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A Carer’s Guide
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1. Caregivers 2. Palliative treatment
I. Hospis Malaysia 3620425
This information guide has been put together to help carers looking after patients with life limiting illness, such as cancer, heart failure, kidney failure and degenerative neurological diseases.

Caring for a patient is a challenging task. It can also be very rewarding as it often brings people closer together. Feedback from carers has suggested that they need more information to feel more in control of what is happening. We have put together this guide using our clinical experience and medical knowledge as well as input from carers and patients to cater to that need.

This guide offers information related to areas that often cause distress to patients and carers as well as links to other resources that provide useful information. If you do not have access to the internet and would like to read more about some of the topics included here, do let us know and we can pass you more information.

It is important to remember that no two situations are the same and so it is always helpful to discuss your problems with the clinical team as well.

In your role as a carer you may well have come across other useful resources that are not in the guide. If you think they would be helpful to others, please let us know. We welcome feedback about this guide and will always be looking for ways to make it more useful for carers and patients.

In the back of the guide we have some charts where you can record the patients medication and there are spaces for you to write comments about the patients conditions or questions. You may find it useful to take this guide with you when you go for hospital visits.
The Distress Thermometer

Together with this guide, there is a picture of a thermometer (distress thermometer) and a check list for you to use to find out your needs. The nurse will ask you to fill it out before the visit and you can discuss any problems when you see her.

**Distress Thermometer**

**Step 1**
Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

**Step 2**
Please indicate if any of the following has been a problem for you in the past week. Please tick either YES or NO for every question.

Do you have any problem dealing with:

1. the patient’s symptoms
2. the patient’s day to day care
3. the patient’s emotions
4. family members and friends
5. healthcare providers (e.g. doctors and nurses)
6. your daily living
7. finances
8. your own emotions
9. uncertainty about the future

**Other problems :**
Hospis Malaysia

Hospis Malaysia was established in 1991 to provide palliative care to patients at home. Today we receive over 1,500 referrals a year from doctors around the Klang Valley, so we continue to build on our already extensive experience in taking care of patients and their families with life limiting illness.

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

We also provide palliative care education to medical students, nurses and other health care providers.
The Clinical Team

Nurses and Doctors

The aim of the palliative care team is 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.

The Palliative Care team are:

• Nurses
• Doctors
• Pharmacist
• Occupational Therapist
• Administration Staff

You will be assigned a nurse according to the area in which you live. Our nurse is your first point of contact with the team and will visit you regularly. The visits will be arranged according to patients’ needs. At times you may be visited by one of the doctors.

The clinical team will:

• help you manage physical symptoms such as pain, nausea and vomiting, breathlessness etc.
• support you emotionally through this difficult time
• teach you nursing skills such as mouth care, wound dressing, turning the patient in bed, care of colostomies.
• advise you if they think you need to go to hospital and will keep in touch with the hospital doctors.
• offer bereavement support

If your loved one is admitted to hospital, one of the nurses may visit but their care will be directed by the hospital doctors.
Occupational Therapist
The occupational therapist helps with:
• problems related to mobility such as helping patients improve their walking or showing families how to transfer patients from bed to wheelchair
• exercise, which is also important for patients but it has to be appropriate for their condition.
• activities of daily living such as eating, dressing and speech
Your nurse will refer you to the occupational therapist.

Pharmacist
The pharmacist will answer any queries about:
• how the medication should be taken
• where to get the medication
If it is a more complicated question, she will refer you to the nurse in charge of your case.

The Administration Staff
There are administration staff at Hospis Malaysia who will:
• take calls during office hours
• make sure messages get through to the clinical team
• arrange for the delivery of any equipment you may need to borrow
Daycare
Hospis Malaysia offers a daycare service. Patients can come to Hospis Malaysia for the day to socialise with other patients, do some exercise and get involved in various activities. It is run by a team of volunteers who can arrange transport for the patient to and from the centre. Daycare is available from 10.00am to 4.00pm on Tuesdays and Thursdays allowing carers a short break. A nurse and a doctor will be on hand to deal with any medical problems.

Patients are referred to day care after assessment by the nurse.

Education
Hospis Malaysia is also involved in teaching palliative care to medical students, nurses and other healthcare providers. Sometimes your nurse may be accompanied by students on their visits. It is important for students to understand how patients and carers deal with illness in the community and we value your contribution to the students' education. If you prefer not to have students at the visit, please let the nurse know.

Equipment
Hospis Malaysia has a variety of equipment which may help you in caring for your loved one. Hospital beds, ripple mattresses, wheelchairs, oxygen concentrators and walking aids are some of the items we loan free of charge. Your nurse will advise you about any equipment that may help the patient.

Please note that Hospis Malaysia does not provide transport. We can however give you the contact details of a delivery company if you need one and you can deal with them directly.
How to Contact the Clinical Team

During Office Hours
Office hours are from 8.00am to 5.00pm Mondays to Fridays. Please call the centre on 03-91333936 to speak to the nurse. If the nurse is out on visits, the message will be passed on and your call will be returned.

Emergency On Call Service
There is a nurse on call after office hours and during weekends and public holidays. You can reach the on call nurse by calling 03 2718 1079, give the patient’s name and contact number to the pager service and the nurse will call you back. This emergency number is only to be used by carers and patients registered with Hospis Malaysia.

You should contact the clinical team during office hours if you have any routine enquiries or concerns. If for example, the patient’s symptoms are getting worse, the medication is not working or if they have developed new problems, please contact us at any time. The nurse on call will give you advice or visit as necessary after discussing the situation with you.

Costs
Hospis Malaysia’s services are free of charge. We give a limited supply of medication during visits but for long term treatment patients will be asked to buy the medication with a prescription.

DURING OFFICE HOURS
Mondays to Fridays
8am to 5pm
Call: 03-9133 3936

EMERGENCY ON CALL SERVICE
After Office Hours, Weekends and Public Holidays
Call: 03-2718 1079
Patients with life limiting illness often have symptoms such as pain, breathlessness, constipation, vomiting and others. One symptom may also lead to another. For example, if a patient is in pain they may not sleep well and become increasingly tired. Likewise, severe pain can also make a patient feel nauseous and interfere with breathing and mobility.

There are many things that can be done to help the patient feel more comfortable. With medication, symptoms can be controlled, allowing the patient to have a better quality of life. It is important to treat symptoms early because they become more difficult to treat if allowed to develop.

The palliative care team will assess the patient’s symptoms, look at the causes and recommend treatment and other nursing procedures that may help. If, for example, the patient cannot swallow medication, the team will give medication using a syringe driver.

If the patient is experiencing symptoms, please bring it to the attention of the nurses early.
Below are some useful resources that help explain more about each of the common symptoms. They can be found at:

- **Constipation**: http://www.palliativecareguidelines.scot.nhs.uk/documents/Managing%20constipation.pdf
- **Fatigue**: http://www.palliativecareguidelines.scot.nhs.uk/documents/Managing%Fatigueleaflet.pdf
- **Managing a Sore or Dry Mouth**: http://www.palliativecareguidelines.scot.nhs.uk/documents/Managing%20a%20sore%20and%20dry%20mouth.pdf
- **Breathlessness**: http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects/Othersymptomssideeffects/Breathlessness.aspx
Medication

The clinical team will discuss the medication with you.

It is helpful to keep a record of all the medications and update it regularly. It is important to know what each medication is for, how often and how much should be taken and for how many days it should be continued. This chart may be useful for you to keep a record.

You should also make sure you know where to get more medication from in case it runs out. Your nurse will tell you how to get more medication.

Patients may need to take a variety of medication over the course of the illness. There is a medication chart at the back of this book to help you to keep a record.

Below are some links to information about some of the medication the patient may use.

http://www.palliativecareguidelines.scot.nhs.uk/documents/Oral%20Morphine.PDF

http://www.palliativecareguidelines.scot.nhs.uk/documents/Fentanylleaflet.PDF

http://www.palliativecareguidelines.scot.nhs.uk/documents/Oral%20Oxycodone.PDF

Sometimes medication is given by injection or using a syringe driver (a small machine that allows the medication to be given continuously.)

Dealing with the Patient’s Day to Day Care

Patients who are very ill often feel very tired and often say they have no energy. It helps for them to have a routine so that they keep activities to the part of the day when they have the most energy.

Activity

Exercise is important as it may well help to lessen the feeling of fatigue as well as increasing confidence and ability to do things. It is a good idea to have a routine that includes some exercise and periods of rest and to have small goals that the patient can achieve each day. It may be something as simple as sitting in the garden for half an hour. The important thing is that it is a realistic goal so that the patient feels they have succeeded.

Sleep

Sleep patterns often change when someone is ill and night time can be very difficult for both the patient and the carer. If the patient is having difficulty sleeping there are many possible causes. It may be due to discomfort because of physical problems, or simply because they have slept a lot during the day or the place they are sleeping is not their usual bed. Sometimes it is because they are worried. So check that the patient is comfortable and that the environment is suitable. If they are worried or anxious, having someone nearby can help. Talk to your nurse about the need for medication.

Diet

Eating a balanced diet will help maintain your energy levels. However, it is more important that the food is enjoyable because that will help increase the appetite. You will hear many people talk of foods that can or can’t be eaten but there are in fact no food taboos. So encourage your loved one to eat small portions of their favourite food. Many patients need to eat little and often rather than large portions.

Another common problem is that patients experience a change in their sense of taste. Ask your nurse for more advice about the patient’s diet. We have found some of the things that patients enjoy which are easy to digest alongside the usual diet of soups and porridge, include jellies, cendol or ice-kacang, taufu-fa, ice-cream and drinks such as 100 plus. Ginger and assam flavoured food help with nausea and pineapple chips have helped patients with dry mouths.
No two people are the same.

We all react differently to difficult situations. Patients may experience a spectrum of emotions during the course of their illness. They may be sad, angry, quiet and withdrawn but most patients have good days and bad days.

Times of increased stress often occur when there are changes of treatment, or when there are physical changes which might indicate that the patient’s condition is getting worse. Many carers worry about upsetting the patient. Try to keep in mind that often a patient’s emotions are related to the disease and the situation they are in.

One source of distress for patients is the sense of losing control and feeling as if they are a burden. Whilst they are well enough, patients generally benefit from staying involved in making decisions about their care and the every day decisions about family or work that they have always taken part in. It is important to remember to ask the patient their opinion and keep them involved in family life.

Some people believe that if the patient knows their diagnosis or prognosis they will get depressed or may even give up. Experience shows that people generally cope well with bad news and although they may be sad at times, they still find ways to cope and carry on.

Anxiety is usually related to fear of the future and not understanding what is happening. This is another reason why it is helpful for patients to be informed of what is wrong with them. Many suspect there is a problem because they notice physical changes but they may not want to worry their family members and so hide their fears.

As a carer, it is important to listen and give your loved one the opportunity to talk about their feelings if they want to. When people are scared to talk to each other openly it can lead to misunderstandings so if you are having difficulty communicating with your loved one, ask the nurse for help.
Dealing with Family Members and Friends

Family members and friends will be a source of support. They may offer practical help like providing transport and doing the marketing or give emotional support.

Often they would like to help but are not sure how, so tell them directly how they can be of use. Many may have advice to offer, you will need to consider what their experience is and where they are getting their information before acting on the advice. You can discuss any advice given with your nurse.

Family and friends also frequently want to visit, but you may find too many visits tire the patient. Do tell them that their visits are welcome but that you may have to limit the number of visits in the interests of the patient’s comfort. People usually understand the need for rest.

Sometimes there is conflict within families about the best way to care for the patient. Open communication is vital to resolve these issues and your nurse will be able to arrange a family conference if necessary.
Dealing with Healthcare Providers

The Hospis Malaysia clinical team would like to work together with you as a member of the team to provide the best possible care for the patient. Your input is very important to us. When there are many options for treatment or many things going on at once, it can be very confusing.

It is helpful to think about what you need to know and write down questions as they come up. Then ask the team when they visit next.

When dealing with hospital appointments:
- make a list of important questions for the doctor
- consider taking another person with you who can take notes and clarify information. You and the patient may be too upset or too tired to take it all in
- if you are in any doubt about appointments or when you should go for tests, call to check with the relevant people
- please take along all the patient’s information, like X-rays and scans, discharge summaries and letters

Different doctors and nurses have different areas of expertise. So make sure you are talking to the right person about the problem. If you are not sure who that person is, ask the Hospis Malaysia nurse.
Dealing with Daily Living

Caring for someone very ill often means juggling many roles. Don’t be afraid to accept help from neighbours and friends to do some of the practical tasks.

If you have family support, try to share the jobs that need doing. Write up a roster of who is doing what and when. If you need help asking for time off work, or extensions of leave, your nurse can give you a letter to support your application. If you are thinking of employing extra help such as private nurses, you can ask your nurse for contact numbers.

Dealing with Finances

When someone has a life limiting illness, it is inevitable that finances suffer, both through the cost of treatment and through loss of income.

Hospis Malaysia does not offer financial support but all visits and loans of equipment are free. Please discuss any financial issues with your nurse who may be able to suggest other organisations that might offer financial aid.
Dealing with Your Own Emotions

Caring for someone who is very ill is a demanding task. You will find that when you are physically tired, it is more difficult to deal with your emotions. Make sure you get adequate rest, food and exercise. Try and arrange for a family member or friend to sit with your loved one so that you can take a break.

Most people find it helpful to have someone they can confide in. Sometimes it is hard to talk to family members because they too are distressed, it may help to talk to a member of the clinical team.

You may experience a whole range of emotions from anxiety and frustration to pleasure at being able to share special moments with your loved one. At times when you are tired you may feel resentment at having to spend so much time away from your usual activities. Some people feel guilty that they may not be doing enough. All of these are quite normal reactions to caring for someone very ill. If you find your mood is very low much of the time and you are not coping well, you may be depressed and you may require more help so please do tell your nurse.
Dealing with Uncertainty about the Future

Knowing your loved one’s condition, you may be wondering what is going to happen in the future and what you need to be prepared for.

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

Being prepared for all possibilities is not the same as giving up hope. Many of us think about the worst but hope for the best. Each patient is different and some of the changes will be related to the type of illness they have, so ask your doctor or nurse what to expect.

As time goes on your loved one will become weaker, less able to do things for themselves and more in need of assistance for things like bathing and eating. You will notice that they sleep more and more and find it difficult to concentrate. They spend less time doing their normal activities.

In the last days of life, the patient will be bed bound and need total care.

- They may become unable to respond to you and unable to swallow medication or food
- Medication can be given using a syringe driver
- As their body is shutting down they will not need food, just sips of fluids
- They may be restless or confused
- As they enter the final phase you will notice changes in their breathing pattern; sometimes it slows right down and then they take a few rapid breaths
- Their arms and legs will become cool to touch
- The breathing may change in sound, you may hear a rattle sound caused by secretions collecting in the mouth. Positioning the patient slightly to one side can help with this
- You will know when your loved one has passed away if they have not taken a breath for the last 10 minutes
After your loved one has passed away:

- if you have already made funeral arrangements, you should contact the undertaker and be guided by them
- if you are Muslim you can contact your mosque
- you will need to make a police report by taking the patient’s IC and any documentation (e.g. hospital discharge summaries, appointment cards) about their illness to the police station. The police will issue a certificate
- if the patient is young, the police may ask for a doctor’s certificate. You can get it from a doctor in a nearby clinic
- Hospis Malaysia doctors do not certify deaths but if you have any problems with this process, please contact us

There are many websites on the internet that offer information that may be of help. Here are some of the sites we think may provide you with a starting point.

**Overseas Organisations**

- [http://www.palliativecareguidelines.scot.nhs.uk/default.asp](http://www.palliativecareguidelines.scot.nhs.uk/default.asp)
  Palliative Care Guidelines have been developed by a multidisciplinary group of professionals working in the community, hospital and specialist palliative care services. This website contains reliable and useful guidelines, patient information and online resources for professionals and patients with life limiting illness.

- [http://www.macmillan.org.uk](http://www.macmillan.org.uk)
  A website that supports people with cancer and their families with specialist information, treatment and care.

  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.

  Marie Curie Cancer Care is a care charity organisation that provides nursing care for cancer patients. This website contains useful information for caregivers.

- [http://www.cancerhelp.org.uk/](http://www.cancerhelp.org.uk/)
  CancerHelp UK is a website that provides free information on cancer and care for people with cancer and their family. It has useful information on how to control pain.

**Malaysian Organisations**

- [http://www.cancerlinkfoundation.org/](http://www.cancerlinkfoundation.org/)
  The Cancerlink Foundation website provides information and resources for cancer patients and their families.

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

  The National Cancer Society Malaysia (NCSM) was established in 1966. It was the first cancer related NGO in the country and provides education, care and support services for people affected by cancer.
<p>| Date | Name of Medication | Dose | Purpose | How taken | 12 am | 2 am | 4 am | 6 am | 8 am | 10 am | 12 Noon | 2 pm | 4 pm | 6 pm | 8 pm | 10 pm |</p>
<table>
<thead>
<tr>
<th>Date</th>
<th>Name of Medication</th>
<th>Dose</th>
<th>How taken</th>
<th>Time Given (write time in box)</th>
</tr>
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Break Through Medication Chart (write when the Break Through Analgesic was given)
# Additional Contact Numbers

**OXYGEN REFILL SERVICE**
- ESC Gases (M) Sdn Bhd, Balakong 03-89427882 Mon-Fri 8.30-5.30pm
- ESC Gases (M) Sdn Bhd, Puchong 03-80604561 Mon-Fri 8.30-5.30pm
- Gasworld Sdn Bhd, Kepong 03-62506692 Mon-Fri 8.30-5.30pm
- Peng Yam Enterprise Sdn Bhd 03-78033605 Mon-Sat 8.30-5.00pm

**OXYGEN RENTAL AND SERVICE**
- Shantam 017-8850581

**MEDICAL EQUIPMENT**
- Rehab Supplies Sdn. Bhd. 03-7949 2921

**AMBULANCE**
- Extro Ambulance Services 03-7783 8809 / 012-3691462 (En Mohd Ali)
- First Ambulance 03-7785 1919 / 1-300-88-1919
- Maha Mas Medic Services 03-4044 9099 / 03-4024 8999 / 03-4024 9099
- Red Crescent 03-4257 8122
- St John’s Ambulance 03-3371 5005

**TRANSPORT TO HOSPITAL**
- Mobility 03-7957 7255

**SUPPORT GROUPS**
- Alzheimer’s Disease Foundation Malaysia 03-7956 2008 / 03-7958 3088
- Befrienders 03-7956 8144 / 03-7956 8145
- Breast Cancer Welfare Association 03-7954 0133
- Cancerlink Foundation 03-7956 9499
- Malaysian Mental Health Association 03-7782 5499
- Majlis Kanser Nasional (MAKNA) 03-2162 9178
- National Kidney Foundation of Malaysia 03-7954 9048 / 03-79549049
- National Stroke Association of Malaysia (NASAM) 03-7956 4840
- The Malaysian AIDS Council 03-4045 1033
- Ti-Ratana Welfare Society 03-7988 1818

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**DISCLAIMER:** These contacts which we think may be helpful to you. We are not affiliated to the names/companies/organisations and do not endorse them in any way.
The Hospis Malaysia team would like to thank all those who were involved in the production of this booklet. They include:

Patients and Carers for their contributions.

Kamal Salhaimi Fadzil for the photography

Bolt & Nut Connection for the design and layout

This guide was made possible by a grant from the Altarum Institute as part of a Decent Care Values in Palliative Care Project.
You can contact your nurse:

**DURING OFFICE HOURS**
Mondays to Fridays – 8am to 5pm, call: **03-9133 3936**

**EMERGENCY ON CALL SERVICE**
After Office Hours, Weekends and Public Holidays, call: **03-2718 1079**

This emergency number is only to be used by carers and patients registered with Hospis Malaysia.