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Palliative care is holistic care of patients with advanced and progressive lifelimiting 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.

## **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.



## 2. Caring for Loved One

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.

# 3. 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.



# 4. 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.





# 5. Managing Equipment

- **Hospital Bed**

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

- i). Adjustable back rest
- ii). Adjustable back and knee rest
- iii). Adjustable back rest, 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.

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

- **Have the contact number of a casket company at hand**

It will be most 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.

## 7. 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:

- a) CCOD.
- b) Original NRIC of your loved one.
- c) 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.



## 8. What's next when loved one passed on from Covid

1. You will receive a call from hospital aslong 1-2 family member to identify this is your loved one.
2. We understand this process is emotional and has to be done outside the room as to protect you.
3. Our it Inspector will meet you in ward to explain the next steps.
4. You loved one will be brought to forensic sheptment and once ready to be brought for crematian / burial
5. For muslims Pejabat Agama will assist in burial either in bandar Ainesdale / prefer place an certain landtians
6. For nun muslim it would be good to have a casket company numbers at hand. Sometimes cremation might need to be delayed acceding to opration heers.

During this time, you can Still see your love one from a distance of 10 - 20 meters.

7. This is every defficult moment for most people, some family members do not cope with the gieving process and will need additional support ( contact us at Unit Psikologi Kaunseling ext 4710 / 4766 ( Cik Suraya ) at a later date )

# 9. Bereavement : Caring For Yourself After A Death

Grief is our natural response to loss. It can affect every part of our lives. Even when a death is expected, we still experience varying levels of grief responses when the death occurs. When all the necessary rites and rituals such as the wake, funeral, cremation, are completed and it is time to ease back into the routines of life, some of us may become more aware of our grief reactions.

## Common grief reactions

### Emotions:

- Shock.
- Sadness.
- Guilt.
- Helplessness.
- Relief.
- Anguish.
- Numbness.
- Fear.
- Worry.
- Peace.
- Disbelief.
- Anger.
- Emptiness.
- Irritation.

### Thoughts:

- Confusion.
- Self-blame.
- Thoughts of injustice.
- Difficulty concentrating.
- Constantly reviewing certain events surrounding the death.

## Behaviour:

- Crying.
- Lack of care for hygiene, meals.
- Difficulty carrying out daily tasks.
- Withdrawal from friends or family.
- Loss of interest in activities one previously enjoyed.
- Preoccupied with personal belongings of loved one.

## Spiritual:

- Anger at God or higher power.
- Question your faith and meaning of life.

## **Grief is unique**

There is no “right” or “wrong” way to grieve. There is no right way to resolve it. One’s grief experience is also influenced by several factors, including:

- events leading to the death.
- your emotional connection and relationship with the person you have lost.
- your familial, social and religious support network.
- your personality.
- your previous experience with loss and grief.
- the presence of other stressful events or situations during the period of grief.

## **Grief has no timeline**

Take your time to grieve. Some are able to adjust to a new life routine quicker, while others may require more time and a conscious effort to do so. It is not uncommon to still experience the sadness years after the loss.

## **Death ends a life, not a relationship**

Death may have taken your loved one away from you physically, but the treasured memories will remain with you. As you draw on your inner strength and external support to continue living without your loved one, consider openly sharing or reminiscing the cherished memories of your loved one from time to time.

## **How you can help yourself as you grieve**

Here are some steps you can take to help yourself through the grieving process:

- You may ask yourself “If only....” or “Why....” questions such as If only I had called the doctor sooner. If only I had spent more time with him. Why did she have to die? Why didn't I do more? Dwelling on the past is painful. Address your guilt and regrets if you have to, but allow some space for yourself to live in the present too.
- Take the time you need to find your footing in life again. Don't compare your grief journey with others as each journey is unique.
- Be kind to yourself. Don't pressure yourself to “move on” by a certain time.
- You may need to learn new skills or take up new roles, e.g. you may now need to be caregiver for your elderly mother, a role once played by your late father. Start with a simple routine, then gradually build up over time at a comfortable pace.

- Include some “me time” in your new routine to relax or even take the time to remember your loved one – listening to a favourite song, writing a letter, doing something you used to enjoy together.
- Rest well, eat healthily and engage in simple exercises or activities. Take care of yourself and your well-being.
- Spend some time with close family or friends. Grieving maybe more manageable if you share your experience with people you trust and are comfortable with. Do not hesitate to let them know the type of support you need.

When it comes to birthdays, wedding anniversaries, death anniversaries, festivities or any other significant event, your feelings of sadness and sense of loss may intensify. It will be helpful to prepare yourself for such events in advance.

## **When grief is a concern**

While we encourage everyone to take their time to grieve and emphasise that each grief journey is unique, there are some individuals who may need further support in their grief journey. If you experience any of the following symptoms, or if people who know you well make such observations about you, it would be wise to seek professional help.

- Difficulty functioning in daily life.
- Constantly thinking of the death and unable to focus on other things.
- Excessive feelings of sorrow, anger, resentment or guilt.

- Neglecting personal care, hygiene and grooming.
- Substance abuse – turning to alcohol, drugs or other vices.
- Hearing voices or seeing things that are not actually there.
- Persistent thoughts and feelings of being worthless and hopeless.
- Unable to find joy, positive feelings or meaning in life.
- No longer taking part in social activities, e.g. meeting friends for meals, going for company events.
- Having thoughts of suicide or self-harm.

Please reach out to us at 06-7684657 during office hours and we will arrange a time to meet up and assist you in getting help.

# Managing your stress

There are many caregivers who may potentially suffer from physical and emotional strain caused by heavy multi-tasking, feeling underappreciated, compromising on their personal time, trying to meet high expectations of care and having to deal with the death of their loved one.

It is important to talk to someone about it if you are feeling stressed from being a caregiver - and to note that acknowledging your stress is not a sign of weakness.

Below are some common symptoms of caregiving stress:

- Feelings of depression and frustration
- Constant fatigue
- Sudden weight loss or gain
- Insomnia
- Headaches or other symptoms

## Caregivers' Stress Checklist

Let's check your stress level. There is no right or wrong answer. Please tick the response that best applies to you and up the points.

<b>In the last 2 weeks, have you been...</b>	<b>Yes (1point)</b>	<b>No (0point)</b>
Feeling more irritable than usual?	<input type="checkbox"/>	<input type="checkbox"/>
Feeling more unhappy or resentful about looking after your care recipient?	<input type="checkbox"/>	<input type="checkbox"/>
Having less energy to complete your daily tasks?	<input type="checkbox"/>	<input type="checkbox"/>
Having less interest in attending or participating in social events?	<input type="checkbox"/>	<input type="checkbox"/>
Deriving less interest from your favourite activities?	<input type="checkbox"/>	<input type="checkbox"/>

**In the last 2 weeks,  
have you been...**

**Yes  
(1point)**

**No  
(0point)**

Getting angry very quickly?

Feeling tired most of the time?

Spending less time on yourself as compared  
to before?

Feeling less motivated to get up in the morning?

**TOTAL SCORE**

*\* if you score more than five points, you are likely to be feeling more stressed than usual. Should these feeling persist, seek advice from your family doctor or professionals involved in the care of your care recipient.*

While most caregivers are efficient in managing their care recipient's conditions, they tend to neglect their own needs. It is important to look after yourself before you can take good care of your care recipient. Below are some tips on managing your stress:

**Take good care of yourself** - Give yourself frequent breaks to rest before continuing the long caregiving process. You may consider respite care to help take care of your care recipient during your break.

**Find time for your personal life** - Spend some time with your friends to unwind and recharge.

**Learn to appreciate yourself** - Learn to focus on your successes. You may not be the perfect caregiver but you are doing your best.

**Get support from your family** - Seek help your family members with various tasks to ensure some personal time to yourself.

**Plan your finances** - Financial difficulties can most likely lead to stress. Plan your budget and check out various financial assistance schemes that can help you.

# 10. You matter too

**The journey from the time of diagnosis till 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.

After you have lost your loved one, you might experience grief. We have a grief and bereavement service to offer if you find difficulty coping with the loss.

Please don't hesitate to reach us at this number to make appointment : 06-7684657



# 11. 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, equipments 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](http://www.cancer.org.my)
- provides education, care, and support services for people affected by cancer



## 12. Useful Contact:

### 1. **Pertubuhan Hospice Negeri Sembilan**

Contact number: **06-7621216**

Operating hours: **Mon-Fri 9AM-4PM**

( Closed on weekends and public holidays )

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

- HospiMed - **012-2330451**
- OHO - **016-6685652**
- HospiMed - **019-2611923**

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

- OHO - **06-7673800**
- HospiMed - **012-2330451**
- Wong Van Mama - **016-9759883**

### 4. **Ambulance Services**

- Emergency Service Police,  
Ambulance & Fire Brigade - **999**
- Private Ambulance Zainal - **017-2779504**
- St John's Ambulance Jasmani - **012-3607797**

