



# END OF LIFE CARE

GUIDE BOOK FOR CAREGIVERS

PALLIATIVE CARE UNIT HTJS

## What is Palliative Care?\*

Palliative care is holistic care of patients with advanced and progressive life limiting illnesses. The focus of palliative care is to address the patient's individual needs. The goal of palliative care is to improve the quality of life for both the patient and the family and to relieve suffering through good symptom control as well as emotional, spiritual and social support.

## Introduction

End of life care is an important aspect of palliative care, which enables patients to live well and die with dignity. Terminal discharge/TD refers to discharge from hospital where death is imminent. Some patients prefer to be cared for and die at home. Hence, terminal discharge allows care at home and end of life wishes to be fulfilled.

## Final Hours

The "final hours" refers to the period just before death occurs. It may range from the last hours to short days. This booklet will walk you through the process as you prepare to bid goodbye to your loved one. Do not hesitate to approach your doctor/nurse/social worker or other healthcare professionals for guidance in understanding this stage.

Your loved one may experience any of the following symptoms. You can do simple things to help your loved one feel more comfortable.

## **Signs & symptoms to look out for \***

### **1. Pain**

- Your loved one may be experiencing pain. Fear anxiety and depression can make the situation worse.

### **2. Tiredness, Drowsiness/excessive sleeping**

- Your loved one will be very sleepy and may not respond to you

### **3. Refusal to eat**

- Your loved one may no longer have interest in food or he/she may feel nausea.
- Your loved one may be experiencing a sore or dry mouth.
- He/she may have constipation
- Moreover, food consumed may cause stomach discomfort.
- Artificial nutrition/hydration such as nasogastric tube feeding and intravenous hydration do not carry any survival benefits for terminal patient

### **4. Confusion/hallucination/agitation**

- Your loved one may appear very restless and uncomfortable as they fidget in bed, gesture with their hands, or speak incoherently.

### **5. Mottling**

- Purplish blue discolouration appears at their palms and soles of their feet

### **6. Weak Pulses**

- Their pulse will be very weak, or may not even be felt. Your Home Visit Team will be able to inform you when this happens.

### **7. Cool hands/feet**

- Their fingers and toes become cool to touch

### **8. Change in breathing pattern**

- The patient might have a change in breathing pattern such as pauses in breathing, and rapid or shallow breathing when nearing end of life
- The patient may also breathe with his/her mouth open.
- Blood pressure and oxygen level readings are expected to be abnormal

### **9. Rattling throat secretion**

- The patient may make gurgling/rattling sounds from the throat/chest when he/she is too weak to swallow respiratory secretion/saliva.
- Usually rattling does not cause discomfort.
- However, if rattling becomes excessive, please seek hospice/palliative advice

## What can I do at the bedside?

### 1. Oral care

- Clean the patient's oral cavity with moist swabs or a wet cloth gently, as frequently as needed.
- Oral spray with drinking water can be applied to the oral cavity if it is dry, as frequently as needed.
- Lip balm such as Vaseline/oral gel can be applied to lips to prevent dryness/cracked lips.

### 2. Skin care

- Turn the patient gently every 2-3 hours to prevent bedsores. However, if turning causes pain/discomfort, frequency of turning can be reduced as tolerated.
- Prevent prolonged lying on pressure points of the body, including ears, scalp and buttocks.
- Clean the patient's face and body with a wet towel.
- Apply moisturizer such as aqueous cream/Vaseline ointment when the skin is dry.
- Apply barrier cream/zinc oxide to the sacral/diaper area as skin protection.
- Change diapers when soiled to avoid pro-longed skin contact.
- Your loved one may appreciate being massaged gently during this time.

### 3. Eye care

- Apply eye drops if the patient suffers from dry eyes.
- Apply eye pad/cover at night if the patient is unable to close eyes completely, to avoid dust/irritants entering the eyes.

### 4. Nutrition

- Offer comfort feedings as tolerated, in small amounts.
- If the patient does not feel like eating/drinking, do not insist or force feed.

### 5. Music/ Prayers

- You can play calming music or your loved one's favourite music softly in the room if he/she likes it.
- Prayers can also be recited to provide spiritual reassurance

### 6. Offer assurance

- Hold your loved one's hand and speak gently into their ears.
- Help your loved one to relax with simple breathing exercise.
- Use short, simple sentences to reassure them that you are by their side.
- Orientate your loved one by telling him/her the day of the week, the hour of the day and what has been happening in your life. You can reminisce the past with them.
- You may also wish to express your feelings. The four important things you may want to say:  
Please forgive me      Thank you      Forgive me  
I forgive you              I love you

### 7. Spiritual support

- Spiritual/religious support in accordance with the patient's wishes is encouraged.

*If at any point your loved one appears uncomfortable, or if the caregiver is unsure of what to do, do inform the Home Visit Team.*

## Managing Medication

Here is a simple guideline on how to manage your loved ones medicine, especially if there are many. This guideline may help you.

- Always remember to wash your hands **before** and **after** you administer medication
- Understand what each medicine is for
- Remember/record down the dosage, how frequently and how long each medication should be taken
- Read the labels and understand it. You may need to add more details to help you remember.
- Ask your nurse where to get the supply from, if you face a shortage
- It is wise to keep a medication log and keep updating it regularly. There is a sample of the medicine log at the back of this booklet.
- Place all medication in one place, except for those requiring refrigeration
- Unused or expired medication should be returned to the nurse, pharmacy, or hospital to be disposed safely. **Do not throw in your house rubbish bin or flush down the toilets.**

## Managing Equipment

### Hospital Bed

You can loan 3 types of hospital beds from Pertubuhan Hospice Negeri Sembilan.



1. Adjustable backrest
2. Adjustable back and knee rest
3. Adjustable backrest, knee rest, and height.

Your Home Care nurse will teach you how to operate the bed.

Sanitize the bed frame and mattress daily and at the same time change the bedsheet.

### Oxygen Concentrator



Your Home Care nurse will teach you how to operate the oxygen concentrator.

Please plug into a MAIN socket and do not use multi socket points.

Please use it in a clean room. Make sure to clean the humidifier and the oxygen administration tube daily with water.

Clean the dust filter every fortnightly with a vacuum cleaner or wash with water.

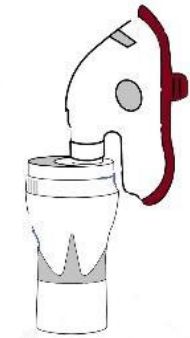
## Ripple Mattress



Your Home Care nurse will teach you how to operate the ripple mattress.

Use a sanitizer and clean the ripple mattress as often as you can.

## Nebuliser



Your Home Care nurse will teach you how to operate the nebuliser.

Clean the mask and solution chamber with water and dry it.

Sanitize the nebuliser often.

## Some important practical matters that need to be prepared:

### Have the medical report of patient at hand

It will be good to get a copy of the patient's medical report in hand. It might make it easier on you when you call 999 (Ambulance Service) and to come and certify death.

### Have the contact number of a casket company at hand

It will be ideal if your loved one is willing to be involved in discussions of last rites before he/she becomes too ill to do so. This would ensure his/her preferences for closure are acknowledged and honoured. However, you may also engage a company of your choice when your loved one is dying. Some families prefer to consider the available options before choosing the available casket package.

### Assigning duties

You may wish to pre-assign family and friends certain duties and tasks to be carried out when death occurs, e.g., informing a certain group of family or friends that their family member/friend has passed on, informing their spiritual leader, calling the casket company, registering the death, etc. This ensures that needed tasks are performed and does not overwhelm one person.

### Spiritual needs

If deemed important, the family is encouraged to seek local religious or spiritual assistance from the nearest mosque, church, temple or spiritual organization for assistance.

## You matter too

The journey from the time of diagnosis until the last hours is usually exhausting.

- Changing emotions are normal reactions when caring for your loved one.
- You are juggling many roles while care giving.
- In a life limiting illness, cost of treatment and loss of income can cause financial struggle.
- Conflicts between family members may happen about the best way to care for your loved one

Caring for yourself is also important. Do remember to:

- Drink plenty of water to stay hydrated
- Eat well and healthily
- Ensure you have enough sleep. Take shifts with other family members or friends when you need to
- Allow yourself short breaks to stretch and breathe some fresh air
- Open communication is important to resolve issues
- Speak to your nurse. She may be able to give guidance.

While many keep vigil to catch their loved one's last breath, our loved one may choose to quietly slip away in that little moment when we dozed off, when we needed the bathroom or when we stepped away from the bed for a minute. We may not be able to explain why, but take comfort in precious memories of time spent with your loved one in this final journey.

## How do we know our loved one has passed away?

You can look out for the following signs:

- There is no breathing
- There is no pulsation that can be sometimes seen in the neck.
- The eyelids may be slightly open, the pupils (black of the eye) are enlarged and the eyes are fixed in one position
- The jaw is relaxed with the mouth partially open
- The body is usually still warm to touch when death has just occurred. It will gradually become cool to touch

When you notice that breathing has stopped,

- Stay calm
- Watch for 10 minutes to confirm that your loved one has stopped breathing
- Allow yourself to some quiet moments
- Switch on the air conditioner (if available) to keep the room cool

Take your time to inform other family members and friends. There is no need to rush into handling the practical matters. Registration of death can be done later, as long as it is done within 24 hours of the death

## What's next?

After your loved one has passed on, there are matters that will need your attention:

### 1. Certificate of Cause of Death (CCOD)

This is the medical report issued by the doctor or if the death happened at home, call the ambulance service (999) to certify the death. You will be advised to go to the nearest police to make a report (bring patient's IC and the medical report).

### 2. Police Report

Upon reporting the death, the police will issue a Burial Certificate. These documents are required:

1. CCOD
2. Original NRIC of your loved one
3. Original NRIC of the person reporting the death

### 3. Death Certificate

This is issued by the Jabatan Pendaftaran Negara. At the police station, you will be given a form to fill.

### 4. Call the casket company/undertaker

The casket company will assist and guide you through the necessary arrangements, e.g. cremation or burial time slots, booking of venue for wake, etc.

### 5. Call your religious leader

You may or may not need to inform your religious leader. Some families would appreciate a prayer said at the bedside before the body is claimed by the undertaker.

### 6. Inform family and friends

Use the pre-assigned duties and tasks list, if there is one. You may consider asking for help in specific duties and tasks. *Remember that you are not alone.*

## Useful resources on palliative care and caregiving

### 1. Macmillan cancer support

- [www.macmillan.org.uk](http://www.macmillan.org.uk)
- information on cancer, common symptoms and treatment

### 2. Hospis Malaysia (does not cover Negeri Sembilan)

- [www.hospismalaysia.org/resources/](http://www.hospismalaysia.org/resources/)
- information on caregiving for advanced illness in English, Malay, Tamil and Chinese
- information on palliative care, morphine, advanced care planning

### 3. Hospis Negeri Sembilan (06-7621216)

- [phns.org.my](http://phns.org.my)
- information on home palliative care, equipment in Negeri Sembilan

### 4. Singapore Hospice Council

- [singaporehospice.org.sg/caregiver](http://singaporehospice.org.sg/caregiver)
- information on nutrition in advanced illness, caring for yourself after death and understanding final hours

### 5. Cancerlink Foundation

- [www.cancerlinkfoundation.org](http://www.cancerlinkfoundation.org)

- information and resources for cancer patients & families

**6. National Cancer Society**

- www.cancer.org.my
- provides education, care, and support services for people affected by cancer

**Useful Contact:**

**1. Pertubuhan Hospice Negeri Sembilan**

**Contact number:** 06-7621216

**Operating hours:**

Mon-Fri 8AM-4PM

Closed on weekends and public holidays

**2. Oxygen Concentrators & Medical Equipment (Rent/Sale)**

- HospiMed - 012-2330451
- Elango - 016-6685652
- Alpro Rasah - 019-2611923

**3. Oxygen Cylinders (Rent/Sale) or for Refill**

- OHO - 06-7673800
- HospiMed - 012-2330451

**4. Medical Equipment**

- Wong Van Mama - 016-9759883

**5. Ambulance Services**

- **Government Hospital**  
Seremban General Hospital – 06 – 762 3333
- **Emergency Service**

Police, Ambulance & Fire Brigade – 999

- **Private Ambulance**

Zainal - 017-2779504

- **St John’s Ambulance**

Jasmani - 012-3607797

**Important Contacts:**

**Hospice Nurse:**.....

**Hospice:** .....

**Doctor:**

Number 1:.....

Number 2:.....

**Casket Company:**

Company name:.....

Contact person:.....

Phone number:.....

**Religious Group:**

Contact person:.....

Phone number:.....

<b>NAME</b>	<b>TO INFORM/TO DO</b>	<b>CONTACT NO.</b>