# Providing Palliative Care for Patients with COVID-19

# Home Based Care Guideline

HPCA
CARE & SUPPORT
Hospice Palliative Care Association of South Africa

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# Introduction to Covid – 19

## Purpose of this Guideline:

The Covid-19 pandemic presents a unique challenge and opportunity for Hospices in South Africa. This guideline is an attempt to provide an easy procedure for the provision of Home Based Care to Palliative Care patients who may have Covid-19 or who may be at risk of Covid-19.

At all times Health Care Workers must abide by guidelines issued by the Department of Health at both a national as well as provincial levels. Where these guidelines are available, they will be placed on the HPCA website in a resource portal.

## What is Covid-19?:

In essence, Covid-19 is a virus that affects the respiratory systems. It is transmitted through large droplets that are produced while sneezing and/or coughing.

The main symptoms of Covid-19 are as follows:

- High temperature or fever (greater than 38ºC);
- Mild to severe respiratory illness with a cough;
- Sore throat;
- Shortness of breath or difficulty breathing;
- Loss of taste or smell;
- Muscle pain;

It is to be noted that symptoms range from mild through to severe and people with underlying conditions and the elderly are more at risk. Covid-19 has a very high infection rate and is easily transmitted. The details on infection control are very important in this regard to try and prevent the transmission of the virus as much as possible.

For more detailed information, please consult various on-line resources as mentioned in the Annexure at the end of this document as well as the HPCA website.

# Infection control

The following infection control suggestions are recommended. However, each Hospice must decide what can be afforded and therefore, what can be implemented. If PPE is not available at the particular Hospice for whatever reason, direct contact with Covid-19 patients should be discouraged. Contact with known Covid-19 patients should only happen with the use of all available PPE. The use of PPE should be encouraged at all times even in visiting patients who Covid-19 status is unknown.

## Personal Protective Equipment for Health Care Workers:

For Health Care Workers caring for known or suspected Covid-19 patients, compulsory Personal Protective Equipment (PPE) consists of the following:

- Gloves;
- Surgical Masks (the use of N95 masks is recommended);
- Gown/Apron;
- Visors/eye protections;

## General infection control measures:

General infection control measures that should be communicated to patients and families as part of the palliative care interventions for Covid-19 patients are detailed below. All such interventions must be documented on the patients file for inclusion in patient statistics and reporting on as required.

### Patients and families

- Refrain from touching face (mouth, nose);
- Refrain from touching eyes;
- Use of a cloth or surgical mask if needing to visit supermarkets etc.;
- Regular washing of hands with soap and water (for at least 20seconds);
- Use of alcohol-based hand sanitizer where soap and water are not available;
- Regular cleaning and/or disinfecting of surfaces – soap and water is sufficient or use of an alcohol-based cleaning liquid;
    - In the home a solution of Jik/Bleach will work;
- Implementing a strict cough etiquette;
- Educate patients and families on symptoms and signs of Covid-19;
- Identify who to contact if a patient or family member develops any of the symptoms and signs of Covid-19;

The following general guidelines are provided for families who are caring for a known Covid-19 patient at home. The isolation of the patient within the home:

- Make use of a separate room (preferably with an on-suite bathroom);
- Limit access to this room at all time;
- Have some simply system for the patient to call for assistance;
- Make use of gloves and other PPE as described above;

- Linen, clothes, etc. should be cleaned using a hot wash (60ºC or above) and dried in the sun;
- Cutlery and crockery should be washed in hot water with the addition of bleach and then washed with regular dish-wash liquid/soap;
- Clean surfaces all times with a solution of bleach;
- Open windows for air flow and allow sunlight into the room if possible;

### Hospice staff:

An infection control plan should be put in place detailing what PPE is available, a process whereby more can be purchased/sourced, a responsible person to oversee the plan and communicate with relevant persons about the plan.

The most effective infection control measure is to avoid persons with Covid-19. However, this is not possible for Health Care Workers, so every precaution must be put in place to ensure the safety of members of the Care Team[1].

It is recommended that if a member of the Care Team is caring for a patient who is known to have Covid-19, then that HCW should not provide care to any patient(s) who do not have Covid-19. That in the event that HCW are providing care to Covid-19 patients a special Covid-19 care team be put together who will exclusively provide care to these patients. This will limit the spread of the virus by HCW to other patients. In the case where there is an IPU, IPU staff who are caring for Covid-19 patients should not have contact with staff who are providing Home Based Care.

It is further recommended that regular (preferably, daily) screening of staff take place where care is being provided to patients with a known Covid-19 diagnosis.

## Management of waste:

All PPE needs to be disposed of carefully and the Health Care Worker needs to be aware of the potential for the Covid-19 virus to survive for up to 9 days on different types of surfaces.

PPE, once removed, needs to be placed in a secure plastic bag and hand hygiene needs to be conducted. The plastic bag must then be secured and placed inside the container for hazardous waste at the office. All Hospices should have a procedure for the disposal of hazardous material that may involve a third party company[2]

## Transporting of patients:

If it become necessary to transport a patient with a known Covid-19 diagnosis or a suspected diagnosis the following should be observed:

1 This is also a requirement of all Occupational Health and Safety Programmes. For more information consult the various OHS plans within the organisation or consult with an external expert.
2 Local procedures in this regard must be reviewed to ensure that they are adequate.

- The current (and any future) transport provisions relating to the state of disaster must be observed;
- The vehicle used may not be more than 70% occupied;
- The vehicle must be well ventilated with windows open;
- All occupants of the vehicle must be wearing a surgical mask (minimum);
- The vehicle must be cleaned with a bleach solution before, and after each transporting of a patient;
- Any restrictions on the movement of Covid-19 patients must be researched and observed;

## Home Based Care for Palliative Care Patients with Covid -19

Within Hospices throughout South Africa a system/process should exist whereby patients are admitted in terms of a set policy/procedure. The Hospice determines the admissions policy and the types of diagnostic tests that need to be completed prior to the admission of the patient in the Home Based Care systems of that particular Hospice. It is conceivable in the current environment and that there will be requests made to Hospices to provide Home Based Care to patients with a primary diagnosis of Covid-19. The extension of care to as wide a section of the community is encouraged at all times. Hospices are encouraged to ensure that they have the necessary resources available to extend this care. A patient with Covid-19 symptoms may not necessarily be needing direct face-to-face care at the onset. However, Covid-19 can be classified as a life-threatening illness (in particular when there are underlying diagnoses that may render a poor prognosis) and as such all Covid-19 patients will need Palliative Care. The focus of this care may well be psycho-social in nature for the most part, but clinical care should not be excluded from the planning.

The Association of Palliative Care Practitioners of South Africa (PALPRAC) have suggested a severity scoring of Covid-19 patients which focuses on the symptoms and the related type care such a patient may need[3].

Please take note that provinces may implement the requirements of Covid-19 care in slightly different ways. It is strongly encouraged that at all times the requirements of your province are implemented.

## Classification of Covid-19 severity:

A simple classification of Covid-19 patients is listed in the resource list at the end of this document.

The following table gives a brief overview:

3 PALPRAC document “Providing Palliative Care in South Africa during the Covid-19 Pandemic”

| Severity of the Disease | Symptoms | Interventions |
|---|---|---|
| Mild-to Moderate COVID-19 cases | Less likely to need oxygen | • Education on COVID-19, Infection control at home for patients and Families<br>• Symptom 'management control<br>• Delivery of medication<br>• Important number, referral pathways<br>• Psychosocial support for patient and family |
| Severe COVID-19 cases | Less likely to need mechanical ventilation. Likely needs oxygen | • Education on COVID-19, Infection control at home for patients and Families<br>• Symptom 'management control<br>• Delivery of medication<br>• Important number, referral pathways<br>• Psychosocial support for patient and family |
| Critical COVID-19 cases | Probably needs mechanical ventilation | • Palliative Care<br>• Psychosocial support for family |
| Expectant of not surviving COVID-19 | Survival not possible with care available | • Palliative Care<br>• Psychosocial support for family |

# Mild to Moderate Covid-19 Patients:

## Infection control procedures:

At all times standard infection control procedures to be implemented by all Health Care Workers who are providing direct (on-site) patient care. It is a good idea to assume that the patients/household has Covid-19 and to take the necessary precautions.

There must remain a focus on hand sanitation, use of appropriate protective wear and in particular respiratory masks and eye protection measures;

Instruction and education to be provided to family members on infection control measures (documented) and (if available) to provide such PPE to the family/household.

Patients and families must be educated on the signs and symptoms of Covid-19 and what to do and who to contact if the symptoms become more severe.

## Clinical Care provided:

The focus of care should be directed to the underlying reasons for the patients admission (initial diagnosis) with additional care being provided to address and control the symptoms of Covid-19. The focus is on symptom control.

The following treatments are recommended[4]:

- **Fever:** Paracetamol 1000mg 6hrly PO PRN;
- **Anxiety:** Lorazepam 1mg-2mg s/l q2h prn until patient has settled, then 6-12 hourly PRN or alprazolam 0.5-1mg 8hrly PRN;

4 With thanks to PALPRAC document "Providing Palliative Care in South Africa during the Covid-19 pandemic"

- **Dyspnoea:** Morphine syrup (Mist Morphine) 2.5-5mg PO 4hrly. Note: the amount of morphine syrup will vary depending on the strength at which it is mixed. Common strengths are 5mg/5mL (in which case give 2.5-5mL), 10mg/1mL (in which case give 0.25-0.5mL) or 20mg/5ml (in which case give 0.6-1.25ml). Specify strength in the script eg Mist morphine **(20mg/5ml) 0.6ml 4 hrly**.
- If patient is already on morphine for pain control, increase the total 24-hour dose by25% to add additional dyspnoea benefit Fever.
- In the elderly and those with renal failure, start at lower doses.

For treatment of any other symptoms related to the patients underlying medical condition, please follow HPCA clinical guidelines.

At all times all available PPE must be used as directed. Health Care workers should only nurse (provide care to) one patient at a time during this time. If it is possible and indicated, designated individuals from within the Care Team should be providing care to patients with Covid-19 and they should provide care to patients without Covid-19.

Given that patients with a Covid-19 diagnosis will be required to be in isolation (either formally or informally) an important support tool could be to offer to collect medication for the patient/family. Permission in writing to do this will be needed.

## Psycho-social care provided:

Given some of the uncertainty and fears that surround most patients when they are diagnosed with a life limiting/life threatening illness, the need for counselling is pre-eminent. This counselling can be delivered by nurses initially, but frequently will need to be provided by social workers in the long run. Given that Covid-19 has created more fear and uncertainty (and related fake news) it is imperative that counselling (psycho-social support) be provided to all patients who have been diagnosed with Covid-19. At the very least such counselling should seek to ally fears and any fake news that the patient/family may have heard/read.

All these interventions can and should be provided telephonically to limit the direct contact between patients and care workers.

Given the risks of infection the opportunity created by the Covid-19 should be exploited to develop alternative means of communicating with patients/families. Use of telephones, WhatsApp and other related media should be explored. Centralised messaging to patients in similar circumstances can be explored and set up within organisations with limited resources. WhatsApp groups for patients within similar categories can be created. Where e-mail correspondence is possible this gives an opportunity to provide more detailed messages.

## Severe Covid-19 Patients:

### Infection control procedures:

At all times standard Universal Precautions measures to be implemented by all Health Care Workers who are providing direct (on-site) patient care.

There must remain a focus on hand sanitation, use of appropriate protective ware and in particular respiratory masks.

Instruction and education to be provided to family members on infection control measures (documented) and (if available) to provide such PPE to the family/household.

### Clinical Care provided:

The focus of care should be directed to the underlying reasons for the patients admission (initial diagnosis) with additional care being provided to address and control the symptoms of Covid-19. The focus is on symptom control.

Patients showing severe Covid-19 symptoms may be in need of oxygen. Education for the patient and the family needs to be provided on the correct use of available equipment.

The following treatments are recommended[5]:

- Patients showing severe Covid-19 symptoms may be in need of oxygen. Education for the patient and the family needs to be provided on the correct use of available equipment:
- **Oxygen Therapy**: Oxygen therapy is likely to be the single most effective supportive measure in COVID-19 patients. As per the COVID Clinical Guidelines, any patient with hypoxaemia (saturation <90%) should be given supplemental oxygen to achieve O2 saturation >90% (aim for >92% in pregnant women);
    - Nasal cannula: 21-40% oxygen (with surgical mask covering to prevent droplet spread); O2 dose 1-5L/min;
    - Simple face mask: 40-60% oxygen; O2 dose 6-10L/min;
    - Non-rebreather facemask: 60-95% oxygen; O2 dose 10-15L/min; ensure proper fit, to reduce risk of aerosol spread;

5 With thanks to PALPRAC document “Providing Palliative Care in South Africa during the Covid-19 pandemic”

Oral treatments:

- **Fever:** Paracetamol 1000mg 6hrly PO PRN;
- **Anxiety:** Lorazepam 1mg-2mg s/l q2h prn until patient has settled, then 6-12 hourly PRN or alprazolam 0.5-1mg 8hrly PRN;
- **Dyspnoea:** Morphine syrup (Mist Morphine) 2.5-5mg PO 4hrly. Note: the amount of morphine syrup will vary depending on the strength at which it is mixed. Common strengths are 5mg/5mL (in which case give 2.5-5mL), 10mg/1mL (in which case give 0.25-0.5mL) or 20mg/5ml (in which case give 0.6-1.25ml). Specify strength in the script eg Mist morphine **(20mg/5ml) 0.6ml 4 hrly**.
- **If patient is already on morphine for pain control, increase the total 24-hour dose by25% to add additional dyspnoea benefit Fever;**
- In the elderly and those with renal failure, start at lower doses;

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

- **Fever:** Paracetamol 1000mg 6hrly IV may be given rather than oral (if available);
- **Anxiety:** Haloperidol 2-5mg SC stat and add 5mg over 24 hours CSCI (as alternative to Midazolam);
- **Dyspnoea:** Give Morphine Sulphate 1-2mg SC/IV and Midazolam 5mg stat SC. Then:
    - CSCI with ASP: mix in a 20ml, 30ml or 50ml syringe
        - Morphine 15mg
        - Metoclopramide 30mg
        - Midazolam 10-15mg
        - Fill up with ‘water for injection’, to a volume as determined by the device used, if needed. Set up to run over 24 hours OR:
    - for IV infusion with infusion pump: mix in 200ml 0.9% sodium chloride
        - Morphine 15mg
        - Metoclopramide 30mg
        - Midazolam 10-15mg
        - Run in over 24hours using an infusion pump;
- **If patient is already on morphine for pain control, increase the total 24-hour dose by25% to add additional dyspnoea benefit Fever;**
- In the elderly and those with renal failure, start at lower doses.

For treatment of any other symptoms related to the patients underlying medical condition, please follow HPCA clinical guidelines.

At all times all available PPE must be used as directed. Health Care workers should only nurse (provide care to) one patient at a time during this time.

### Psycho-social care provided:

Psycho-social interventions for these patients should focus on the fears associated with a severe illness. In particular if the patient is elderly and/or the patient has an immune compromising illness. The fear of possible death for the patient as well as the family could be heightened. These must be addressed as part of a comprehensive and holistic counselling programme from the Hospice (preferentially provided by a social worker or relevantly trained lay person – under supervision). Attention to estate planning can be included.

A very real and emotionally charged situation is that a patient with severe symptoms may be in isolation and the family may not have access to the patient. This creates additional strain and fears on the part of the family. These particular fears must be addressed as well.

There may still be room for group electronic interactions at this level, but individual interactions are to be encouraged. Only a family member should be providing care at this stage.

## Critical and Terminal Covid-19 Patients:

### Infection control procedures:

It is unlikely that patients who are critical with Covid-19 are going to be in need of Home Based Care.

### Clinical Care provided:

The clinical care needed by these patients should be provided within institutions. However, the psychosocial care may well be lacking within these institutions and the focus of Hospice care for these patients should be on counselling for the patient and the family.

### Psycho-social care provided:

Psycho-social interventions for these patients should focus on the fears associated with a severe illness. In particular if the patient is elderly and/or the patient has an immune compromising illness. The fear of possible death for the patient as well as the family could be heightened. These must be addressed as part of a comprehensive and holistic counselling programme from the Hospice (preferentially provided by a social worker or relevantly trained lay person – under supervision). Attention to estate planning can be included and Spiritual care.

A very real and emotionally charged situation is that a patient with severe symptoms may be in isolation and the family may not have access to the patient. This creates additional strain and fears on the part of the family. These particular fears must be addressed as well.

There may still be room for group electronic interactions at this level, but individual interactions are to be encouraged.

## Additional suggestions:

- Collection of medications: Given the need for physical distancing (social isolation) the ability to assist with the collection of medications for patients will assist in allowing patients with underlying illnesses to remain secure in their homes.
- Mental well-being: Design tools and systems to preserve the mental well-being of patients who are affected negatively by the physical isolation measures. Discussions with the local Mental Health organisation may be able to provide suitable tools and ideas on preserving and developing mental health in the community during this time.
- Of particular concern are family members who will be living alone as a result of the death of the patient during this time of lock-down. Particular bereavement support will be needed in these instances. The bereaved may want face-to-face visits simply to alleviate the monotony of being alone (by themselves) after the death of a loved one. Where possible remote counselling must still be provided and special care to universal precautions implemented if a home visit is indicated.
- Advance Care planning: There are generally challenges when discussing advance care planning with patients and families and these challenges are recognised. It is imperative however, that patients and families consider future treatment options within a Covid-19 environment. The potential for complications of pre-existing conditions is heightened and the challenges faced during isolation and quarantine will affect future care planning. Social worker and nurses should raise these potential issues as gently as possible (made more difficult if this is taking place remotely). Treatment options should be discussed, planning for children (if relevant) and estate planning should all form part of these discussions. The need for excellent referral networks becomes obvious and should be used as necessary.

# Bereavement and spiritual care

Given the mortality rate of Covid-19 it is inevitable that some of our patients with this diagnosis will die as a consequence. Bereavement preparation and care and related spiritual care needs to be provided depending on the resources of the Hospice concerned. It is very important that those who provide the bereavement and spiritual care (if they are not part of the regular care team) must also be trained in the use of PPE as described below. They must also receive training on Covid-19 to ensure their safety.

It may be necessary, as part of the bereavement preparation, to discussed Advanced Care Planning (understanding some of the cultural challenges involved). This has the potential to begin to place the patient/family back in control of the care processes.

Spiritual care should focus on the place of the patient in the wider scheme of things and the assurance of continuance of life in what appears to be a very dark time. The interconnectedness of all things may well lend a sense of hope and also help patients to situate themselves in a wider scenario.

For patients of faith, the particular elements of that patient's faith (possibly in consultation with the family) that support the oversight of the divine can be used to help the patient find hope and support.

## Referral system:

The need for continuum of care for those diagnosed with Covid-19 is critical. Given the severity of this pandemic many procedures that Palliative care patients may normally undergo may well be delayed for a period of time. This will lead to challenges in the care of palliative patients as well as to uncertainty being experienced by the patient as well as the family.

Correct referrals to and from various institutions will go a long way to alleviating some of these uncertainties and the experience of vulnerability. These referrals can be facilitated by ensuring that clear networking is taking place and advocacy on the part of the patient is foremost on the mind of the care team at all times. Delays and challenges in communication may need to be specifically addressed through specific communication with the right people at the right time.

A document/resources depicting the referral pathways within each province should be made available for the Care Team. This will need to be updated on a regular basis. At the very least the following list of numbers/contacts should be made available to the care team and then also passed on to patients and families as part of the general education on Covid-19:

- National Covid-19 number:
- Provincial Covid-19 number:
- Local[6] disaster management (Covid-19) number:
- Contact number to arrange screening/testing:
- Which local hospital is accepting Covid-19 patients:

In the case where a patient with known or suspected Covid-19 dies at home, the following should be observed. These may differ in the provinces and it is suggested that additional details be obtained for your specific province:

- A patient with severe Covid-19 will most likely die within an institution;
- On death, the family or care staff are to notify the appropriate authorities and/or undertakers;
- Do not touch the body at all – leave the body in the room where they have died. This may be difficult given some cultural and religious practices but in order to prevent further spread of the virus, do not touch the body;
- All linen and clothes must be washed in hot water and with the addition of bleach/jik;

6 The local number may be the same as the provincial number

- The entire room must be wiped down with a bleach solution;
- When the funeral takes place, an open casket can be allowed, but no touching or kissing of the deceased;
- These may be difficult in certain circumstances, and appropriate counselling by social workers to facilitate these actions will assist the family in coping with the death of their loved one.

## Training

The following training needs to be provided to all Health Care Workers providing Home Based Care to patients who may have Covid-19. As there is uncertainty at this stage as to how soon a Covid-19 patient become infectious (able to spread the disease to others) it is better to err on the side of caution and make an assumption that the risk for infection always exists.

- Basic hand washing procedures ensuring that hands are washed for at least 20 seconds with soap and in running water.
- Use of alcohol-based sanitizers, including some of the side effects of (or reactions to) these products;
- Use of masks, which masks should be used by health care workers, those to be used by patients or members of the community;
- Use of gloves and aprons/gowns;
- Use of eye visors;
- The value of physical distancing (social distancing);
- Training on removal of PPE and correct disposal of said items as detailed above;

All this training must be documented[7] and it should be provided to patients and families as well. Training provided to patients and family members must also be documented.

## Occupational health and safety considerations

A comprehensive Risk Management Assessment and Plan needs to be designed and implemented that conforms with all the regulations of the Occupation Health and Safety Act. This should include at a minimum the following items each with their own set of procedures:

- Use of PPE and training in use of PPE;
- Cleaning/disinfecting of all surfaces;
- Cleaning/disinfecting of surfaces inside vehicles;

7 This is very important for all staff and volunteers as it may be required as evidence if any staff contract the virus as part of their regular duties.

- Correct/adequate procedures to report infections among staff and the completion of the required documentation and submission to compensation fund;

It may be necessary to plan for HCW to be tested on a regular basis for Covid-19.

## Care of the carer:

The care team leader must take time to assess the emotional and physical wellbeing of the care team. This can be done in a variety of ways and the assistance of social workers will go a long way to making this programme effective. The following are offered as suggestions:

- Reduced patient load;
- Remote patient care;
- Debriefing and reflection sessions;
- Well informed team with the correct information (dispel the myths);
- A regular screening regime with referrals to the nearest testing facility;

# Attachments/Annexure

The following list of documents is recommended for further education. These resources are available on the HPCA website as a reference to all who may need them.

1. PALPRAC – Providing Palliative Care in South Africa during the Covid-19 Pandemic;
2. DoL Covid19 audit check list;
3. HPCA Clinical guidelines;