

CAREER'S GUIDE BOOK

Introduction

Caring for your loved one

Medication and equipment

Caring for yourself

End of life

Good to know



Sometimes you may need more than just a hand to hold.

CONTENTS

| | | | |
|------------------------------------|-----------|---------------------------------|--|
| | 01 | INTRODUCTION | |
| | 05 | What is palliative care? | |
| | 05 | About Hospis Malaysia | |
| | 08 | Emergency numbers | |
| CARING FOR YOUR LOVED ONE | 02 | | |
| Identifying and managing symptoms | 13 | | |
| Common physical symptoms | 14 | | |
| | 03 | MEDICATION AND EQUIPMENT | |
| | 25 | Managing medication | |
| | 26 | Administering medication | |
| | 28 | Tips for equipment use and care | |
| CARING FOR YOURSELF | 04 | | |
| Your emotions | 31 | | |
| Your well-being | 31 | | |
| Finances | 31 | | |
| Family members and friends | 31 | | |
| | 05 | END OF LIFE | |
| | 33 | Symptoms at the end of life | |
| | 33 | Burial permit and legal matters | |
| GOOD TO KNOW | 06 | | |
| Online resources | 35 | | |
| Additional contacts | 36 | | |
| Home medication schedule and chart | 37 | | |

INTRODUCTION

We may not know exactly how you are feeling as you read this, but we will do our best to guide you through this journey with your loved one.

What is Palliative Care?

Palliative care is an area of healthcare that focuses on relieving and preventing the suffering of patients with life-limiting illnesses.

It uses a multi-disciplinary approach to formulate a plan of care that addresses the patient's individual needs. This includes input from doctors, pharmacists, nurses, psychologists, and other healthcare professionals.

The goal of palliative care is to improve quality of life for both the patient and their family.

About Hospis Malaysia

Hospis Malaysia was established in 1991 to provide palliative care to patients at home.

Each year, we receive over 2,000 referrals from doctors around the Klang Valley.

Our clinical team makes house visits to assess the patient and help with problems related to the illness, be it physical, psychological, or social. Patients who live outside the areas covered by Hospis Malaysia can make an appointment to be seen as outpatients at our centre in Cheras.

The Clinical Team

They are here to help you and your loved one maintain the best possible quality of life so that you can make the most of your time together.

Who are they?



Nurses & doctors



Occupational therapist



Pharmacist



Administrative staff

What do they do?

Nurses & Doctors

- Help manage physical symptoms (e.g. pain, nausea, breathlessness).
- Teach nursing skills (e.g. mouth care, wound dressing).
- Advise if a hospital visit is necessary and keep in touch with the hospital doctors.
- Offer emotional and bereavement support.

You will be assigned a nurse according to where you live. They will be your first point of contact and will visit regularly according to your loved one's needs. Your nurse will be supervised by doctors, who will also visit when required.

Occupational Therapist

- Address and improve problems related to mobility (e.g. walking).
- Show carers how to transfer patients from bed to wheelchair.
- Teach patients simple exercises that are suitable for their condition.
- Address daily living activities (e.g. eating, dressing, speech).
- Run group exercises at our centre if the patient is well enough.

Your nurse will refer you to the occupational therapist.

Pharmacist

- Explain the purpose of the medication and how it works.
- Show how medication should be taken.
- Advise where to get medication.

Administrative staff

- Take calls during office hours.
- Ensure messages are conveyed to the rest of the team.
- Arrange for the loan of medical equipment.

Equipment

You can loan a variety of equipment from us at no charge, but a deposit* may be required for some equipment.

Equipment available are:

- Hospital beds
- Ripple mattresses
- Wheelchairs
- Walking aids
- Oxygen concentrators
- Syringe drivers

Your nurse will advise on what equipment your loved one may need.

**Deposit can be banked-in or paid in cash. It will be refunded once equipment is returned.*

Please note that Hospis Malaysia does not provide transport. However, we can provide contact details of a delivery company if required.

Education

Hospis Malaysia is also involved in teaching palliative care to other healthcare providers. Sometimes, your nurse may be accompanied by students during visits. If you prefer not to have students, just let us know.

Cost

Hospis Malaysia's services are free of charge and we provide a limited supply of medication during visits. However, for long term treatment, patients may be asked to buy medication with a prescription.

Handwriting practice area consisting of two columns of horizontal lines. The left column has 20 lines, and the right column has 20 lines. A dashed vertical line separates the two columns, with a small scissors icon at the top.



It is during our darkest moments that we must focus to see the light.

- Aristotle

CARING FOR YOUR LOVED ONE

Identifying and Managing Symptoms

Patients with life-limiting illness often have symptoms such as pain, breathlessness, constipation, vomiting, and tiredness.

One symptom may lead to another. For example, if a patient is in pain, they may not sleep well and become increasingly tired. Likewise, severe pain can cause a patient to feel nauseous, interfering with breathing and mobility.

Many things can be done to help your loved one feel more comfortable. With the right medication and management, symptoms can be controlled, allowing for a better quality of life.

It is important to treat symptoms early as they become harder to treat as they develop.

Tip: If your loved one is experiencing new symptoms, please inform the nurses early.

Common Physical Symptoms

1. Pain

Many people are frightened of pain. However, there are many effective painkillers and methods to manage it.

Everyone feels pain differently, even patients with the same condition. It is important to help doctors and nurses understand exactly where the pain is, how it feels, and how it affects your loved one, so they can manage it effectively.

Many people believe in putting off the use of painkillers for as long as possible, only taking them when the pain gets unbearable. However, if the pain is not treated, it may become more difficult to manage. Therefore, it is important to take painkillers in the way the clinical team advises.

Different types of painkillers

Different types of painkillers treat different levels of pain.

| | |
|---------------|---|
| Mild pain | Mild painkillers such as paracetamol. |
| Moderate pain | Weak opioid painkillers such as codeine. |
| Severe pain | Strong opioid painkillers such as morphine. |

Sometimes, other drugs are prescribed in addition to painkillers, such as anti-inflammatory drugs (e.g. ibuprofen), antidepressants, anticonvulsants (usually used to treat epilepsy), and muscle relaxants.

If the pain is frequent or constant, take painkillers regularly. Each dose should be enough to manage the pain until the next dose.

If the pain comes back before the next dose is due, inform the clinical team so they can prescribe a more effective dose or drug. It may take a few days to get the doses or drug right, so be willing to keep trying.

Tip: Record whenever the pain starts and how your loved one feels after taking painkillers. This can help detect potential triggers, uncover side-effects, and learn which painkiller works best.

Side-effects of painkillers

Drowsiness

It usually wears off after a few days, so it is possible to be free of pain and still be alert.

Nausea

Anti-sickness pills can help, and it usually settles gradually over a few days. If the nausea doesn't settle after 7 days, let the clinical team know. Switching to another painkiller may stop the sickness.

Constipation

It is such a common side-effects that anyone on strong painkillers should take laxatives regularly. Usually, two laxatives are taken: one to soften the stools and another to stimulate the bowels.

Administering painkillers

Painkillers usually come in the form of tablets. If your loved one can't swallow or is vomiting medication, it can be given via injection, skin patches, or tubes.

Tubes are inserted just under the skin of the tummy or arm. A small portable pump (also known as a syringe driver) will administer dosages continuously for 24 hours. Your doctor or nurse will set up the pump.

Painkillers do not cause addiction

Doses are carefully tailored to your loved one's needs and will only increase if the pain gets worse. Many patients stay on the same dose of morphine for months.

It can be harmful to stop taking morphine suddenly. If the pain is relieved by other treatments (e.g. radiotherapy), the dose can be reduced gradually under the supervision of your doctor or nurse.

Emotions and pain

It is important to treat the emotional causes of pain. Strong emotions such as fear, anxiety, and depression can worsen it. However, this does not mean pain is just a matter of the mind.

Learning to relax can get rid of fears and anxieties, and can help manage the pain. Your loved one can be more relaxed by being aware of different groups of muscles in the body and relaxing them. Advise them to do this consciously when under stress or in pain.

2. Breathlessness

Breathlessness or shortness of breath (also known as dyspnoea), is very common in people with lung diseases, or who are very weak and ill.

The feeling of breathlessness makes people anxious. They become tense as shoulder, neck, and chest muscles tighten while taking short shallow breaths. Breathing this way takes a lot of effort and it doesn't get much air into your lungs. This causes breathlessness and sets up a cycle of fear in patients.

Trying to cope with breathlessness alone is very difficult and may worsen during activities such as walking, bathing, and dressing. Emotional distress can also make breathlessness worse.

What causes breathlessness?

Many medical conditions can cause breathlessness. The common ones are:

- Advanced heart disease.
- Advanced lung disease.
- Lung cancer or any cancer that spreads to the lung.

Here are some suggestions for your loved one.

- Sit down when washing, dressing, or preparing food.
- Resist the temptation to hold their breath when dressing and undressing.
- Avoid bending down. Make use of equipment and aids such as grip bars or walking frames.
- Keep items they use often within easy reach.
- Wear loose clothing around the waist and chest.
- Increase the air-flow around them by opening windows or using a fan.
- Pace activities throughout the day to conserve energy.
- Have periods of rest between activities.
- When climbing stairs or slopes, breathe in on one step, breathe out on the next, wait a moment, then repeat.
- Pause before speaking and after each sentence.
- Consider using a wheelchair for long distances.

Controlled breathing technique

This technique helps your loved one produce a more relaxed and gentle breathing pattern. It works best when your loved one is rested and relaxed, while sitting back or lying down.

Steps:



1. Relax shoulders.



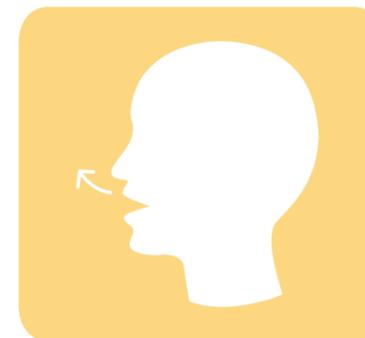
2. Place one hand on the chest and the other on the belly.



3. Inhale through the nose for about two seconds.



4. As your loved one breathes in, their belly should move outward more than their chest.



5. Breathe out slowly through the mouth while gently pressing on the belly. This will push the diaphragm to help get the air out.



6. Repeat.

Treatment and medication for chest conditions

After assessing the cause of breathlessness, the clinical team may recommend the appropriate treatment or medication.

3. Nausea and Vomiting

Nausea

The unpleasant, wave-like feeling that one is about to vomit. It can be experienced for a long time prior to vomiting, or vomiting may not even occur. Nausea can be more distressing than vomiting.

Vomiting

The forceful expulsion of the contents of the stomach through the mouth.

What causes nausea and vomiting in advanced diseases?

- Obstruction of stomach and intestines.
- Medications with nausea and vomiting as side-effects.
- Imbalances such as high calcium, cancer by-products, or waste products due to kidney or liver failure.
- Chemotherapy.
- Pressure in the brain due to tumour growth.
- Sight, taste, smell, and pain.
- Being frightened, anxious, or exhausted.
- Imbalance in the inner ear, resulting in dizziness and motion sickness.

Coping with nausea and vomiting.

- Taking anti-nausea medication regularly.
- Open windows, use a fan, or bring your loved one outside to ensure there is a constant supply of fresh air.
- Compress a cool towel on the forehead or back of the neck.
- Keep mouth clean. Brush or rinse at least twice a day, and after vomiting.
- Taking ginger or any ginger-flavoured food and drinks.
- Eating in small amounts throughout the day. Empty stomachs are more prone to nausea.
- Sit upright or lie down with head raised for an hour after eating to relieve any pressure on the stomach.
- Have distractions such as listening to music and watching TV.

Symptoms of nausea or vomiting.

When these symptoms appear, inform the clinical team immediately so they can diagnose and provide treatment.

- Blood in the vomit.
- Frequent vomiting and unable to keep any medication, food, or liquid in.
- Weakness, dizziness, or confusion.
- Pain associated with the nausea and vomiting.
- No bowel movement for more than 3 days.

4. Lack of Appetite (Anorexia)

A lack of appetite is a common symptom in advanced diseases. Among its causes are:

- Nausea and vomiting
- Constipation
- Fatigue
- Change of taste
- Mouth or throat irritation
- Inactivity
- Depression
- Medication
- Weakening effect from severe illness

Some of these causes may be interrelated to each other.

Coping with lack of appetite:



Inform the clinical team

They will diagnose and try to find a treatment.



Managing the environment

Introduce fresh air and eliminate unpleasant food smells. Use unperfumed cleaners, disinfectants, and air fresheners. Avoid strongly perfumed flowers.



Eat and drink frequently in small amounts

Serve varied and nutritious drinks with a small meal every two to three hours, rather than three big meals a day. However, do not force your loved one to eat.

Some say certain foods should be avoided, but it is not true. Do serve your loved one small portions of their favourite food. The main principle is to view meals as a way to promote quality of life.



During mealtimes

Keep a moistened towel in the fridge to freshen your loved one's face and hands before meals.



Oral health

Regularly rinse mouth or clean teeth and dentures with water. Chewing gum or sucking sugar-free lollies increases saliva flow. Other alternatives include pineapples, ice chips, and ice popsicles.



Explore different dishes

A common problem is the change in taste so try out different dishes. We recommend:

- Soups and porridge
- Cendol and ais kacang
- Tau foo fah and jellies
- Ice cream
- 100 Plus
- Ginger and assam-flavoured food
- Pineapple chips (particularly good for people with nausea or dry mouth)

5. Fatigue

Fatigue (or extreme tiredness) can affect your loved one's relationships with their family and friends. It may cause them to be impatient with people, leading them to avoid socialising all together.

Causes of fatigue

- Previous treatments (e.g. chemotherapy).
- Anaemia (low blood count).
- Eating problems.
- Pain.
- Breathlessness.
- Psychological effects from illnesses.

Effects of fatigue:

- Difficulty doing small chores and everyday activities (e.g. brushing hair, showering, or cooking).
- Wanting to spend the whole day in bed.
- Lack of concentration.
- Trouble thinking, remembering, speaking, or making decisions.
- Feeling breathless after light activities.
- Dizziness or light-headedness.
- Difficulty sleeping.
- Feeling more emotional than usual.

Coping with fatigue

Planning ahead is important. Include time to rest when planning the day. Know what your loved one can do and try not to let them do too much.

Keeping a diary can help discover how different treatments affect your loved one's energy levels.

6. Sore or Dry Mouth

Soreness and ulceration of the mouth is known as mucositis and can be very painful.

Mouth infections

A fungal infection called thrush (also known as candidiasis) usually appears as white patches or as a white coating over the mouth and tongue lining. It is treated with anti-fungal medicines.

Keeping a healthy mouth

- Inspect mouth daily for signs of redness, swelling, sores, white patches, or bleeding. Let the clinical team know if you see these signs.
- Clean teeth or dentures every morning, evening, and after each meal.
- Use a soft-bristled or a children's toothbrush. Bristles can also be softened with hot water. Replace toothbrush frequently to prevent infection.
- If toothpaste stings or brushing makes your loved one feel sick, try using plain water or mouthwash.
- Use sodium bicarbonate mouthwash (1 teaspoon of sodium bicarbonate to 300ml of water).
- If your loved one is sick, rinse their mouth before brushing or cleaning as acid from vomit can damage teeth.
- Keep lips moist with lubricant.
- Avoid dry food. Crunchy foods may cause bleeding gums and should be avoided.
- Drink more but avoid acidic drinks such as orange juice. Warm herbal teas can help soothe your loved one.

7. Constipation

Constipation is best prevented, but can be managed successfully in most cases.

Preventing constipation

Get your loved one to do a little exercise every day, make sure they eat well, and give them more time in the toilet.

Overflow diarrhoea

During constipation, the bowel can leak out watery stools that might look like diarrhoea.

If your loved one is constipated and develops diarrhoea, talk to the clinical team before administering anti-diarrhoea medication. Even though your loved one has diarrhoea, they may still be constipated.

Managing constipation

- Medications called laxatives prevent and treat constipation.
- If your loved one is on painkillers like morphine or opioids, they should also take laxatives.
- Having one bowel motion does not mean constipation is resolved. Therefore, it is important to take laxatives regularly.

8. Confusion

Confusion is the clouding of consciousness or limited awareness.

Causes of confusion

- Fever.
- Medication.
- Anything that affects the amount of oxygen reaching the brain (e.g. heart or lung diseases).
- Diseases that affect the brain directly (e.g. brain tumour or stroke).
- Pain or other physical discomfort.
- Chemical imbalances within the body due to disease processes or failure of vital organs.
- Constipation.
- Changes in routine, site of care, or the people caring.

Effects of confusion

- Being unable to think clearly and respond appropriately.
- Incoherent and rambling speech.
- Being unaware of surroundings.
- Misinterpretation of sights, sounds, or experiences.
- Being anxious, restless, and agitated.
- Usually worsens during evenings and nights.

What should you do?

Inform the clinical team about behaviour changes immediately. Confusion can clear up quickly if it is diagnosed and treated.

How to handle confusion:

- Don't argue with your loved one about their delusions.
- Gently remind your loved one who you are and where they are.
- Sit with your loved one, take their hand and talk to them, even if they seem unaware of you.
- Talk reassuringly about what you are about to do while you tend to them, even if you think they do not hear or understand you.
- Avoid changing your loved one's surroundings.
- Make sure your loved one is not too hot or too cold.
- Remove anything that may be causing irritation.
- Leave a light on at night.
- Don't make too much noise. However, playing music might help.

MEDICATION AND EQUIPMENT

Managing Medication

Handling your loved one's medication can be confusing but don't worry, we will guide you.

It is important to understand what each medication is for, the required dosage, how frequent, and how long it should be administered.

Do know where to get more medication if you run out. Your nurse can also advise on where to find them.

Common Palliative Care Medication

| Type of medication | Purpose |
|--|---|
| Analgesics Opioids (morphine, oxycodone, fentanyl, methadone) and non-opioids (paracetamol, ibuprofen, diclofenac, celecoxib). | Treat and reduce pain. |
| Anti-emetic Metoclopramide, domperidone, haloperidol, prochlorperazine. | Treat or prevent nausea and vomiting. |
| Laxatives Lactulose, macrogol, bisacodyl, senna/sennosides, saline glycerine enemas. | Treat and prevent constipation. Help push hard stools. |
| Adjuvant medications Dexamethasone, amitriptyline, gabapentin, lorazepam, midazolam, mirtazapine. | Usually used for other conditions but can be used to manage pain too. |

For more information on other types of medication, do ask the clinical team.

If your loved one needs a variety of medication, we recommend keeping a medication record/log and updating it regularly. There is one at the back of this guidebook to get you started.

Administering Medication

Remember to wash your hands BEFORE AND AFTER you administer medication.



Oral medication (e.g. pills and liquids)

- Read the medication label carefully to ensure it is the correct medicine, the correct dose, and the right time to administer it.
- Always provide water when giving oral medicines.



Transdermal patches (medication in the form of a patch or plaster)

- Read the information label before use. Each product will have specific instructions.
- Replace as scheduled.
- Ask your nurse/pharmacist what to do if the patch loosens or falls off before it is time to replace it.



Subcutaneous injections

- A number of medications can be given continuously via infusion or intermittently using injections.
- Continuous medication infusion is normally given via a syringe driver (a small, portable, battery-operated machine).
- Your nurse will teach you how to use and administer subcutaneous medication.

Tips:

- Store all medication in one place unless they require refrigeration. This will help in emergency situations and when the clinical team want to review the medication.
- DO NOT throw unused or expired medicines into household rubbish bins or flush them down the toilet. Medicines disposed of in rubbish bins may be accessed by others (especially children) while medicines flushed down the toilet could end up in the water system and harm the environment.
- Take unused medication to your local pharmacy, hospital, or Hospis Malaysia to be disposed of safely.

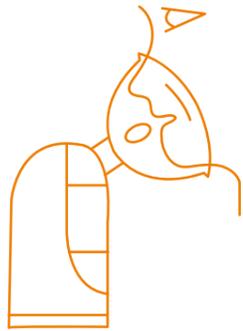


Be faithful in small things because it is in them that your strength lies.

– Mother Teresa

Tips for Equipment Use and Care

Nebuliser



Used when your loved one has difficulty breathing.

Step 1: Pour in the amount of medication prescribed by the clinical team into the solution chamber. Attach it to the nebuliser mask with the tube.

Step 2: Attach the other end of the tube to the machine.

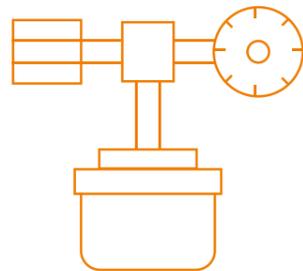
Step 3: Turn the machine on. Place the mask over the nose and mouth. Get your loved one to breath normally for 15 minutes.

The clinical team will advise on how often you should use the nebuliser.

Caring tips:

Wipe with a damp cloth or a sanitising agent. For the mask and the solution chamber, clean with water and dry well.

Oxygen concentrator



There are two types of oxygen concentrators. One is just a concentrator and another combines with a nebuliser.

Step 1: Unscrew the humidifier bottle and fill it with filtered, boiled, or mineral water. Let boiled water cool before pouring. **DO NOT USE TAP WATER.**

Step 2: Screw the flask back and connect the oxygen tube to the humidifier nozzle.

Step 3: Turn the concentrator on. Wait until the high pitch sound stops to start using it. Ensure the oxygen level is according to the clinical team's recommendations.

Important: Ensure it is plugged into a main socket and NOT into multi socket points.

Caring tips:

Daily — Clean the humidifier and the oxygen administration tube with water or water with a cleaning agent. Let water run through the tube and dry well.

Weekly — Wipe the body with a damp cloth.

Fortnightly — Clean the dust filter with a vacuum cleaner or wash with water.

Place the machine in a clean room.

No smoking is allowed close to the machine.

Oxygen tank



Step 1: Unscrew the humidifier bottle and fill it with filtered, boiled, or mineral water. **DO NOT USE TAP WATER.** If it is boiled water, let it cool before pouring.

Step 2: Screw back the flask to the oxygen tank.

Step 3: Connect the nasal chamber to the humidifier flask.

Step 4: Turn the knob clockwise for oxygen to flow. Observe the meter and ensure that the level of oxygen is what the clinical team recommended. If the needle of the meter touches the red band (or in some meters it reaches '0'), it is time to refill.

Step 5: Turn the black knob anticlockwise to turn off the oxygen.

Caring tips:

Daily — Clean the humidifier and the oxygen administration tube with water or water with a cleaning agent. Let water run through the tube and dry well.

Weekly — Wipe the body with a damp cloth.

Ripple mattress



Step 1: Insert the tubes from the electric pump machine into the nozzles from the ripple bed.

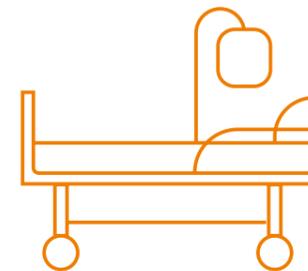
Step 2: Turn the electric pump machine on. First time use? Set the electric pump pressure to 'firm'. Once the mattress is fully inflated, set the pressure to soft.

Step 3: Keep the machine on at all times. Air will leak out if it's turned off.

Caring tips:

Clean as often as you can with a sanitising agent.

Hospital bed



There are 3 types of hospital beds that you can loan from Hospis Malaysia:

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

They are operated manually. Hospis Malaysia also has electric beds for patients where maintaining independence is important. The clinical team will teach you how to operate these beds.

Caring tips:

Wipe the frame with a damp cloth daily. Use a sanitising agent to wipe the mattress and change the sheets at the same time.

CARING FOR YOURSELF

Your Emotions

You may experience a range of emotions – from anxiety and frustration, to joy when sharing a special moment with your loved one. Sometimes, when you are tired, you may feel resentment for having to spend so much time away from your usual activities. But you may also feel guilty for not doing enough.

Changing emotions are normal reactions when caring for your loved one. If you find yourself in a low mood almost all the time and not coping well, you may be depressed and require help. You can inform your nurse if this happens.

Your Well-being

Caring for a loved one often means juggling roles. Don't be afraid to ask for help from neighbours and friends. When you are physically tired, it is more difficult to deal with emotions. Try and get adequate rest, food and exercise by getting a family member or friend to take over so you can take a break.

If you need time off work, your nurse can write a letter to support your application. If you want to employ extra help such as a private nurse or helper, discuss with your nurse.

Sometimes it is helpful to confide in someone but it may be difficult to confide in family members because they are also distressed. Perhaps you can talk to your nurse.

Finances

When a family member has a life-limiting illness, finances may suffer, both through the cost of treatment and loss of income. Your nurse may be able to suggest organisations that might offer financial aid. Hospis Malaysia does not offer financial support, but all visits and loan of equipment are free of charge.

Family Members and Friends

Family members and friends are a source of support. They may offer help like providing transport, doing grocery shopping or even giving emotional support. Often, they like to help, but are not sure how to. So tell them directly how they can help.

Many may have advice to offer, but do consider their previous experiences and where they are getting their information from before acting on the advice. Perhaps discuss with your nurse.

You may be getting frequent visitors. And too many visitors may tire your loved one. Do tell them visits are welcomed, but the number of visitors should be limited in the interest of your loved one's comfort.

Sometimes, there may be conflicts between family members about the best way to care for your loved one. Open communication is important to resolve these issues. Your nurse can arrange a family conference if necessary.

END OF LIFE

Symptoms at the End of Life

With your loved one's condition, you may be wondering about what will happen in the future, and what you need to be prepared for.

Note: Some prefer not to know or to think too far ahead. If this is true for you, you may not want to read this section.

- Being prepared for all possibilities is not the same as giving up hope. Many think the worst but hope for the best.
- Every patient is different. Some of the changes will be related to their illness. Ask the clinical team for what to expect.
- As time goes by, your loved one may become weaker and need assistance for daily activities. They may sleep more and find it difficult to concentrate.
- In the last days of life, your loved one may be bedridden and need total care.
- They may become unable to respond to you and unable to swallow medication or food. When this happens, medication can be given using a syringe driver.
- As their body shuts down they will not need food; only sips of fluids. They may be restless or confused.
- In the final phase, breathing patterns will change. It slows down, followed by a few rapid breaths. It may also sound different. You may hear a rattle caused by secretions in the mouth. Slightly positioning your loved one to one side can help.
- You will know your loved one has passed away if they have not taken a breath for the last 10 minutes.

Burial Permit and Legal Matters

What to do after your loved one has passed away:

- If you made funeral arrangements, you can contact the undertaker. If you are Muslim, you can contact your mosque for help.
- You will need to make a police report. Take your loved one's IC and any documentation about their illness (e.g. hospital discharge summaries, appointment cards) to the police. They will issue a certificate.
- If your loved one is young, the police may ask for a doctor's certificate. You can get one from a nearby clinic.
- Hospis Malaysia's doctors do not certify deaths but if you encounter any problems with this process, do contact us.

GOOD TO KNOW

Online Resources

There are many websites that offer information that may be of help. Here are some of them to give you a starting point.

Overseas organisations

www.palliativecareguidelines.scot.nhs.uk

Palliative Care Guidelines is developed by a multi-disciplinary group of professionals working in the community, hospital, and specialist palliative care services. This website contains reliable guidelines, patient information, and online resources.

www.macmillan.org.uk

Macmillan supports people with cancer and their families with specialist information, treatment, and care.

www.hospiceuk.org

Hospice UK (formerly known as Help the Hospices) is a charity organisation supporting hospice care in the UK. This website provides useful information for patients, carers, and those who are involved in hospice care.

www.mariecurie.org.uk

Marie Curie Cancer Care is an organisation that provides nursing care for cancer patients. This website contains useful information for carers.

www.cancerhelp.org.uk - or - www.cancerhelp.org.uk/coping-with-cancer

CancerHelp UK provides information for patients with cancer and their families. It has useful information on how to manage emotional, physical, and practical effects of cancer.

www.palliativecare.org.au

Palliative Care Australia provides reliable patient and carer information, and online resources.

Malaysian organisations

www.cancerlinkfoundation.org

Cancerlink Foundation provides information and resources for cancer patients and their families.

www.malaysiaoncology.org

Malaysia Oncology Society provides useful and up to date information about cancer development in Malaysia and other resources.

www.cancer.org.my

National Cancer Society Malaysia (NCSM) is an NGO in Malaysia that provides education, care, and support services for people affected by cancer.



Additional Contacts

Oxygen refill service

| Name | Contact | Operational hours |
|--|---|-------------------------------|
| ESC Gases (M) Sdn Bhd www.esc-gases.com | 03 5888 7882 (Balakong) 016 912 5796 (Puchong) | Mon – Fri, 8.30am – 5.30pm |
| Gasworld Sdn Bhd, Kepong www.gasworld.com.my | 03 6279 9459 | Mon – Fri, 8.30am – 5.30pm |
| Peng Yam Enterprise Sdn Bhd www.pengyam.com | 03 7803 3605 | Mon – Fri, 8.30am – 5.30pm |

Oxygen rental and service

| Name | Contact |
|--|---------------------------------------|
| ESC Gases (M) Sdn Bhd | 012 3111 321 (Mr Low) |
| Shantam | 017 8850 581 |
| Puteri Ambulance www.puterimalaysiaambulance.com | 03 7877 8899 012 3980 999 (Mr Raj) |

Medical equipment

| Name | Contact |
|---|---|
| Rehab Supplies www.rehabsupplies.com.my | 03 5631 7519 |
| Lee Prosthetic www.leeprosthetic.com | 03 9131 4569 |
| Lifeline Innovators www.lifeline.com.my | 03 5880 4638 |
| Maycare www.maycare.com | 03 5510 8990 (Shah Alam) 03 2283 2990 (Bangsar) 03 4252 8990 (Ampang) 03 2691 0451 (IJN, KL) |

Social welfare

| Name | Contact |
|--|--------------|
| My Kasih Foundation Groceries www.mykasih.com.my | 03 7720 1800 |

Hospice Organisations in Malaysia

There are 26 recognised hospice organisations in Malaysia. All of them operate independently.

| State | Name | Contact |
|------------------------|--|---|
| Kuala Lumpur | Hospis Malaysia | 03 9133 3936 |
| Selangor | Hospice Klang Kasih Hospice Assisi Palliative Care | 012 622 3073 03 7865 6522 03 7783 8833 |
| Penang | Penang Hospice Society Pure Lotus Hospice of Compassion Charis Hospice | 04 2284 140 / 04 2264 662 04 2295 481/ 04 2778 953 04 8279 668 |
| Kedah | Persatuan Hospis Kedah | 04 733 2775 |
| Perak | Perak Palliative Care Society Taiping Palliative Society | 05 5464 732 05 8072 457 / 016 595 0585 |
| Negeri Sembilan | Hospis Negeri Sembilan | 06 7621 216 |
| Malacca | Hospice Melaka | 06 281 4532 |
| Johor | Palliative Care Association of Johor Bahru Persatuan Hospice Ark | 07 222 9188 07 2899 278 |
| Pahang | Persatuan Hospis Pahang | 09 560 6359 |
| Terengganu | Hospis Terengganu | 09 621 2121 ext 2058 |
| Kelantan | Persatuan Hospis Kelantan | 09 7452 000 / 09 7452 257 |
| Sarawak | Sarawak Hospice Society Kuching Cancer Care Palliative Care Association of Miri Pusat Jagaan Two Three Hospis Kuching | 082 276 666 082 337 689 / 082 235 809 012 8456 480 011 1098 2323 |
| Sabah | Persatuan Hospis Tawau Palliative Care Association of Kota Kinabalu Palliative Care Association Of Sandakan Persatuan Hospice St Francis Xavier Home Care Hospice Programme | 089 711 515 088 231 505 089 236 219 087 339 114 089 236 219 |



From caring
comes courage

– Lao Tzu

The Hospis Malaysia's Carer's Guidebook is a handbook produced to assist and support caregivers of our patients as they embark on an often difficult journey of caring for a loved one. This handbook is adapted and revised from "A Carer's Guide" which was produced by Hospis Malaysia with funding from the Decent Care Values in Palliative Care Project at the Altarum Institute. The Decent Care Values in Palliative Care Project was a collaboration between the Altarum Institute, The Diana, Princess of Wales Memorial Fund, and the World Health Organization.

Hospis Malaysia would like to thank everyone involved in making the production of this handbook possible. We would especially like to thank patients and families for giving their consent for their photos to be used in this publication. Special mention also to the team at Creative Juice Kuala Lumpur for dedicating their time in working with Hospis Malaysia to produce this handbook.

The Carer's Guide Book is a handbook produced by Hospis Malaysia.

Copyright © 2018

All rights reserved. No part of the Carer's Guide Book may be reproduced or reprinted or utilized in any form or by any electronic, mechanical, or other means, now known or hereafter invented, including photocopying, photographing, and recording or in any information storage or retrieval system, without permission in writing from Hospis Malaysia.

Printed by

Tinggi Press Sdn. Bhd.

AN INITIATIVE BY



SUPPORTING



Hospis Malaysia (223675-X)
2 Jalan 4/96, Off Jalan Sekuci, Taman Sri Bahtera
Cheras, 56100 Kuala Lumpur

Tel: + (60)3-9133 3936

Fax: + (60)3-9133 3941

e-mail: patientcare@hospismalaysia.org

Website: www.hospismalaysia.org

Facebook: @HospisMy