Palliative Care Guidelines for COVID - Part 1

Care for Palliative and Bedridden Patients in Communities on Enhanced Community Quarantine

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Prepared by

Philippine Society of Hospice and Palliative Medicine (PSHPM)

and

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Care for Palliative and Bedridden Patients in Communities on Enhanced Community Quarantine

Background

While the number of complicated cases of severe pneumonia and COVID-19 remain and require vast health resources, we recognize that there are other conditions that also require attention and care especially those with chronic illnesses, bedridden patients and those with terminal conditions at home in communities on Enhanced Community Quarantine. These are provisional recommendations that aim to enable health professionals and workers make decisions and provide continuing care for these conditions. This provisional guidance document is developed by the Philippine Society of Public Health Physicians (PSPHP) in collaboration with the Philippine Society of Hospice and Palliative Medicine (PSHPM) in consultation with the National Hospice and Palliative Care Council of the Philippines (Hospice Philippines) and the Philippine Academy of Family Physicians (PAFP).

Purpose of this Guidance Document

This guidance aims to provide recommendations for quality palliative care for patients of all ages, facing serious illness. It will enable families and communities to participate in the palliative care of patients through the prevention and relief of suffering, as they attend to the physical, functional, psychological, practical and spiritual consequences of serious illness, in partnership with their primary health care provider. Patients who need palliative care include individuals with *cancer, chronic respiratory and cardiovascular diseases, AIDS and diabetes*. Other conditions that require pain management and palliative care include disabling *degenerative illness, specific organ failures (such as chronic kidney disease, kidney failure, advanced chronic obstructive pulmonary disease, advanced congestive heart failure, liver cirrhosis and liver failure), chronic neurological disease (ex. stroke), dementia, congenital anomalies, genetic conditions and drug-resistant tuberculosis*.

Target Users

This guide is written for community health workers including Municipal Health Officers, RHU physicians, public health nurses, other RHU staff and community health workers so they can

strengthen local resources and provide advice to family members/ caregivers with palliative patients.

Definition of Palliative Care

According to WHO, palliative care is an approach to care that improves and emphasises quality of life and this approach to care not only apply to patients but to their families as the same time it is specific for patient and families facing problems associated with life threatening illness and the approach not only involves treating the symptoms but as with primary care, it starts with preventing, understanding what could cause the symptom, and predicting what symptoms could occur in certain illness to control them. After the prevention comes the relief of the symptoms based on the underlying illness and then provides rehabilitative support[9].

Common Health Concerns for Primary Palliative Care

Physical care needs

● Pain (all types) ● Respiratory problems (dyspnoea, cough) ● Gastrointestinal problems (constipation, nausea, vomiting, dry mouth, mucositis, diarrhoea)	● Delirium ● Wounds, ulcers, skin rash and skin lesions ● Insomnia ● Fatigue	● Anorexia ● Anemia ● Drowsiness or sedation ● Sweating

**Adapted from WHO (2016)*

Psychological, emotional and spiritual care needs

● Psychological distress ● Anxiety	● Suffering of family or caregivers ● Spiritual needs and end-of-life questions	● Depression ● Bereavement support for family. caregivers

**Adapted from WHO (2016)*

Care in the Home

Here are general reminders for health professionals to enable families and caregivers to effectively provide palliative care in the home.

- Empower the family members by teaching them how to take care of the patient and reassure them of their capacity to take care of the patient[8].
- Make sure two or three family members/ caregivers are familiar with palliative care principles and skills. During the phase of social-distancing, limit care of the patient to only these identified family members/ caregivers.
- Make sure that they are separated from other people as much as possible, especially those that have exposure to COVID patients or persons exhibiting flu-like symptoms. The caretakers should regularly wash their hands, not share personal items to the patient, clean “high touch” surfaces and monitor one’s symptoms.
- For COVID 19 patients for palliative care at home, ensure that the patient's coughing is covered, that the caretakers have personal protective equipment and steps to prevent the spread of infections is being followed. This is for the worst-case scenario wherein patients with low survival rates will be advised for home palliative care.
- Monitor patients symptoms and watch out for new onset of fever, coughing and other flu like symptoms.
- Monitor for care-takers for signs of burn-out and provide psychosocial support.
- Prepare a contact list for essential referrals and support e.g. caregiver, hospital, social welfare, emergency transportation, church, etc.

Pain Management at Home

Pain is psychosocial morbidity a very common symptom in palliative care and uncontrolled pain could lead could. To address this problem, here are some pointers for health professionals to remind families with palliative patients.

Assess the patient for pain (in all patients)

- Determine the cause of the pain by history and examination.[3,8]
- Pain could be of two types
    - Background pain - pain that the patient usually experience most of the time
    - Breakthrough pain (pain which could be incidental, like triggered through movement, or could be spontaneous also known as pain exacerbation

- Assess if the patient is suffering from uncontrolled background pain or breakthrough pain.
- Assess if there is a psychological or spiritual component[8].
- Grade the pain with FACES (especially in children) or through the scale of 0 to 10, with 0 being no pain to 10 being the highest possible pain like is shown below.[3,8]

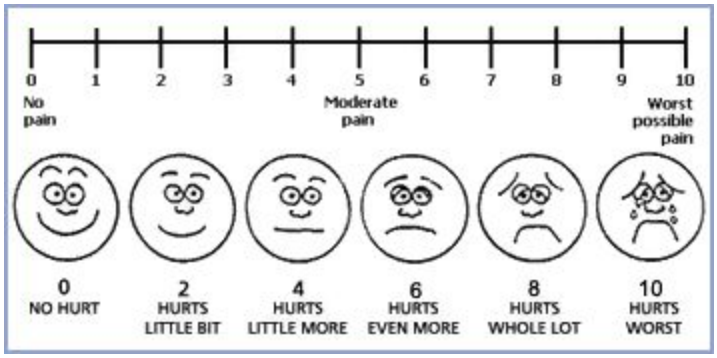

Figure 1. Wong Baker Pain Scale

Treating pain

- For chronic pain, if possible medication should be given by mouth (rectal is an alternative). Pain killers should be given at fixed time intervals with the next dose being given before the previous dose wears off. The medication should be tailor fitted to the individual with the first and last dose linked with waking and sleeping times[8]
- Treating pain should follow the WHO analgesic ladder. Patients with mild pain are treated with non opiates like paracetamol and NSAIDS. Moderate pain characterized by pain score of 4-7, are treated with mild opiates like tramadol but some could use low dose opiates such as low dose morphine or low dose oxycodone. For severe pain, most of the time they benefit from opiates, morphine, oxycodone, fentanyl, etc. [8]

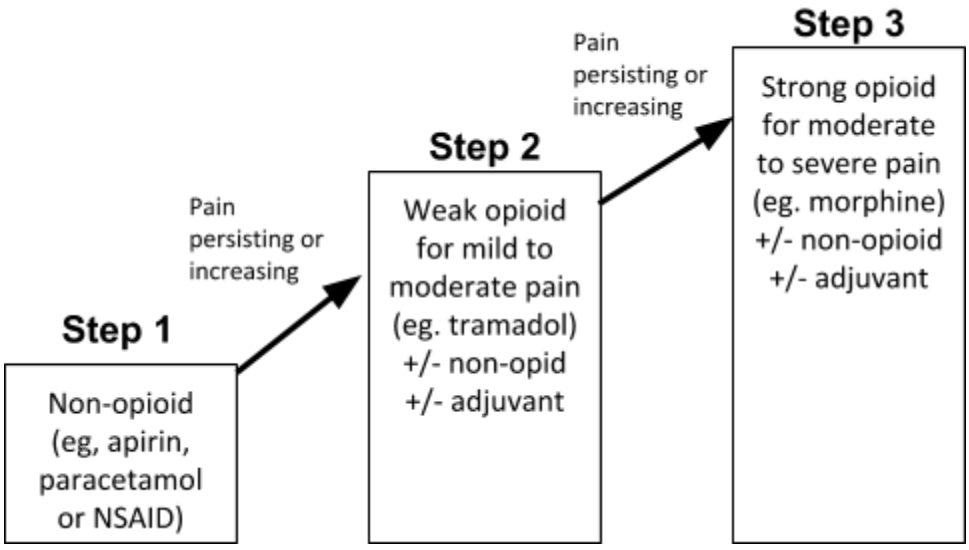

Figure 2. WHO analgesic ladder

- There are pain medicines available over the counter and not requiring doctor's prescription: ibuprofen, naproxen, diclofenac and paracetamol. Study the proper uses and contraindications of these medicines.
- For known palliative care patients, it is necessary to know if they are taking pain medications regularly. If they are taking these medications regularly but they are experiencing an increase in the average pain, they would usually benefit from increasing their medications by 50% or 100%.
- For patients suffering from breakthrough pain, it is important to ask if they have medications for breakthrough pain and if they are taking it in a timely manner. Patients should be advised to take the medication when the pain starts to increase more than the average and not wait for the pain to reach scales of 10 out of 10. Breakthrough pain medication which is usually 10% of the total opiate dose if they are maintained on any opiate.
- Health professionals should teach the family and caregiver how to give pain medicine appropriately. The frequency and importance of giving medication regularly should be adequately explained[7].
- Ensure ready access and adequate supply of pain medicines prescribed and that patients are taking them diligently.

Considerations for COVID-19 or suspected patients

- For COVID or suspected patients, the initial approach is to not treat them with opiates immediately. The pain would be coming from joint pains, body pains, headaches, typical of flu symptoms. Usually for this patients they would see benefit in controlling their fever and chills otherwise health workers could combine different pain medications (multimodal analgesia). For COVID or PUI patients, their pain could be treated with round the clock paracetamol or NSAIDs or to lessen polypharmacy celecoxib or eterocoxib once a day could be given.
- During this Covid 19 crisis, monitoring and evaluation of the patients could be done through telephone calls or SMS or social media messages in order to closely monitor them without physical interaction. Follow-up of patients should be done 6 hours or 8 hours after the first dose or for breakthrough pain medication, after 30 or 60 minutes.

Advice family on additional methods for pain control

- Non pharmacologic interventions such as warm compress, warm sponge bath and deep breathing may alleviate pain[3].
- Provide encouragement and emotional support and communicate with the patient often. Distraction may help in the form of family time, television and other means[8].
- If a patient experiences total pain, existential pain, spiritual pain, using active listening and open ended questions could help[7].

Symptom Management at Home

Key information to keep in mind in evaluating symptoms:

- Is the symptom highly distressing and frightening for patients and caregivers?
- Does it require rapid and assertive management?
- Is it highly responsive to non-pharmacologic and pharmacologic treatment?

General Symptom Management Approach

<table>
<tr><td colspan="2">Determine and treat the underlying cause of the symptom</td></tr>
<tr><td>Physical</td><td>Non-physical</td></tr>
<tr><td colspan="2">Treat symptoms without causing new symptoms (side effects)</td></tr>
<tr><td>Drug Measures</td><td>Non-drug measures</td></tr>
<tr><td colspan="2">Best interest of the patient</td></tr>
</table>

What can we ask from families?

- Review timing of onset
- Symptom characteristics
- Associated symptoms
- Participating/relieving factors
- Impact on functional status
- Responses to medications

Common symptoms and how these can be managed at home or in isolation units:

Common symptoms	**Home management**

Respiratory symptoms	Dyspnea	Position the patient in order to keep the head up, leaning forward, consider breathing exercises. Open windows to allow in fresh air. Cool the face by using a cool cloth.[4] Give the patient water frequently. Help address anxiety and provide assurance[3] Identify situational components (e.g. what triggers the dyspnea attack?) Teach behavioural interventions (e.g. relaxation, hypnosis, lifestyle modifications)
Respiratory symptoms	Cough	Sit up and positioning[4] Humidify air with steam[4] Physiotherapy to assist secretion drainage Offer cough suppressants (if previously prescribed) Stop any smoking in room as well as use of stoves, kerosene lamps, etc in house[3,4]
Gastrointestinal symptoms	Nausea and vomiting	Frequently offer small foods.[8] Take drinks slowly and more frequently. If vomiting and unable to sit up, turn them to the side.
Gastrointestinal symptoms	Constipation - less frequency of stool per week, per day - difficulty of bowel movement in more than 25% of the time	Causes: - Inactivity, dehydration, low food intake, fear of opening bowels due to pain, caretakers not addressing toilet needs regularly, bowel obstructions, neurological dysfunctions, drug related Actions ● Offer drinks often (water, prune juice, fiber rich mild)[7]. ● Abdominal Massage ● Change positions (for bed-ridden patient) ● Apply warm bag on abdominal area ● Rectal Stimulation (gently apply petroleum jelly or soapy solution into the rectum)[7] ● Manual evacuation (for those with neurologic causes of constipation)

General body symptoms	Anorexia, weight loss, weakness, and fatigue	Assessment ● For weight loss, evaluate if it is acute (<2 weeks) or chronic (>6 months or more). This is because for bedridden cancer patient, the weight loss may be due to their end stage cancer, thus irreversible. ● Check oral thrush, check for medications that causes nausea Actions ● Explore what the patients wants to eat (permit and encourage any unusual cravings)[7] ● Offer smaller meals of soft foods (non-spicy) ● Offer frequent sips of water but not to force them ● Learn to accept that oral intake will reduce as condition progresses ● Ensure daily oral hygiene (keep mouth moist, daily brushing, gargle with alcohol free mouthwash)
Psychological, emotional symptoms	Confusion, delirium, restlessness	Assessment ● Determine what is the cause. Is it reversible? Is it medication related? Are there electrolyte imbalances? Are there infections? Or other neurologic symptoms? ● It is important because health workers need to communicate to the family if it is still reversible or not. Actions ● Keep the patient in a familiar environment. ● Remove dangerous objects. ● Reassure the patient by talking to them calmly and speaking simple sentences, one person at a time. ● Explore for uncontrolled hidden pain (bedsores, urinary retention) or other uncontrolled symptoms (constipation)

**Adapted from the WHO, 2004*

Preventive Interventions at Home

For preventive intervention, there is a need for frequent head to toe examination. Therefore the families to be trained how to do the examination and what to look out for.

Preventive Interventions	Instructions
Preventive oral care	Use a soft toothbrush to gently brush the teeth with toothpaste. Gargle with gargle solution such as chlorhexidine or 1% povidone iodine solution. An alternative to over-the-counter oral antiseptics is a salt water solution (combining ¼-½ of table salt with 8 ounces of warm water) For patients who can not gargle, dip a soft cloth or clean gauze into the solution to brush the teeth, tongue and inner cheeks twice a day[8]. Check for sore areas and white patches at the tongue, gums and inside the cheek[2]
Prevent bedsores in all bedridden patients - Three primary contributing factors for bedsores that needs to be addressed: pressure (pressure on bony prominences), friction (rubbing against for example the bedsheets) and shear forces (usually happens when trying to grab the patient to a sitting position)	Change the positions frequently: bed turning every 1-2 hours will lessen the pressure on the skin, reducing the risk of developing pressure ulcers. Use of Pillows: putting pillow between parts of the body that press against each other or bony prominences is another effective way to prevent bed sores. Keep skin, clothes and beddings clean and dry; moist, damp and wet skin triggers the onset of pressure sores. Exercise: passage range of motion exercise also decreases the risk of having bedsores. Keep the beddings clean and dry[7]. Look for changes in colour (such as redness) on the back, shoulders, hips and other bony prominences every day[8]. Zinc oxide+calamine on sites of redness to avoid progression to bedsores.
Bathing Different kinds of bathing: 1. Complete bedbath 2. Partial bath	Provide privacy during bathing[7]. For patients who could still go to the bathroom, place a monoblock chair in the bathroom where they could sit with support on their back. Do not rush the bathing process and should be thorough so that the caregiver could also do a complete physical examination. Use warm water in batching the patient.

	For patients that are uneasy, soothing music could be played or aromatherapy oil could be burned to make them more comfortable. For patients with preexisting painful conditions, pain medications may be given few minutes prior to bathing Dry the skin with a soft towel then oil the skin with cream, body oil or vegetable oil[8]. Use plastic sheets under the bed sheets to keep the bed dry when doing a tepid sponge bath or bed bath or when patients can not control their urine or defecation. Also for patients who can not control their urination or defecation, Zinc Oxide + Calamine lotion could be applied on their anal oriface as antiseptic or to prevent anal fissures/sores[8].
Prevention of pain, stiffness and contracture in muscles and joints	For patients who are able to move, encourage mobilization and assist them[8]. If the patient is immobile, do a simple passive range of motion exercises on the key joints[8]. For patients with preexisting painful conditions like contractures, cancer pain or bone pains, giving pain medications few minutes prior to movement may control the incidental pain. Light massage is also effective to the patients.

Care in Communities

Rural Health Units, District Health Centers, Barangay Health Stations, and other primary care facilities are the first-line health care institutions in the community. These provide primary health care as well as essential public health, disease surveillance, health education, health promotion, and disease prevention services. These facilities can also link patients and families to essential social and support services in local governments. It is important to maintain contact details of community resources.

As first contact for patients, the health workers should be trained and prepared to:

- Reach patients with all chronic conditions and limited life prognosis
- Start a palliative approach early in the course of the illness and treatment
- Meet all dimensions of need: physical, social,psychological and spiritual
- Provide care in all settings: clinics, care homes and at home, thus preventing unnecessary hospital admissions
- Support family caregivers and provide bereavement care;

- Promote community involvement in supporting people with advanced illness

**Adopted from Murray et al (2015).*

Providing Care in the RHU and Barangay Isolation Units

- Some patients may need to be temporarily held in the RHU or Barangay Isolation Units while awaiting transfer to a higher level of care.
- For patients which are probable or suspected as COVID 19 patients with mild symptoms, ensure that they always wear a medical mask.
- Ensure patient records are complete. Review the records or inquire from family members or caregiver in terms of medicines that should be provided for pain or other symptoms.
- Implement all infection prevention and control measures based on standards set by DOH and relevant professional organizations.
- Assess presence of pain and other symptoms. Determine the type and possible cause of pain and manage accordingly. Prevent and recognize the side-effects of pain medication.
- **Many palliative care patients may require medicines not readily available in the RHU or in localities. Health providers are encouraged to call the Hotline Provided in the Guidance document.**
- There are existing Clinical Guidelines and other Guidance Documents for COVID-19 Response. Health officials and professionals are advised to refer to these documents.

Referral Network

This table provides quick information on resources in cities, provinces and municipalities. Provincial, City and Municipal Health Officials, Hospital officials/ staff, Family Physicians, Palliative care specialists and/ or other health professionals are encouraged to fill up this table to identify local networks for referral. This may be used as a plan and guide for health workers.

Category	Institution	Name of Contact	Telephone/ Mobile Number
RHU, District Health Center or City Health Office			
District Hospital			
Provincial Hospital			
Regional Hospital			
Palliative and Hospice Care Specialist			
Geriatric Specialist			
Oncologist			

Social Welfare			
Religious Workers			
Palliative Care Hotlines	`		
Pain Specialists			

Indications for referral to higher health facility /provider

- Initial control of moderate to severe symptoms related to serious, complex or life limiting health problems.
- Control of refractory suffering.

Strengthening the Capacity of the Local Health System

Health officials are advised to conduct a rapid review of capacities in their locality in order to provide adequate care. These are some pointers and activities that may be done.

Supplies

- Conduct a quick assessment with your barangays to estimate the actual needs for palliative care. See Barangay Rapid Survey Tool in the Annex.
- Ensure the availability of oxygen in the RHU.
- Ensure the availability of medications to acutely manage patient symptoms.
- In handling confirmed, suspected or probable COVID 19 cases, adequate amount of personal protective equipment such as medical mask and gloves for non aerosolizing procedures and full PPE (face shield, N95 mask, fluid resistant gown, gloves and shoe cover) for aerosolizing procedures such as intubation, chest compression, bag valve mask ventilation, nebulization and suctioning. [5]

Staff

- Ensure that there is a nurse or midwife in charge of the database of patients and information on clinical/ primary care guidelines for palliative care. This officer in charge may first study guidance materials from the Black Box.
- Identify physicians and nurses in the area with knowledge and experience in palliative care.
- Identify community resources for psychosocial support, grief and bereavement counseling e.g. social workers, pastors, priests, and other religious workers. Refer patients and families as necessary.

- Ensure that identified front-line workers have knowledge and skills to deliver appropriate psycho-social and spiritual care and in dealing with their own pressures and concerns.
- Ensure that identified front-line workers are capacitated to communicate and discuss to family members palliative care.

Space and Systems

- Ensure that palliative care patients are included in triage protocols.
- Ensure protocols are in place to protect health workers from contracting COVID 19.
- Take time to train/ orient family members and/ or caregivers for home-based palliative care.
- Ensure care in the last weeks/ days of life.
- Ensure transfer transportation for patients that may need a transfer from homes to hospitals and back.

**Adopted from Clark, 2020*

End of Life Care

The goal in end of life care is more of comfort and assuring the patient that their family is also there for them and giving the family the confidence in caring for them because they know what to look-out for.

Patients in the terminal phase of Non-COVID related diseases

- Maintain standard infection control procedures.
- Provide support and communicate to the family the likely course of the patient.
- Offer patients active listening, counselling and social/emotional support and make sure that patients get help with feelings of guilt or regret.
- Encourage communication within the family and talk to them on what to do after death.
- Monitor and address symptoms with nursing care and medications.
- Cease non-essential medications.

COVID 19 positive patient

- Care must be given to the safety of other patients, visitors and staff.
- If patient is assessed to be in the irreversible phase of illness, inform and support family and / or next of kin.
- Full PPE should be worn when performing essential bedside care.
- Psyco-Social and spiritual support may be provided via “tele-care”or video-calls.
- If death is imminent and family wish to stay with their loved one staff must advise them that they should wear full PPE
- Encourage the family to maintain brief yet meaningful communication with the patient.

- Full PPE should be worn when performing post mortem care.

- Ensure that utmost sensitivity and respect in handling the patient's body is maintained.
- A body bag should be used in transferring the body as the movement could expel small amounts of air from the lungs.
- The deceased properties, such clothes and blankets, should be disposed of and items that could be safely wiped down such as jewelries should be disinfected.
- The body should be cremated within 24 hours of death.

**Adapted from Lawrie, Lain and Murphy, Fiona (2020)*

Bereavement

For the patient

- Look and respond to grief reaction (denial, disbelief, confusion, shock, sadness, bargaining, yearning, anger, humiliation, despair, guilt, acceptance)
- Keep communication to the patient open.
- Help the patient accept his/her own death.
- Offer practical support.
- Discuss Advanced Directives with patient in the presence of a responsible family member.
- Make sure that what the patient wants is respected.

**Adapted from the WHO, 2004*

For the family

- Look and respond to grief reactions (denial, disbelief, confusion, shock, sadness, bargaining, yearning, anger, humiliation, despair, guilt, acceptance).
- Help the family accept the death of the loved one.
- Encourage them to talk and share the memories.
- Offer simple expressions and take time to listen.
- Try see if friends can offer practical help in the house.
- If the family has monetary problems try to refer them to social welfare or other institutions that can help.
- Encourage them to have patience and that the grieving process could take a while.
- Refer to a community bereavement support program if available

**Adapted from the WHO, 2004*

Ensuring Family Support

- Check spiritual dialogue and guidance. Most Filipino families have a strong faith in God and have specific beliefs in death and afterlife. Feel free to discuss with the family regarding their faith and religious involvement. Normally, their local religious leaders or workers may visit them at home or in the hospital. In the current scenarios, such arrangements may be limited. Video conferences or phone calls may be the best option.
- Funeral services. Due to the enactment of social distancing, the usual wake and burial processes and social gathering are highly discouraged and this increases the risk of

individuals and their families to suffer from complicated grief. You may discuss alternative options for bereavement. (Adapted from WHO 2004)

- Social welfare. Secure contact details of the Social Welfare Office of your local government and refer families as necessary.

For the Public Health and Primary Care Providers

Debriefing Program for Primary Care and Public Health Providers. Health workers face a lot of pressure and stress in these conditions. In addition, witnessing patients and families go through end-of-life can cause additional emotional and psychological burden. Take time to listen, listen and listen to your physicians, nurses, midwives and health staff on their experiences and thoughts. At best, you can develop a debriefing program for your public health and primary care providers. You may also provide further information regarding Self-Care Strategies.

For Further Assistance

Clinical Practice Guidelines, DOH Advisories and other Guidance Documents may be accessed at http://www.palliativecolab.com/

PSHPM, Hospice Philippines and The Ruth Foundation may be reached through the Palliative Collaborative hotline for inquiries and concerns:
09063141421 Globe
(02) 8938-0069 PLDT mobile landline

References

While this is a reference list, the Technical Committee for COVID-19 Response will make these documents available.

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DISCLAIMER

This is a Provisional Guidance Document. In the context of COVID Emergency Response, this is being developed and disseminated among members of PSHPM, PAFP, PSPHP, AMHOP and other medical professionals as a guide/ reference to assist in decision-making, setting of local care systems and primary care. For more specific clinical or public health guidance, users are advised to refer to guidelines issued by DOH, hospitals and professional societies. For further concerns, questions and inquiries, you are advised to call PSHPM-Hospice Philippines Hotline at

09063141421 (Globe) or (02) 8938-0069 PLDT mobile landline. This Provisional Guidance Document will be updated as soon as new recommendations become available.

Annexes

Annex A. Barangay Rapid Needs Assessment

This form is for submission to City Health Department or Municipal Health Office

General Information

Name of Barangay	
Name of Barangay Captain	
Name of Barangay Kagawad on Health	
Name of Barangay Midwife in Charge	
Names of all BHWs and other health volunteers	
Name of Nurse in Charge	
Name of Barangay Officials/ Staff in Charge of Social Welfare/ Service	
Name of District Health Center	
Name of Doctor in Charge	

Needs for Palliative and Rehabilitative Care

Barangay Population	
No. of Elderly/ Senior Citizens	
No. of Elderly/ Senior Citizens above 90 years	
Total No. of Population (Children) 17 years and below	
Total No. of Persons with Disabilities	
No. of Persons with Disabilities 18 years and above	
No. of Children with Disabilities 17 years and below	
No. of Barangay Residents undergoing regular Physical Therapy and/ or Occupational Therapy Sessions	
No. of Barangay Residents Diagnosed with Cancer	
No. of Barangay Residents Diagnosed with Leukemia and Lymphoma	
No. of Bedridden persons in the barangay	

Annex B. Target Client List for Palliative Nursing Care in the Community

This list is only for the use of Barangay/ Community Health Workers

Elderly/ Senior Citizens 90 years and above

Name	Condition	Home Address	Name of Family Representative	Contact Number	BHW/ Caregiver in Charge

Bedridden Patients

Name	Condition	Home Address	Name of Family Representative	Contact Number	BHW/ Caregiver in Charge

Patients with Cancers and other Conditions who are terminally ill

Name	Condition	Home Address	Name of Family Representative	Contact Number	BHW/ Caregiver in Charge