th>PSYCHO-SOCIAL SUPPORT DURING COVID-19</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SASSA</strong></td>
</tr>
<tr>
<td><strong>National SASSA call centre</strong></td>
</tr>
<tr>
<td><strong>Eastern Cape</strong></td>
</tr>
<tr>
<td><strong>Free State</strong></td>
</tr>
<tr>
<td><strong>Gauteng</strong></td>
</tr>
<tr>
<td><strong>KwaZulu-Natal</strong></td>
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<td></td>
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<tr>
<td><strong>Limpopo</strong></td>
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<tr>
<td><strong>Mpumalanga</strong></td>
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<tr>
<td><strong>Northern Cape</strong></td>
</tr>
<tr>
<td><strong>North West</strong></td>
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<tr>
<td><strong>Western Cape</strong></td>
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<table>
<thead>
<tr>
<th><strong>Childline National number and regional offices</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Childline National number/email</strong></td>
</tr>
<tr>
<td>Tel: (+27)-(0)31-201 2059</td>
</tr>
<tr>
<td>Fax: (+27)-(0)86 511 0032</td>
</tr>
<tr>
<td>Email: <a href="mailto:admin@childlinesa.org.za">admin@childlinesa.org.za</a> (General Enquiries)</td>
</tr>
<tr>
<td>Email: <a href="mailto:olcadmin@childlinesa.org.za">olcadmin@childlinesa.org.za</a> (Counselling/Case Enquiries)</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td><strong>Childline Eastern Cape</strong></td>
</tr>
<tr>
<td>Tel: (+27)-(0)43 722 1382</td>
</tr>
<tr>
<td>P. O. Box 11127, Southernwood, 5213</td>
</tr>
<tr>
<td>Email: <a href="mailto:admin@childlineec.org.za">admin@childlineec.org.za</a></td>
</tr>
<tr>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td><strong>Childline Free State</strong></td>
</tr>
<tr>
<td>Tel: (+27)-(0)51-4303311</td>
</tr>
<tr>
<td>PO Box 1011, Bloemfontein, 9300</td>
</tr>
<tr>
<td>Email: <a href="mailto:reception@cwcl.org.za">reception@cwcl.org.za</a></td>
</tr>
<tr>
<td>Web: <a href="http://www.childwelfarebfn.org.za">www.childwelfarebfn.org.za</a></td>
</tr>
<tr>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td><strong>Childline Gauteng</strong></td>
</tr>
<tr>
<td>Tel: (+27)-(0)11-6452000</td>
</tr>
<tr>
<td>PO Box 32453, Braamfontein</td>
</tr>
<tr>
<td>Email: <a href="mailto:admingauteng@childline.org.za">admingauteng@childline.org.za</a></td>
</tr>
<tr>
<td>Web: <a href="http://www.childlinegauteng.co.za">www.childlinegauteng.co.za</a></td>
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</tbody>
</table>
### South African Depression and Anxiety Group (SADAG)

<table>
<thead>
<tr>
<th>Service</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Counselling</strong></td>
<td>To contact a counsellor between 8am-8pm Monday to Sunday.</td>
</tr>
<tr>
<td></td>
<td>Call: 011 234 4837 / Fax number: 011 234 8182</td>
</tr>
<tr>
<td><strong>Suicide Emergency helpline</strong></td>
<td>0800 567 567</td>
</tr>
<tr>
<td><strong>24 hour helpline</strong></td>
<td>Cell: 0800 456 789 / WhatsApp: 076 88 22 775</td>
</tr>
<tr>
<td><strong>Destiny Helpline for Youth &amp; Students</strong></td>
<td>0800 41 42 43</td>
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</table>

### Other support services

<table>
<thead>
<tr>
<th>Service</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hospice Palliative Care Association (HPCA)</strong></td>
<td>021 531 0277 / Can provide details of hospices in your area for home care support</td>
</tr>
<tr>
<td><strong>Akeso Psychiatric Response Unit</strong></td>
<td>0861 435 787</td>
</tr>
<tr>
<td><strong>24 Hour</strong></td>
<td>24-hour helpline 0861322322</td>
</tr>
<tr>
<td><strong>Lifeline</strong></td>
<td>0800 12 13 14 / SMS 32312</td>
</tr>
<tr>
<td><strong>Department of Social Development Substance Abuse Line 24hr helpline</strong></td>
<td>0800 012 322 / SMS ‘help’ to 31531</td>
</tr>
<tr>
<td><strong>Gender-based violence command centre</strong></td>
<td>0800 428 428 / or dial: <em>120</em>7867# (free for mobile)</td>
</tr>
<tr>
<td><strong>Person with Disabilities</strong></td>
<td></td>
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<tr>
<td><strong>AIDS Helpline</strong></td>
<td></td>
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<tr>
<td><strong>Woman Abuse Helpline</strong></td>
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APPENDIX E: HOMEMADE PROTECTIVE CLOTHING

BASIC HAND HYGIENE

If you are looking after a loved one at home who is COVID-19 positive, you need to be able to protect yourself from getting the virus. The **BEST WAY** to do this is to ensure good and proper **HAND HYGIENE**. This means that you need to wash your hands regularly.

*How to handwash*

**Use:** soap and water

**Steps:**
1. Wet the hands
2. Apply the soap onto the hands
3. Rub the hands together for 20 seconds, making sure you rub the front and back, between fingers and under the nails.
4. Rinse the hands under running water.
5. Dry the hands with a clean towel or paper towel if possible.

- *If no running water, wash hands in a basin or bucket with soap. Discard the water away from the house.*
- *The towel assigned to the COVID-19 patient should not be shared with other members of the household.*

Wash your hands:

- 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 the patient’s nappy
- After blowing your nose, coughing or sneezing
- After touching an animal or animal food
- After handling garbage

**Sanitizer**

**Hand sanitizing:**

- Sanitizer can also be used in between washing hands when working with the patient. Sanitizer needs to contain at least 70% alcohol to be effective. **SANITIZING DOES NOT REPLACE HANDWASHING**
- Keep a bottle of sanitizer in the patient’s room where they are staying in the home and use after washing hands when going in and out of the room.

**Sanitizing surfaces:**

- Surfaces in the patient’s bedroom and through the house, especially the bathroom, if shared, need to be sanitized. You can use six (6) tablespoons of bleach mixed with four (4) cups of water.
The virus can spread through droplets, when people sneeze, cough and talk, therefore it is **VITAL** that you wear a mask. Masks can be made from 3-layers of fabric. These masks need to be worn **AT ALL TIMES** when working with the patient and should be washed in hot water at the end of every day, dried and ironed before next use. It is wise to have more than one mask so you can have a clean one on and the other can be washed. If you do not have a mask you can use a scarf or bandana too **BUT REMEMBER THE MASK/SCARF/BANDANA MUST COVER YOUR NOSE AND MOUTH AT ALL TIMES.**

*See the poster below for information on how to safely wear your mask at home and when caring for your loved one*

**Masks**

The virus can spread through droplets, when people sneeze, cough and talk, therefore it is **VITAL** that you wear a mask. Masks can be made from 3-layers of fabric. These masks need to be worn **AT ALL TIMES** when working with the patient and should be washed in hot water at the end of every day, dried and ironed before next use. It is wise to have more than one mask so you can have a clean one on and the other can be washed. If you do not have a mask you can use a scarf or bandana too **BUT REMEMBER THE MASK/SCARF/BANDANA MUST COVER YOUR NOSE AND MOUTH AT ALL TIMES.**

**Storing your mask safely**

When looking after your loved one at home you will be wearing your mask inside their room when you are working with them (feeding them, bathing them etc). Once you have finished and exit the room, you will need to remove your mask, so you do not spread the droplets that may have settled on the outside of the mask to anyone else in the house. You will therefore need to safely remove and store your mask for when you next need to go into the room during that same day (**remember masks must be washed and dried, then ironed at the end of each of day**). Below are some ways that you can safely remove and store your mask:

**Using a Ziploc (sealable plastic) bag:**

- **ALWAYS** remove the mask from behind touching ONLY the straps/ties of the mask.
- **NEVER** touch the front of the mask.
- Place the mask into the Ziploc bag and seal it.
- Spray the bag with sanitizer or wipe it down with a cloth and warm soapy water. **WASH**
YOUR HANDS AFTERWARDS.

- Store safely out of reach of children.
- When you need to use the mask again, open the bag and take the mask out TOUCHING ONLY THE STRAPS/TIES NEVER THE FRONT OF THE MASK. Place it over the nose and mouth and wash hands afterwards.

**Using a plastic rectangular shaped container:**

- Choose a container that has a lid and will fit your mask fully inside, and able to cover your nose and mouth.
- Make some small holes in the sides of the container, to let air into the container.
- When finished wearing your mask, take the lid of the container off.
- With one hand place the container over your nose and mouth area, covering your mask fully. You will touch the outside of the container not your mask.
- For a mask with “over the head straps”: With your other hand bring the straps from the back of the head over to the front, and over the outside of the container.
- For a mask with ear loops: With the other hand undo the ear loops from the ears.
- The mask will then be inside the container and you can remove the container from the face and put the lid in place.
- Spray the container wipe it down with a wet, soapy cloth.
- WASH YOUR HANDS AFTER THIS.
- Store safely out of reach of children.
- When you need to use the mask again, wash your hands, take the lid off of the container.
- Holding the outside of the container with one hand, place the mask over your nose and mouth area, then using the other hand pull the straps over the head or put the ear loops in place.
- WASH YOUR HANDS AFTER THIS.
- **NOTE: storing your mask safely when not using it, does not replace washing your mask. Masks must still be washed at the end of the day.**
HOW TO WEAR A NON-MEDICAL FABRIC MASK SAFELY

**Do’s**

- Adjust the mask to your face without leaving gaps on the sides
- Cover your mouth, nose, and chin
- Avoid touching the mask
- Clean your hands before removing the mask
- Remove the mask by the straps behind the ears or head
- Pull the mask away from your face
- Store the mask in a clean plastic, resealable bag if it is not dirty or wet and you plan to re-use it
- Remove the mask by the straps when taking it out of the bag
- Wash the mask in soap or detergent, preferably with hot water, at least once a day
- Clean your hands after removing the mask

**Don’ts**

- Do not use a mask that looks damaged
- Do not wear a loose mask
- Do not wear the mask under the nose
- Do not remove the mask where there are people within 1 metre
- Do not use a mask that is difficult to breathe through
- Do not wear a dirty or wet mask
- Do not share your mask with others

A fabric mask can protect others around you. To protect yourself and prevent the spread of COVID-19, remember to keep at least 1 metre distance from others, clean your hands frequently and thoroughly, and avoid touching your face and mask.
A mask is the most important protection for the face. Eye protection is not always needed. Eye protection is a good idea when the patient is coughing or talking a lot and you are close to them while you care for them, such as washing, changing etc. Or if the patient struggles to wear a mask due to breathlessness and feeling anxious. Goggles and face-shields are used to protect the eyes from droplets entering, as well as prevent you from touching/rubbing the eyes without thinking and with hands that have not been washed and may carry the virus. At home you can wear your normal glasses to protect the eyes or you can try and make a “face-shield” that can be worn while working with the patient.

To make the face-shield you will need the following:

- A plastic or firm fabric headband (Alice band)

- A plastic sleeve for filing papers

1. The plastic sleeve has one side with a strip that has holes in it. At the bottom of this strip you will find an opening.

2. Take the head band and insert one end of the headband into this opening, feed the head band through the opening until you reach the other side of the strip.

3. Once the headband is all the way through, make sure the plastic sleeve is not “bunched up” anywhere along the headband.

4. You can now place the head band around the top of the forehead with the ends of the head band facing towards the back of the head. This will form your face shield.

5. When using the face shield, you STILL need to use a mask, the mask will be placed on first, as usual and the face shield will go on after.

6. ALWAYS wash your hands before and after putting the face shield on and try to only touch the sides of the headband not the front of the face-shield.

7. The face shield can be cleaned with an alcohol-based sanitizer spray or hot soapy water and left to dry, out of reach of children.

You can access a video on this here: [https://youtu.be/fw7z9Xe4b78](https://youtu.be/fw7z9Xe4b78)
Wearing an Apron can help prevent the droplets that are sneezed/coughed by the patient from landing onto your clothes and spreading the virus to others.

- The apron would be worn ONLY in the room with the patient.
- Once finished working with the patient you would remove the apron before leaving the room.
- Leave the apron in the room, preferably hanging up off the floor, so it is ready for use the next time you need it.
- You would WASH and sanitize your hands after touching the apron.

Making your own apron

An apron can easily be made using a black refuse bag. Below is one way of making the apron from a bag.

- Cut a round hole in the bottom of the bag (the sealed side), this is for your head to go through.
- Cut a smaller hole on each side of the bag for your arms to go through.
- The bag can then be put over the head and the arms can slide through either side. This will protect your clothing.
- When taking the bag off or putting the bag on try to touch the outside as little as possible and make sure you wash your hands after touching the bag.
- ONLY wear the bag when working with the patient, REMOVE when finished, do not wear around the house.
- At the end of each day spray the bag with sanitizer or wipe it down with a soapy cloth and let dry.
- Discard the bag if it gets torn.
- To discard, ensure that the bag is placed into a waste bin lined with a packet and then the packet is closed and put into another bag (double bagged) which can be left outside for 3-5 days and then added to the rubbish for collection by the garbage truck.

The picture below shows you a way to make an apron from a garbage bag with ties that will go around the neck and the waist. This could also be used for protecting the clothes.

https://i.pinimg.com/originals/4e/f4/7f/4ef47f6ce8e4273164da4f12468ff0dd.jpg
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