

No Greater Gift could we hope to give - than helping someone else to live...



HOPE  **HANDBOOK** 
A Guide for Cancer Caregivers

A Community Service Project by
Malaysian Oncological Society and Pfizer Malaysia



MALAYSIAN ONCOLOGICAL SOCIETY
www.malaysiaoncology.org

MESSAGE

from the Ministry of Health, Malaysia



Over the years, due to the change in lifestyle patterns, there has been an increase in the number of recorded cancer cases in Malaysia. Equally of concern is the trend for younger people to be afflicted by cancer – those in the 30-40 age group. Cancer is now a disease that strikes indiscriminately regardless of race, religion as well as social and health status.

When you consider this scenario, it is evident that current public education efforts must be stepped up in combating the disease. With cancer being one of the major causes of death in Malaysia, providing reliable and authoritative information is crucial in combating this disease in the long run.

While the government has always been aggressively concentrating on public education efforts, it welcomes the innovative efforts of private bodies and professional organizations in creating cancer awareness. The Ministry believes that mutual collaboration between the government and other parties in a concerted effort is key to winning the battle against cancer. This is why the government is pleased with the proactive effort by Pfizer Malaysia and the Malaysian Oncological Society in publishing this excellent resource for cancer patients and their caregivers.

If the first HOPE handbook focused on the cancer patient, it is a sensible move to have the second publication focusing on the key target group of caregivers and the support circle of friends and families. The HOPE Handbook 2: A Guide for Cancer Caregivers is an excellent resource for this extended group to understand and cope with cancer and also to assist their loved ones. The uniqueness for this handbook is that it's designed specifically for Malaysian caregivers with information and testimonials relevant to the local scene.

We expect this handbook to also receive a positive response from all quarters just like its predecessor. The government will help to ensure that this handbook reaches the grassroots through the network of hospitals and clinics across the country, to truly empower caregivers with the knowledge, contacts and techniques to be more effective in fulfilling their roles.

A large, stylized handwritten signature in black ink, appearing to read 'Dato' Sri Liow Tiong Lai'. The signature is fluid and extends across the width of the page.

Dato' Sri Liow Tiong Lai

MESSAGE

from the Malaysian Oncological Society (MOS)

From our experience working with cancer patients and their families, one of the key issues is the lack of understanding of the disease due to unavailability of information, especially information for caregivers, particularly relevant for Malaysians.

The sense of helplessness, worry and doubt among caregivers and the extended support circle often results in unnecessary mental, emotional and physical distress for many Malaysian families.

MOS is aware that public education efforts must continue and perhaps be increased; especially in communicating with those who lack access to mass media and reliable information sources such as the poor and rural communities. A continuous educational effort is needed to bridge the gap between being informed and being not informed; or even misinformed.

This brings us to the HOPE Handbook community service project. Like in the first publication, Hope Handbook 2: A Guide for Cancer Caregivers helps MOS achieve its objective; which is continued education and awareness creation. The difference is we now rope in the support circle of family and friends, which is a critical target group.

It is friends and family members who often shoulder the responsibility of being a caregiver. Often, during this difficult time, they are unsure on whom to turn to for support and assistance. The HOPE Handbook is able to provide some assistance through concise information and tips in addition to useful contacts and reference sources.

Hope Handbook 2: A Guide for Cancer Caregivers also dispels many of the common misconceptions and fallacies surrounding cancer and cancer care. With its easy-to-understand language and reading style, we hope that this handbook will make it possible for the caregivers to get a better understanding of how to care for their loved ones who are suffering from cancer.

Just as we were happy to be involved in the first HOPE Handbook publication, MOS is pleased to be also contributing in the second installation of this project. We are grateful to Pfizer Malaysia for their unwavering support in our mission. We are most thankful to the various cancer survivors and caregivers who gave their willing permission for us to publish their stories in this HOPE Handbook 2: A Guide for Cancer Caregivers .

We believe the HOPE Handbook series will serve to give more than just hope, but practical help for caregivers and the extended support circle of family and friends.

Sincerely,

President

The Malaysian Oncological Society (MOS)

MESSAGE

from Pfizer Malaysia

The emphasis on helping caregivers is crucial when one considers that the quality of care extended by caregivers is a major factor in the comfort, healing and recovery of cancer patients, both physically and emotionally.

Building on the overwhelming positive response from the first Hope Handbook publication as well as the frequent requests from cancer caregivers for information, we decided to embark on a dedicated publication targeted at caregivers.

When someone gets cancer, the news comes as shock to everyone. Lifestyles and relationships change, there are emotional upheavals and strong feelings felt by all. But how we respond makes a major difference.

HOPE Handbook 2: A Guide for Cancer Caregivers helps caregivers respond more proactively in ways that make a positive impact to the patient's and their own lives. For us at Pfizer, this is where the latest HOPE Handbook matters most; in its ability to assist Malaysians make that all important difference in the lives of their loved ones.

Most importantly, caregivers can draw satisfaction from being able to see the positive results they have brought into their loved one's life. This will serve as a motivation to spur them on in what can only be described as a difficult time for the family.

This handbook serves as a quick reference for information and tips on caring for cancer patients. The information is presented in a simple yet comprehensive format, covering key areas such as personal hygiene, diet, medication and much more.

From a different perspective, the handbook is not limited to caregivers. Anyone who wishes to extend a helping hand would find it useful. Indirectly, it encourages more people to get involved as well as creates awareness on cancer.

The task of being a carer to a cancer patient may seem daunting. But with some assistance, it becomes much easier. It becomes easier for family members and friends to make a life-changing difference for their loved ones at the time they need it most.

We wish to thank The Ministry of Health, MOS, patients and caregivers who shared their experiences and stories with us and everyone else who has helped make HOPE Handbook 2: A Guide for Cancer Caregivers a reality.

Once you choose hope, anything's possible. ~ Christopher Reeve

Sincerely,

Country Manager

Pfizer Malaysia

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Life is like a game of cards. The hand that is dealt you represents determinism; the way you play it is free will.

– Jawaharlal Nehru



CHAPTER 1 LEARNING ABOUT CANCER

No one plans to be a cancer carer. It just happens.

At the early stage, the news that a friend, spouse, child or relative has cancer comes as a surprise. It may take time to sink in as you go through an emotional upheaval – denial, anger, regret and acceptance.

But you can plan for the life changes as you adjust to your new role as a carer. The first step is being informed. The more informed you are on the disease, the better you can care for your relative or friend. The better equipped you'll be to deal with your own emotions and feelings.

WHAT IS CANCER?

Very simply, cancer is the growth of abnormal cells in the body.

Our body normally creates new cells to replace old ones. Specific cells are created for specific functions.

Cancer happens when this natural process is disrupted and abnormal cells are produced. With time, the number of abnormal cells increases forming into lumps (tumours) which displaces normal cells. This eventually disrupts normal cell production and body functions.

There are over two hundred types of cancer, each is distinctive, with its own characteristics and symptoms and which body part it afflicts.

*it can strike
people of
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HOW DOES IT HAPPEN?

Unless the person has been exposed to toxic chemicals or radiation, there is no exact cause as to why someone gets cancer. Till today, doctors are still trying to find out why cancer occurs in the body.

Certain factors such as age, gender, family history and an unhealthy lifestyle may make a person more susceptible to the disease. But because cancer comes in so many forms and can start from various parts of the body, it can strike people of all ages, ethnic groups and lifestyles.

There is hope.

There have been many stories of people who thanks to early detection, proper medical treatment and good care, coupled with a positive mental attitude have recovered from cancer. They now lead normal lives with some even going back to their pre-cancer lifestyles.

There is always a fighting chance against cancer. And as a carer, you can make a big difference to your loved one.

WHAT IS CANCER SCREENING?

Screening basically means going for tests that will detect signs of cancer. There are different screening methods for different cancers.

In Malaysia, you can be screened for breast, cervical and bowel cancer. There are established procedures for this in government and private medical hospitals. Screening for other types of cancer is also being developed across the world.

Who Should Go For Screening?

The following cancer screening guidelines are recommended for those people at average risk for cancer (unless otherwise specified) and without any specific symptoms. People who are at increased risk for certain cancers may need to follow a different screening schedule, such as starting at an earlier age or being screened more often. Those with symptoms that could be related to cancer should see their doctor right away.

For people aged 20 or older having periodic health exams, cancer-related checkups should include health counselling, and depending on a person's age and gender, might include exams for cancers of the thyroid, oral cavity, skin, lymph nodes, testes, and ovaries, as well as for some non-malignant (non-cancerous) diseases.

As a carer, if the person you're looking after is a family member (parent, child, sibling or blood relative), you should seriously consider screening as the family history may mean you have a higher risk of getting cancer.

Screening Saves Lives

Early detection through screening has saved many lives.

If you can't thwart cancer, the next best thing you can do to protect your health is to detect it early. Recognizing symptoms, getting regular check-ups, and performing self-exams are just a few ways you can do this. Early detection means the cancer is found at a stage when it is still curable or is still controllable. Many patients who discovered their cancers early have made full recoveries and go on to lead normal healthy lives.

It is vital that people go for screening. Consult your doctor if you are not sure about whether or how often you should go for screening.

If I am a woman, what screening tests should I have?

To help find breast cancer early, you should begin by checking your breasts for lumps every month, beginning at about age 20. Doctors can teach you how to check your breasts on your own. You should also have your doctor check your breasts every 1 to 2 years beginning when you're 30 and you should have a mammogram every 1 to 2 years beginning at age 40. If you have risk factors for breast cancer, such as a family history, your doctor may want you to have mammograms more often or start having them sooner.

To help find cervical cancer early, have regular Pap smears. During a Pap smear, your doctor takes a sample of cells from your cervix to be tested. You should have your first Pap smear when you start having sex or by age 18. Continue having a Pap smear once a year until you've had at least 3 normal ones. After this, you should have a Pap smear at least every 3 years, unless your doctor suggests that you need one more often. You should keep having Pap smears throughout your life, even after menopause.



If I am a man, what screening tests should I have?

To help find prostate cancer early, first talk to your doctor about your risk. Doctors don't all agree on whether screening is needed for men who aren't at high risk of prostate cancer.

Your doctor may examine your prostate by putting a gloved, lubricated finger a few inches into your rectum to feel your prostate gland. This is called a digital rectal exam. A normal prostate feels firm and rubbery. If there are hard spots on the prostate, your doctor may suspect cancer.

To help find testicular cancer early, examine your testicles on a routine basis. If you find anything unusual during a self-exam (like a lump or swelling), see your doctor right away. The best time to do the exam is during or right after a shower or a bath. The warm water relaxes the skin on your scrotum and makes the exam easier. Your doctor can give you more specific information about checking your testicles.

The best way to prepare for life is to begin to live.

– Elbert Hubbard



CHAPTER 2

WHAT IS MY ROLE AS A CARER?

A carer is anyone who looks after another person who needs extra care and attention due to physical or mental disability and in this case, due to cancer. Anyone can be a carer – a parent, child, spouse, relative or friend. The person is often not medically trained like a nurse or doctor.



There are no magic phrases, or approaches, which are the correct thing to say, or do.

Your role as a carer is focused on caring for your loved one's daily needs. This can be any of the following:

- Looking after the housekeeping and chores
- Helping out with family matters (looking after children, etc)
- Physically attending to your loved one – providing basic personal care and nursing
- Providing moral support and companionship

It is a challenging role that will require much emotional and physical strength, patience and tolerance. You may find yourself doing things you have never done before.

You are likely to have a close relationship with the person you're caring for which means you will feel more sensitive to the whole experience. You will have your ups and downs. Anybody in your shoes (and there are others) would.

There are no magic phrases, or approaches, which are the correct thing to say, or do. You will need to stay calm, keep a clear and level head and don't let the stress overwhelm you. Just take it day-by-day and you'll be able to cope with your role.

Remember, that your role is vital in helping your loved one cope with his/her difficult time. Your support and care may help them beat cancer. At the very least, you would have made their final moments, more peaceful and comforting, bringing dignity and solace in the final days.

THE ROLE OF A CARER

As a guide, the level of care required by a terminally ill cancer patient compared to someone in the first stage will differ. How well the person responds to treatment i.e. chemotherapy is another factor. His/her emotional or psychological temperament also plays a role.

Some prefer to be as independent as possible, requiring only minor assistance. Others may be in emotional turmoil and your presence may be needed at all time.

In most cases, your role will fall in between these two opposite ends.

Remember, you are there for your loved one as he/she needs and wants you. Do not over impose yourself on them. They may resent the attention even though you have good intentions. Show patience, understanding and just let them know that they can rely on you when needed.

UNDERSTANDING THE SITUATION

When sizing up the situation, consider everyone's needs including yours. In the long run, your needs must also be weighed in for a practical care arrangement.

Do you want to care for your loved one or would you require additional help such as a live-in maid or a nurse? Can you share the load with family or friends?

Here are some useful questions to help you better understand the situation:

- What type of cancer does my friend or relative have?
- How serious is it (treatable or terminal)?
- What kind of assistance do they need? Transport? Food? House-keeping? Personal hygiene?
- Do I need to live with them or can I stay elsewhere and visit during the day?
- Is the caring situation a long or short term one?
- Does my loved one want me to help?
- Am I able to provide the assistance required?
- Why do I want to be a carer?
- Will I feel that I am uncaring or disloyal if I stop later?
- What options are available to me?
- Who else can support me in this role?

*Why do I
want to be
a carer?*

LOOKING AFTER YOUR OWN NEEDS AS A CARER

The key areas you should be considering are your physical, mental/emotional and financial needs.

Financial

Consider how becoming a carer, either full time or part time will impact your ability to earn and be employed. Would you need to give up or change jobs?

If you plan to stay with your present company, are there flexible working options such as time off or working from home? Do you have other income streams such as your spouse or investments that can sustain you?

You do not want to add financial woes to your already challenging role.

Share with your boss and colleagues that your life will be changing. In most situations, they will be understanding and would offer assistance where possible.

Talk to a certified financial planner to see whether there are options available to you such as insurance and so on.

With some creativity, and determination, you can have a career while being a carer.

Health

You need to be in good physical and mental condition to support your loved one. If you are weak or ill, caring would be a difficult task and your sickness will affect your friend's or relative's health as well especially since their body is weaker.

Always eat a well balanced diet and get sufficient exercise. Even easy swimming, cycling or walking around the neighbourhood would be beneficial.

Besides the physical benefits, being in good physical shape will help you feel better about yourself and cope better with stress.

Managing Stress

Stress is experienced by all carers. Caring for someone going through cancer treatment can be very stressful and exhausting. It takes emotional, spiritual, and physical strength. There is a potential financial burden to care giving as well.

If you are at home looking after someone full-time, you may not have much chance to go out or spend time with friends. It may seem easier to stay in all the time, especially if the person you are caring for is very ill and needs lots of attention. Coupled with anxiety, fear and worry of seeing your dear one in such a state, it can all add up to stress.

The tell tale signs of burnout:

- hopelessness
- emotional exhaustion
- detachment
- isolation
- frustration
- powerlessness
- being trapped
- failure
- despair
- cynicism
- apathy
- irritability

This is why you need a good stress management strategy. Here are some tips:

- Get a relative or friend to replace you while you take time outs or have one whole day for yourself. Keep in touch with friends and your social circle.
- Get family and friends involved where possible. Learn to say yes when help is offered, especially for simple things like shopping, cleaning or picking the kids from school and so on.
- Find people you can talk to either friends or even a support network of former cancer patients and carers like yourself. They can share tips and ideas to better cope with your situation.
- Hire a gardener, cleaner or maid to manage household chores.
- Plan things that you enjoy. There are 3 types of activities that you need for yourself: Do things that involve other people, such as having lunch with a friend. Do things that give you a sense of accomplishment, like exercising or finishing a project. Do things that make you feel good or relaxed, like watching a funny movie or taking a walk.
- Pay attention to these activities. Make an effort to notice and talk about things you do as they happen during the day. Watch the news or take time to read the morning paper. Set aside time during the day, like during a meal, when you do not talk about your loved one's illness.

IS THERE SUPPORT FOR CARERS?

Yes, there is.

There are support groups consisting of other cancer care givers or recovered patients, from Non-Governmental Organisations (NGOs) and also from medical associations. Please refer to the end of this handbook for more support organisations in Malaysia.

Getting The Help You Need

You need to ask yourself some basic questions so you can get the help you need:

- Is the support for myself or for my loved one?
- Is it medical or health related assistance? Do I need more information about a type of cancer, a particular drug or treatment?
- Is it physical assistance or just advice and/or someone to share my situation with?
- Is it financial or legal assistance?



*As I grow to understand life less and less,
I learn to love it more and more.*

– Jules Renard



CHAPTER 3

CARERS AND THE MEDICAL TEAM

As a carer, your efforts must complement that of your loved one's medical team.

Support the medical team by following all their instructions. If you have doubts, ask for further clarification.

At times, some carers feel that because they are not medically trained, their efforts are not as helpful as the medical team. Do not feel this way.

Carers help to ensure that the treatment is effective. Your role is important in the recovery, well being and comfort of your dear one.

Opening up the communication passageway no matter how hard it can become, allows both the caregiver and the loved one to process the situation and reach an understanding. This in return will compliment the medical team's effort in prescribing the treatments.

LEARNING ABOUT TESTS & TREATMENTS

The more you know about the tests, treatments and medication prescribed, the better you can care for your loved one.

You will understand why certain drugs have been prescribed instead of the others. Or why only certain tests have been done and not the others.

Ask the medical team to repeat and explain in simpler terms if required. Even if they have explained to you earlier, they would understand that you and your loved one may have been in shock when receiving the information.

You can also refer to authoritative books and the Internet but make sure you visit only reputable medical sources.

There are various tests to identify different cancers.

Tests for Cancer

Medical tests are carried out to confirm if a person has cancer. There are various tests to identify different cancers.

Before any tests are conducted, the doctor will enquire the patient on their ailments, family history and lifestyle. He will also look at the patient's symptoms and complaints.

Based on this information, the doctor will recommend certain tests to diagnose what cancer the patient could have. Tests are never done unnecessarily.

The doctor also may run more tests to confirm the result or to identify other types of cancer. Following are some of the tests you can expect:

Blood Tests

- **Full blood count**

Conducted to examine the number of red, white and platelet cells in the blood. The level of red blood cells will show if the patient is anaemic. White would point to the person's immunity level – if they are fighting an infection. Platelets are checked as they are important in preventing bruising and bleeding.

- **Electrolytes (electrolyte estimation)**

Used to see if there is an imbalance of salts in the blood, particularly sodium and potassium. An imbalance indicates that the patient is unwell.

- **Urea & Creatinine**

Urea and creatinine levels are measured to check kidney function.

- **Liver Function Tests**

The level of protein and certain enzymes are measured to see if the liver is working correctly and efficiently.

- **Special Blood Tests**

Performed when certain specific cancers are suspected such as ovarian and testicular cancer. These tests are also done to measure how well a cancer patient is responding to treatment.

Biopsy

A biopsy may be done either to support blood tests or as an independent test.

Biopsy means removing tissue from the living body for diagnostic purposes.

During a biopsy, the entire lump (tumour) may be removed or just a part of it. It may be done during the patient's first visit to the doctor or during subsequent visits. This is done via a minor surgical operation. The lump is then examined.

Both the timing and size of the lump to be removed will depend on the patient's condition and the location of the lump within the body.

Fibreoptic Endoscopy

Very simply, this test uses a micro camera attached to fibreoptic cables which can be inserted into hollow cavities in the body (the throat, nose, rectum, etc).

It allows the doctor to see inside the patient's body without having to perform surgery. The fiberoptic cables can be controlled from the outside for a more detailed view of the patient's organs and tissues as well as extract a tissue sample for biopsy.

The process is slightly invasive, but not painful. Patients are normally sedated or under anaesthetic during the procedure to reduce discomfort. This technique has several variations:

- **Bronchoscopy**
To examine the airways leading to and directly from the lungs. The tube is inserted through the nose.
- **Oesophagoscopy / gastroscopy / duodenoscopy**
To examine the gastro-intestinal tract (stomach). The tube is inserted through the mouth into the stomach.
- **Colonoscopy**
To examine the intestinal tract with the tube inserted through the anus.
- **Cystoscopy**
To examine the bladder (urethra) with the tube inserted via the bladder itself

X-rays

X-rays help doctors 'see' the tumour in the body, particular those in the stomach (digestive tract) and the breast. You may hear the doctor mention tests such as Barium meal, Barium enema and mammogram (for breasts). These are all X-ray based tests.

Scans

Similar to X-rays but scans can give a better picture of the size, position and shape of lumps in the body. Scans commonly use either CT scans or MRI scans.

Both require the patient to lie still as they capture images or data of the patient's body which is displayed on a computer. The process is painless.

There is also the ultrasound (ultrasonic) scan. Normally used in pregnancy, it can also be used to examine organs. It is non-invasive, harmless and inexpensive.

Treatments for Cancer

Once the doctor diagnoses that a patient has cancer, a treatment plan is prescribed. Following are some of the treatments that your loved one may undergo with regard to their cancer.

Surgery

Surgery is used when the tumour is limited to one area and there is a good chance that the entire tumour can be removed completely. If the operation is done early enough, it can be highly successful in removing tumours and greatly reduce the chance of it recurring.

The initial reaction from many patients is to opt for surgery simply because in their panic or fear, they want to remove the 'sickness' from their body as quickly as possible. But if the cancer has spread too far, the tumour is too advanced or the patient is too weak, other methods may be recommended.

You may need to counsel your loved one on their condition and why surgery is not suitable for them. On the other hand, he/she may be scared of facing surgery. If so, you can assure them that the procedure is safe and necessary for their health.

Tips for surgery:

- Arrive on time for all appointments (normally a day before the procedure)
- Before surgery the patient may undergo blood, urine and general health tests.
- A consent form will need to be signed either by you or your loved one before surgery.
- Ensure that no food or drink is consumed several hours before surgery.
- Based on doctor's instructions, prepare your home so that your loved one will be comfortable upon discharge from hospital.
- Ensure your patient gets enough rest as per doctor's orders and attends all post-surgery appointments.
- Constantly check the wound to see if it is healing well.

Radiotherapy

Radiotherapy uses small quantities of radiation to 'attack' the tumours and eliminate them. Like surgery, it targets a particular area where the tumour is located.

Radiotherapy can be used independently or in combination with surgery and chemotherapy. Radiotherapy first 'shrinks' the tumour so that a less invasive surgery can be done. Or it can be done as a follow-up to surgery just in case some cancer cells remain.

Today, modern technology has made radiotherapy more accurate – attacking the cancerous cells with minimum damage to healthy tissue. Damaged healthy tissue will grow back.

*Radiotherapy
can be used
independently
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combination
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surgery and
chemotherapy*

Watch out for these post radiotherapy side effects:

- **General tiredness**
Solution: Get your loved one to rest more after radiotherapy
- **Redness of the skin (similar to sunburn)**
Solution: Use talcum powder and body lotions as recommended by the doctor.
- **Hair loss (if radiotherapy is aimed at the scalp, armpits and pubic area).**
Solution: Hair will grow after treatment stops.
- **A sore or dry mouth (if radiotherapy is applied to the head or neck)**
Solution: Pay special attention to dental hygiene, avoid spicy food and alcohol.
- **Diarrhoea, nausea and vomiting**
Solution: Have ready anti-diarrhoea and anti-nausea medication. Drinks with hydrating salts are also useful.
- **Cystitis (temporary burning sensation when urinating)**
Solution: Consult your doctor for medication if none is prescribed.

Chemotherapy

In chemotherapy, most drugs are intravenously fed into the patient, which then goes into their body and attacks the cancerous cells.

This treatment is used when the cancer has spread throughout the body or has a good chance of spreading through the body. It is used to combat many cancers such as leukaemia, lymphomas, childhood and adult cancers.

Unfortunately, the drugs used (cytotoxic drugs) also attack normal cells. But with better drugs, the effect on healthy cells has been reduced while maintaining or increasing the damage on cancer cells. A complete chemotherapy course can take from one to several days repeated over 1-4 weeks.

Most patients are unable to continue with their daily lives during chemotherapy. Your physical and emotional support is important in helping them complete the course and reduce the side effects.

The side effects are similar to radiotherapy with some additions:

- Bone marrow damage
- Fertility reduction
- Pins and needles, numbness or pain in hands or feet (temporary)

Things to know about chemotherapy:

- For each visit, the cancer patient will undergo a pre-therapy check for possible side effects. Make sure you are aware of this so you can be better prepared. A blood test will also be done.
- During the treatment, make sure your loved one avoids public places. Chemotherapy can cause a weakened immune system which makes them susceptible to infections.
- Avoid many people visiting your friend or relative during chemotherapy.
- If your loved one has a raised temperature or a sore throat, he/she could be ill.

Targeted Therapy

Targeted cancer therapy uses drugs to destroy cancer cells or block them from spreading. At the same time, the drugs are designed to not damage healthy cells.

The drugs work by blocking specific enzymes and proteins that make the cancer cells grow. This is possible as the drugs can identify specific markers found only in cancer cells. The cancer cells are killed while healthy cells are left untouched. This reduces the impact of side effects on the patient.

Many targeted cancer therapies are being tested and some have been approved for use.

Consult your doctor on whether your loved one can also receive targeted therapy if it is available.

Hormone Treatment

Hormone treatment involves controlling levels of certain hormones in the body to suppress the growth of cancer cells. It is used mainly to treat cancers of the breast, uterus, ovaries and the prostate gland.

The type of hormone treatment recommended would depend on the type of cancer and whether it would respond well to this kind of treatment.

Clinical Trials

Clinical trials are research studies that involve people. They are the final step in a long process that begins with research in a lab and animal testing. Many treatments used today are the result of past clinical trials which have proven the benefit of these treatments.

In cancer research, clinical trials are designed to answer questions about new ways to:

- Treat cancer
- Find and diagnose cancer
- Prevent cancer
- Manage symptoms of cancer or its treatment

Clinical trials may be an option for you and your loved one. Choosing to join a clinical trial is something only your loved one, you, and your doctors and nurses can decide together. You may want to discuss the benefits and drawbacks with your loved one and the doctor. Clinical trials offer high-quality cancer care. However, these new treatments may have side effects that doctors do not expect or that are worse than those of standard treatment.

By looking at the pros and cons of clinical trials and other treatment choices, allow your loved one to play an active role in a decision that affects your life together.

Complementary & Alternative Therapy

You may possibly consider certain complementary treatments to be used with conventional medicine. Acupuncture and reflexology may be helpful in relieving pain and providing comfort. Aromatherapy could have soothing effects for the senses.

Alternative therapy (treatment that replaces conventional medicine) is not recommended. Many of these are not part of conventional medicine because they have not been scientifically tested or proven and may produce no results at expensive cost. By relying solely on these methods, your loved one's cancer may reach a more advanced stage, which is harder to treat.

While it is your friend or relative's decision (and your choice as well) to consult bomoh, sinsehs and other traditional practitioners, consider carefully before doing so.

Ensure that any treatment you opt for has a proven track record of being effective:

- Ask your loved one's medical team before proceeding.
- Be careful about what pamphlets and other material say. Verify the information with the medical team.
- Consult the medical team to ensure that the therapy does not cause complications with prescribed treatment, especially if they are consuming any traditional medicines.
- Encourage your loved one to continue with his /her doctors' prescribed treatment.

Alternative therapy (treatment that replaces conventional medicine) is not recommended.

*There are no classes in life for beginners: right away you
are always asked to deal with what is most difficult.*

– Rainer Maria Rilke



CHAPTER 4

CARING FOR THE PATIENT

What kind of care is required will depend on your friend or relative's condition:

- Whether they are still undergoing treatment or are recuperating.
- How well they are responding to treatment
- Whether they need palliative care

Expect to make changes as both of you adjust to the new lifestyle, at least temporarily.

CARING FROM HOSPITAL TO HOME

Make sure you provide comfortable transport beforehand, ready and waiting. If you can't drive, enlist help from a relative or have a taxi waiting.

Have a comfortable resting place ready. Get the necessary equipment if needed. Speak to the medical team on what needs to be done.

Once your loved one has been discharged or after undergoing treatment, they may be anxious to settle back into their normal routine. Encourage activities that would be good for them (exercise, etc) where possible. Discourage others (alcohol consumption, smoking, etc).



AT HOME

If your loved one is well enough, a small gathering of friends to welcome them home would be nice. Keep it to a small group as after their trauma and treatment, a noisy, high-spirited crowd may be too much.

Have their favourite books, videos or music ready for them. Even favourite foods if the doctor allows it.

If they are able, encourage them to be independent as much as possible. This builds confidence and enables them to see how they are recovering.

EQUIPMENT

Some things you may need:

- Wheelchair
- Urine bottle/bed pan
- Commode
- Sliding Sheets
- Moving Aids
- Bed & Chair Raisers
- Special bed and mattresses
- Pillow support or back rest
- Handrails and ramps
- Bath aids
- Adapted cutlery
- Intercom
- Personal alarms

MEDICATION

As a carer, you will need to know what medication needs to be given, when, in what dosages and so on. Consult the medical team if you are not clear.

If your relative is not stable enough to take medication by themselves, keep all drugs away from them. Administer the correct dosage yourself.

What You Should Do:

- Follow the instructions given on labels and by your medical team. If there are conflicts between the two or you are unsure, refer back to the medical team for an explanation.

- Drugs can be in many forms – pills, liquids, self adhesive patches, etc. Different manufacturers may make the same drugs in different dosages. The doctor may use a combination of drugs to find what works best with your loved one.
- Never stop using a prescribed drug until you are advised by the medical team.
- Make your own chart or timetable if there are many drugs and you feel it's hard to keep track of them all.
- Most pharmacists would supply specially designed tablet containers with separate compartments that you can fill as required.
- Never buy products for your relative off the shelf without medical advice.
- Ensure your medical team is aware of any supplements or complementary therapy you may be taking as there may sometimes be drug interactions.



TRANSPORT

Most likely you will need to arrange for transport either to take your loved one for hospital appointments or perhaps for yourself when attending to other daily needs. Or as your dear one gets better, take them on short trips.

What You Can Do:

- Enlist help of friends or neighbours to drive you and your loved one around. Alternatively, you can also request for their help with errands such as collecting the laundry, doing shopping and so on.
- Arrange for a taxi to pick you and your loved one for hospital appointments and vice versa.
- Make sure your car is in good condition (well serviced). Have the number of a good mechanic or auto breakdown service (such as the Automobile Association of Malaysia or AAM) just in case.

STOMA CARE (COLOSTOMY OR ILEOSTOMY)

Colostomy means that an opening (stoma) is made in the patient's abdomen to allow body waste (stools) to exit the body. This opening leads to the big intestine whereby waste products are channelled from the intestine to the stoma and into an external bag.

Colostomies are performed normally when certain portions of the rectum or colon have to be removed due to cancer. They can be either temporary (until the intestines heal) or permanent.

An ileostomy is the same except that the stoma leads to the small intestine.

Nowadays permanent colostomy users enjoy almost total freedom of lifestyle – going on holidays trips and even enjoy sexual activity. But during the early days, they are likely to need your help in adjusting.

What You Can Do:

- Your loved one may need help in changing their waste bags.
- Talk to your doctor on the type of bag, fixing style, materials and emptying arrangements.
- When they leave the house initially, accompany them in case they need assistance in bag changes and so on. Check out toilet facilities in advance to avoid problems and embarrassment later on.
- If travelling long distance, make sure adequate toilet facilities are available throughout the journey. Have your bag changing kit ready. Take a good supply of anti-diarrhoea medication. Check travel insurance policies if your loved one is covered for trips.

- Diet – wind may be a problem for some patients. Here are some helpful tips:
 - Get your loved one to chew their food thoroughly.
 - Eat smaller portions at regular intervals.
 - Avoid foods that may cause wind such as onions, beans and carbonated drinks.
- Odour – Don't worry too much about odour as bags nowadays have odour proof linings and are tightly sealed with in-built filters. But you can still use deodorant sprays and perfumes when changing pouches.
- Diarrhoea – The main culprits are stomach problems, unsuitable food and excessive fluid or anxiety and stress. Review your loved one's diet. Identify problem food and remove them from the diet until the problem stops. Consult your patient's medical team for further advice if needed.
- Constipation – Review the diet. Identify and remove problem foods.
- Alcohol consumption – Stoma patients can drink alcohol in moderation. Too much beer or lager though may lead to wind and diarrhoea.

BREAST RECONSTRUCTION

Some form of breast reconstruction would be offered if your loved one has undergone a lumpectomy (removal of tumour or cancerous tissue in the breast).

If she has had a mastectomy (removal of the entire breast), a prosthesis would be used. Prosthesis is an artificial breast made of silicone to be worn inside the bra. They now come in a variety of colours, sizes and shapes to achieve as natural a look as possible.

Breast reconstruction is performed either using silicone or saline implants or transplanted tissue taken from elsewhere in the body. All methods are safe and painless.

The psychological and practical advantages of breast reconstruction outweigh that of prosthesis. The former makes dressing easier, and gives the survivor a stronger feeling of being 'whole' again.

However, the new breast will not be identical to the one removed during surgery. The new tissue may be less sensitive and the reconstructed nipple may look different.

What You Can Do:

- Discuss all options for breast reconstruction with your loved one and the medical team. This includes prosthesis, if required. Provide emotional support during this difficult time.
- Take showers instead of baths and carefully dry the area.
- Massaging the area with oils or creams (check with your doctor) will help keep the skin supple and elastic. This will also help reduce fibrous tissue from forming around the area.
- You can help shop for special support bras that your loved one can wear.
- As advised by the medical team, there may be exercises you can get your friend or relative to do which will add suppleness and mobility to the breast.

HAIR CARE

Hair loss is often temporary but the sight of losing one's hair can be distressing for many.

What You Can Do:

- Use soft brushes as the scalp may be sensitive after treatment.
- Avoid using strong chemicals for at least a few months after treatment ends as these can damage growing follicles. Baby's shampoo and mild variants would be better.
- Dry hair with towels rather than driers as heat can make the growing hair brittle.
- Dispose of fallen hair discreetly.
- Provide fashionable hats, caps and other head gear for your loved one to choose from.
- When new growth begins, suggest a short haircut, at least for the first six months. This prevents too much weight dragging on the damaged roots and gives a uniform length until thicker growth is established.
- If the hair loss is in large areas, suggest wigs, hairpieces and suitable caps. Consider whether the wig should be made of real hair or synthetic materials; it fits well and doesn't trigger allergies.

DIET (NUTRITION)

Know that your choice of foods, preparation methods and serving portions will impact how well your loved one copes and even recovers from cancer.

A nutritious diet high in energy, protein, healthy fats and vitamin and minerals will help your dear one:

- Maintain physical strength
- Regain loss weight and prevent malnutrition
- Replace healthy cells faster after chemotherapy and radiotherapy
- Boost the immune system to fight infection
- Look and feel better

Things To Consider

Consider your loved one's body size, age and gender when planning a diet for them. Also, people with cancer often need lots of calories and protein so you may want to think about that too.

But remember, nutritional needs can differ from one person to another and may change over time. Talk to a nutritionist, dietician or the medical team for specific advice.

Also consider that your friend or relative may complain of poor appetite, sore throat, no taste, nausea and other ailments such as:

- Refusing to eat due to depression and worry.
- Dentures no longer fit properly
- Constipation
- Anxious of affecting their colostomy

As a guide, you can refer to the Dietary Management Chart at the end of this chapter for more specific information. The guide will tell you how to manage diet and nutrition based on your loved one's side effects i.e. constipation, mouth pain, etc.

You can also refer to the following tips for some ideas as well.

What You Can Do:

*If he / she
is too weak
to eat, feed
them.*

- If possible, serve familiar and favourite foods. Cancer patients are often more willing to eat these.
- You're encouraged to serve a variety of foods and new foods. But do it progressively without making too many changes too quickly. Let your loved one adjust slowly.
- If you're busy, cook foods the night before and pre-heat the next day.
- Serve foods fresh especially vegetables and fruits. Both are full of nutrients that help prevent and fight cancer by removing toxins, repairing DNA, strengthening the immune system and so on.
- Take note when your loved one is feeling his / her best and schedule meals at this time.
- Healthy snack foods such as cereal bars, cheese and crackers, yogurt may work better than full meals. Keep an ample supply at home.
- Let your loved one eat on request. Do not force feed.
- If he / she is too weak to eat, feed them.
- Try all-in-one drinks if meals are not suitable. Fruit flavoured drinks and juices are good for stimulating taste.
- Ice-cream is a good choice for cancer patients as it is soft, high in calories and tasty. They are great for kids with cancer.
- If your loved one can exercise, encourage them to do so. This helps boost appetite.

- For adult patients, if taste is not a problem, cut back on salt, fat, alcohol and sugar.
- Use disposable plastic utensils if your loved one experiences unpleasant metallic tastes while eating.
- You can give nutritional supplements such as multivitamins. But consult the medical team before doing so.

Nutrition After Cancer

- Continue to provide a well balanced diet of all the food groups in the right portions. Talk to the medical team about developing a menu plan
- Emphasise on fruits and vegetables, high-fibre foods, such as whole grain breads, low-fat dairy products and cereals and reduce fatty foods.
- Keep alcohol consumption as low as possible or in moderation.

Nutrition for Kids With Cancer

- Encourage your child to eat high-calorie, high-protein foods. Don't worry about the fat unless your child has water retention or weight gain due to steroid medication.
- Make the meals attractive with appealing presentation. A cookie cutter is a good idea to cut foods into 'bite sized', fun shapes and sizes. Or make patterns and shapes such as faces out of fruits and vegetables.
- Use colourful cups and utensils.
- Make meal times a fun activity that involves playing and storytelling. Or have a picnic in your backyard, living room and so on if your child is well enough. Invite his / her friends to make it more enjoyable.
- If you can, get your child involved in preparing the meal.

- If your child has a low white blood cell count, he / she is at higher risk of infection. Ensure proper hygiene is maintained during food preparation. Avoid food bought from roadside stalls and hawkers. Clean and cook food well. Also avoid raw food.
- If your child is on steroid medication, your child may develop a bigger appetite leading to weight gain. They may also retain fluid. Choose low salt and sodium foods. Avoid processed and preserved foods.
- Offer your child fresh, nutritious, filling foods, such as fruits and vegetables, homemade soups, non-processed meats, dairy products, breads, and pastas.
- The appetite changes and fluid retention caused by steroids are temporary and will recede after therapy. But expect a temporary appetite loss as the body adjusts after the steroids.
- Some children may have difficulty going back to their normal weight.

Dietary Management Chart for Cancer Patients

Action/Side Effects	Mouth pain	Difficulty swallowing	Dulled taste	Nausea/vomiting	Diarrhoea	Anorexia
Serve food at moderate temperature	✓				✓	
Serve non acidic food	✓					
Serve acidic food			✓			
Serve single textured food		✓				
Use a nutritionally balanced enteral supplement	✓					
Serve bland, non-spicy food	✓			✓		
Serve soft food	✓					
Serve a variety of flavours and textures			✓			✓
Serve low fibre food					✓	
Serve a low-fat, lactose free enteral supplement					✓	
Avoid sticky or slippery food		✓				
Serve plenty of liquids				✓	✓	
Serve small amounts of liquids with meals			✓			✓
Serve snacks between meals				✓		✓
Serve food that smell good			✓			✓
Serve food with mild tastes and light odours				✓		✓
Serve low-fat food				✓	✓	
Serve salty food				✓		
Serve small meals but more often				✓		✓
Serve cold and clear liquids				✓		
Serve food with high carbohydrate				✓		
Serve low lactose dairy products					✓	
Serve caffeine free food/beverages					✓	

Courtesy of Department of Dietetics, University Malaya Medical Centre, Kuala Lumpur.

Adopted from Task Force on Nutrition Support USA and Nutritional and Cancer, Department of Dietetics, Hospital Kuala Lumpur, 1995

Managing Health Issues at Home :
What the Carer Can Do

Signs	What the Carer Can Do
Bleeding in the Mouth	<ul style="list-style-type: none"> • Offer cold water mouth rinses before each meal. Keep ice water nearby. • If mouth is oozing blood, keep a bowl nearby for spitting out mouth rinses. • Make milkshakes or smoothies in the blender, and offer other soft frozen treats. Avoid nuts, caramel, and hard coatings. • Freeze a few wet tea bags, and have the patient use one to press on any area of bleeding. <p>Call the doctor if the patient:</p> <ul style="list-style-type: none"> • is bleeding from the mouth for the first time • has bleeding that lasts for more than a half hour • vomits blood or material that looks like coffee grounds • feels light-headed or dizzy
Blood in Stool	<ul style="list-style-type: none"> • Help the patient watch for bleeding. • Offer extra fluids, fruits, and vegetables to keep stool soft. <p>Call the doctor if the patient:</p> <ul style="list-style-type: none"> • has blood on toilet tissue two or more times • has blood streaks in stool • has bright red blood from rectum • has dark red or black stools
Constipation	<ul style="list-style-type: none"> • Offer prune juice, hot lemon water, or tea to help stimulate bowel movements. • Encourage extra fluids. • Help keep a record of bowel movements. • Offer high fiber foods such as whole grains, dried fruits, and bran. • Talk with the doctor before using laxatives. <p>Call the doctor if the patient:</p> <ul style="list-style-type: none"> • has not had a bowel movement in 48 hours • has blood in or around anal area or in stool • cannot move bowels within one or two days after taking laxative • has cramps or vomiting that doesn't stop

Signs	What the Carer Can Do
Diarrhoea	<ul style="list-style-type: none"> • See that the patient drinks about 3 quarts of fluids each day. • Keep a record of bowel movements to help decide when the doctor should be called. • Check with the doctor before using any over-the-counter diarrhoea medicine. Many of these contain compounds that are like aspirin, which can worsen bleeding problems. It may be better to use a prescription medicine. • Check the anal area for red, scaly, broken skin. If present, see the section on skin sores. • Protect the bed and chairs from being soiled by putting pads with plastic backing under the buttocks where the patient will lie down or sit. <p>Call the doctor if the patient:</p> <ul style="list-style-type: none"> • has six or more loose bowel movements per day with no improvement in two days • has blood in or around anal area or in stool • loses five pounds or more after the diarrhoea starts • has new abdominal pain or cramps for two days or more • does not urinate for 12 hours or more • does not drink liquids for 48 hours or more • has a fever of 100.5°F or higher, taken by mouth • gets a puffy or swollen belly • has been constipated for several days and then begins to have small amounts of diarrhoea or oozing of liquid stool, which could suggest an impaction (severe constipation)
Mouth Sores	<ul style="list-style-type: none"> • Use a flashlight to check the patient’s mouth for red areas or white patches, which often become sores. If patient wears dentures, remove them first. • Offer liquids with a straw, which may help bypass the sore area in the mouth. • Mash or puree hard foods in a blender to make them easier to eat. • Offer pain medicines half an hour before mealtime. <p>Call the doctor if the patient:</p> <ul style="list-style-type: none"> • has redness or shininess in mouth that lasts for more than 48 hours • has bleeding gums • first notices any type of “cut” or sore in the mouth • has a temperature of 100.5°F or higher, taken in the mouth • has white patches on the tongue or inside the mouth • has taken little food or fluid for two days • cannot take medicines due to sores in mouth

Signs	What the Carer Can Do
Nausea and Vomiting	<ul style="list-style-type: none"> • Make meals or ask others to make meals during times the patient is not nauseated. Use kitchen vent fans to reduce smell. • Cover or remove food with strong or unpleasant smell. • Try plastic forks and spoons rather than metal ones, which may cause a bitter taste. • If the patient starts vomiting, weigh him or her at the same time each day, to help decide whether dehydration is getting severe. • Talk to the doctor about medicines to help prevent vomiting. • Watch the patient for dizziness, weakness, or confusion. • Try to help the patient avoid constipation and dehydration. Either of these can make nausea worse. <p>Call the doctor if the patient:</p> <ul style="list-style-type: none"> • may have inhaled some of the vomited material • vomits more than three times an hour for three or more hours • vomits blood or material that looks like coffee grounds • cannot take in more than four cups of liquid or ice chips in a day or cannot eat substantial foods for more than two days • cannot take his or her medicines • becomes weak, dizzy, or confused • loses two or more pounds in one to two days (This means he or she is losing too much water) • develops dark yellow urine, and doesn't have to urinate as often as usual
Scars, Injuries, and Wounds	<ul style="list-style-type: none"> • Help clean wounds or change dressings if the patient is unable to do it for him or herself. If possible, wear new disposable latex or vinyl gloves each time you clean the area and apply new dressing. Wash your hands before and after changing a dressing, even if you wear gloves. • Be sure the patient has enough supplies to change the dressing every day, if that is prescribed. • Check for signs of infection, as noted below. <p>Call the doctor if the patient:</p> <ul style="list-style-type: none"> • has a wound that bleeds for 15 minutes or more • has a wound that appears very red around the edges and is hot or swollen • has more pain than usual at the wound site • develops a bad smell from the wound smells • has yellow pus or greenish liquid that oozes from the wound • has fever of 100.5°F or higher when taken by mouth

Signs	What the Carer Can Do
Seizures	<ul style="list-style-type: none"> • Keep the patient safe. If a seizure occurs while the patient is in bed or on a chair, cradle the patient in your arms to keep him or her from falling to the floor. • Stay with the patient. • Stay calm. • Loosen clothing around the patient's neck. • If patient falls to the floor, place padding (e.g., rolled clothing) underneath head and roll patient onto his or her left side. • Do not move any part of the body forcefully. • Avoid trying to open the mouth during a seizure, even if the patient is biting his or her tongue. Keep fingers and hands away from the patient's mouth. • Avoid moving the patient unless he or she is in a dangerous location (for instance, near a hot radiator, glass door, or stairwell) • Once the seizure is over, cover the patient with a blanket and allow him or her to rest. • If patient is prone to seizures, use side rails and bumper pads on bed. Be sure someone is with the patient when he or she is walking or sitting in a chair. <p><i>Call the doctor if the patient:</i></p> <ul style="list-style-type: none"> • Has a seizure, once it is over and the patient is comfortable (If someone else is with you, stay with the patient and have the other person call the doctor.)
Swallowing Problems	<ul style="list-style-type: none"> • Offer soft, moist foods. Baked egg dishes, tuna salads, and thick liquids such as yogurt may be easier to swallow due to their texture. • Avoid chewy foods or raw crunchy vegetables. • Sauces and gravies make meats easier to swallow. <p><i>Call the doctor if the patient:</i></p> <ul style="list-style-type: none"> • gags, coughs, or chokes more than usual, especially while eating or drinking • has a severe sore throat • has a red, shiny mouth or ulcers in the mouth or on tongue • has a fever greater than 100.5°F taken by mouth • has trouble breathing • has chest congestion • has problems with food sticking as it goes down • cannot swallow medicines or eat

Signs	What the Carer Can Do
Swelling	<ul style="list-style-type: none"> • Watch for any new symptoms, especially shortness of breath or swelling in the face. • Encourage patient to keep the swollen body part propped up as high as is comfortable when sitting or lying down. • Don't add salt, soy sauce, or monosodium glutamate during cooking. • Weigh the patient every day or two on the same scale, at the same time of day. Keep a list of weights and dates. <p>Call the doctor if the patient:</p> <ul style="list-style-type: none"> • can't eat for a day or more • hasn't urinated, or has urinated very little, for a day or more • can press a finger into a swollen area and the fingertip mark remains • has swelling that spreads up legs or arms • develops a puffy or blown up belly • the swollen area gets red or hot • has shortness of breath or racing heart • has a swollen face and neck, especially in the mornings • gains five or more pounds in a week or less

LIFESTYLE

A healthy lifestyle can make a big difference in reducing risk of recurrence.

It is advised that alcohol consumption be reduced or stopped totally for cancer patients.

If your loved one insists, make sure they consume less than the recommended weekly allowance for healthy adults – 20 and 12 units per week for men and women respectively.

They should also have 2-3 alcohol-free days each week. Consult the medical team for further advice.

More Tips:

- Avoid undiluted spirits or drinking on an empty stomach
- Avoid drinking several drinks after a large, rich meal.

If they smoke, quitting the habit will have almost immediate health benefits.

What You Can Do:

- Change routines or avoid situations that would tempt them to smoke. For instance, get them busy with something after meal times when he/ she would be itching for a cigarette.
- Offer substitutes such as tea, nicotine patches and chewing gum.
- Offer plenty of fruit juices to drink to flush out the chemicals in the body.
- Offer plenty of praise and support if they're smoke free. Do not scold or show disappointment if there is a lapse. Just start again.
- Get friends and family to respect your loved one's decision to be smoke free. Tell friends and family not to smoke in his / her presence.
- Talk about the benefits of quitting smoking such as reduced chances for lung cancer and heart attacks, as well as better fitness and energy levels.
- Highlight how much money is being saved.

EXERCISE

Regular physical activity is beneficial for cancer patients – both in physical recovery and mental well being.

However the level of activity must be tailored to the patient's condition. Consult your patient's doctor before starting any exercise.

What You Can Do:

- Encourage your loved one to start slow and progress with time. Choose activities that are pleasurable and not competitive.
- Ensure they warm up before any physical exertion
- As a carer, it would be a good idea to join your dear one as well. For instance, both of you can take walks and go swimming together. Make it a group activity with friends and family. The social and interactive aspect adds to the fun and will encourage your loved one to exercise more.

- Stop immediately if there are signs of discomfort or pain.
- Some patients may experience leg cramps, particularly after a long period of being inactive due to treatment and recovery. Consult your medical team for further advice.



Some beneficial exercises for cancer recoveries include:

- Walking
- Swimming
- Golf
- Bowling
- Badminton
- Yoga
- Cycling
- Dancing

Consider Your Relationship With Your Loved One

The relationship you share with your loved one will evolve due to the life experience you both have shared. The whole cancer episode can alter the dynamics of your relationship.

There may be a greater appreciation for each other. Sometimes, the carer may feel resentful because the cancer patient has got all the attention while you have been shouldering the burden. Or the patient may feel helpless – an inconvenience to the carer. The loss of independence may make them resent their carer.

Parent and child may develop renewed relationships. Between husband and wife, there could be a deeper love shared by both. Or the strains of the trying period could have impacted the marriage. If you are feeling various emotions, it is good to talk to someone.

Good communication with the person you are caring for is the most important part of your role. It may be difficult for the patient to participate in daily planning and decision making because he is dealing with the physical, emotional, and social effects of cancer and treatment. Your job is to involve the person as much as possible, so he feels that he is contributing to his getting better and doesn't feel a burden to you. Below are some things you can try to do to keep the patient involved:

- Help them live as normal a life as possible. To accomplish this you might start by helping them decide what activities are most important to them and help them to continue to do those activities. They might put aside those activities that are less important in order to do those they enjoy most.
- Encourage them to share feelings and support efforts to share. For example, if they began talking to you about how they feel about cancer, don't change the subject, but rather listen and let them talk. You might share how you feel as well.
- Let them know you are available, but don't press issues. This might involve an activity that they are trying to complete such as dressing himself. They may be struggling but it is important that they are able to do this. Let them decide when help is needed.
- Remember that people communicate in different ways. Try sharing by writing or through gestures, expressions, or touching. Sometimes, it may be really hard to say what you are feeling, but a gesture such as holding hands might communicate what you feel.
- Take your cues from the person with cancer. Some people are very private while others will talk more about what they are experiencing. Respect the person's need to share or his need to remain quiet.
- Be realistic and flexible about what you hope to talk about and agree on. You may need or want to talk at a time when the patient does not. Be flexible with your wants and needs.
- Respect the need to be alone. Sometimes, we all need time to be alone. Respect this need.

You may find that your loved one is acting different. They may be angry, quiet and withdrawn, or just sad. If you get the feeling that they aren't talking to you because they want to spare your feelings, make sure they know that you are always open to talking, even about tough topics.

We make our fortunes, and we call them fate.

– Earl of Beaconsfield



CHAPTER 5

WHEN THE PATIENT'S HEALTH FAILS

This may happen sometimes and it is no fault of yours.

However, illness does not necessarily mean that the person you are caring for is heading for the worst. Sometimes, it could be due to your loved one's weakened immune system and they may recover with time.

But be prepared that failing health could be a sign of more serious problems.

It may be better to discuss these details when you and your family are in a clearer and calmer state of mind; rather than try to figure out what to do when the situation actually happens.

CAN I CONTINUE TO BE A CARER?

Ask yourself:

- Can you still care for your friend or relative in their worsening condition?
- Do they require closer supervision than you can possibly give?

If you can carry on with your role, do so.

You may need to start considering additional support or equipment as your workload and responsibilities increase. You need to also consider how the added burden will further impact your physical and mental health.

For instance, you may also wish to contact occupational therapists for equipment or specialist staff if your loved one is suffering from hearing or sight loss or physical handicaps. If you really feel that the patient's failing health is beyond you, there are other options.

Beyond this, there is also your loved one to consider. Inquire gently if they would feel comfortable to be shifted or use an additional support system. Instead of being very thick-headed on the decisions we are making on their behalf, it will help more if the agreement on all decisions are unison. But of course, if your loved one is hospitalised with breathing support, then it is necessary to make the decisions yourself. Approach the doctors, they would be able to counsel you on the best alternatives.

DAY CARE

A live-in maid can be hired to help attend to your loved one's personal care such as washing, feeding, toileting, household chores and so on. Or you can get a maid to come in daily.

If you need more specialised assistance, your medical team may be able to provide recommendations. This includes retired nurses who would be able to come in a few days a week or as often as needed.

NURSING HOMES

When you begin caring, you and your loved one may cope well and may not choose a nursing or care home as an option. However, with failing health, moving to a home may be the best and only option for both of you.

Discuss it openly so that all parties are accepting of any outcome.

When choosing a home, you should consider:

- Whether they have trained staff to care for cancer-afflicted or sick residents.
- Location – ensure the place is near your loved one’s hospital and close enough for visits.
- Capacity – Choose a home which is not fully occupied so there is sufficient space and staff are not too busy caring for many residents.
- Social Factor – Sufficient social stimulation and activity will ensure your loved one is not bored or becomes depressed.
- Financial cost – The cost of having your relative with you against having them stay at a home
- Emotions – Feelings of guilt and separation from a family member or close friend.
- Lack of privacy and independence, but more social company for your dear one.

HOSPICE

A hospice is designed to provide care and comfort for patients who are very ill, especially reaching the end of their life. Hospice treatment can be provided in a hospital, a special facility or at home.

The support offered comes in the form of medical treatment as well as counselling for family members and the patient. Hospice staffs are specially trained to work with people with cancer and other diseases.

In Malaysia, you can contact Hospis Malaysia for more information and assistance on hospice care. Please refer to the list of resources at the back of this booklet for their contact information.



CHAPTER 6

PALLIATIVE & ADVANCED CANCER CARE

We hope that cancer patients make a recovery. But if their disease can no longer be treated, you may have to face the reality that your friend or relative's health is failing.

Palliative care basically means treatment given to provide pain relief and comfort to the patient when a cure is no longer possible. It will also include emotional support for both patient and loved ones.

Many faith traditions place emphasis on the importance of conscious preparation for death as a way of showing respect for and acceptance of life's final adventure. Contact with death often gives us an opportunity to become more aware of spiritual realities. Some people will feel the urge to turn to religion to look for peace and forgiveness. As a carer, you should be careful not to force feed religion when not necessary. Let your loved one make the decision if turning to religion is appropriate for them or not.

As a carer, you still have a vital role in ensuring that these final days are pain free, comfortable and peaceful.

DEALING WITH EMOTIONS

It can be very painful as you go through an emotional roller coaster. Perhaps feelings of frustration and anger you felt in the past may return. You may feel helpless or that your efforts as a carer had been for naught.

You may be afraid – unsure of what to expect or how to cope. Perhaps the rest of the family may be looking to you for strength.

Even your loved one may have issues. Some advanced cancer patients may accept their fate peacefully; others with resentment and fear.

It's alright if you have such feelings. It is not your fault that this has happened. Stay strong. Keep in mind that you should not take on too big a burden. Get the support of family and friends to help you in this struggle.

Speak to your loved ones, sometimes they may want to live something behind; videos, poems, messages etc.

DIET FOR ADVANCED CANCER PATIENTS

The ideas in chapter 4 still apply but here are more tips:

- Encourage your loved one to eat on days when he / she feels better.
- Serve smaller portions of a single meal, if needed every 1-2 hours.
- Get them to eat with others. Make meal time as fun as possible.
- Removing medical equipment and supplies during meal times may help.
- Try to get your friend or relative to maintain their present weight. But don't pressure them to regain lost weight.
- Ensure all prescribed medication is consumed as instructed.

PAIN CONTROL TREATMENT

The reasons for pain are:

- The tumour is pressing against a nerve or organ. Occasionally, the nerves carry the pain some distance from where the tumour actually is.
- An infection may be developing at the cancer site with increased pressure from pus or fluid.
- Scar damage on tissues due to radiotherapy.
- The cancer may have spread elsewhere in the body (secondary site). For instance a 'dull ache' in the limbs can be due to bone cancer.

Early Reporting

Early detection will help your loved one greatly. So pay special attention if he/she complains of pain. Try to be as specific and detailed as possible. Get him/her to:

- Mention where the pain is
- Whether it is a sharp sensation or a dull ache
- Does it come and go or is it a permanent feeling
- Does it get better or worse at certain times of the day (morning, night, etc)
- Would changing positions increase or decrease the pain
- Does it interfere with sleeping, eating or other activities
- Rate it on a scale of 1-5 to which future pain can be compared and whether it resembles any other pain say like a toothache, a wound, etc.

Inform the medical team for further action. Early reporting is crucial to alleviate fears as the medical team can check and perhaps find out that the pain is non cancer related.

Dealing with Pain

As a carer, you may wish to try some techniques at home to relieve the pain. They include:

- Complementary therapies (see chapter 3)
- Positioning – Make sure that the body is positioned comfortably and not straining muscles or scar tissue. This applies to the patient when lying down and sitting especially. Changing positions regularly (sleeping on different sides) may help as well.
- Temperature – Pain can be soothed by placing an ice pack or a hot water bottle over the area. The warm or cool sensation can alleviate the pain, giving relief and allowing a patient to sleep at night. Always place a protective layer before applying hot or cold packs.
- Distraction – For some patients, it has been proven that taking their mind off the pain with pleasurable pastimes such as watching TV, playing computer games, listening to music and so on has been effective. You may want to try this.

Medical Treatment for Pain

As part of palliative care, medical treatment would involve drugs; probably a combination in different levels based on your loved one's needs. There could also be low doses of radiotherapy, especially if the pain is in the bones and other sites.

Alternatively, both radiotherapy and medication could be prescribed for your loved one. You will be advised accordingly on palliative treatment and what drugs are being administered.

What about Addiction to Painkillers?

You do not have to worry about addiction in your relative. Patients who take these drugs for pain relief do not get addicted. It is only when the drugs are abused for recreational purposes that people get addicted.

END OF LIFE ISSUES

As your loved one slips closer to his / her final hours, your role remains to keep them pain free and comfortable as much as possible. If there are any last wishes or requests, this is the time to look into them, if you had not done so earlier.

You can draw solace that you have been with them throughout their battle; at their side and have helped to make this part of their life easier. Know that you have done all you can.

What You Should Do:

- If your loved one is still conscious and able to speak, continue to talk to them and reassure them. Promise that all requests will be fulfilled such as location of burial / cremation, clothing to wear for the funeral and so on.
- Allow them the final comfort of making up with friends, saying sorry, that someone will talk to their children, etc.
- Inform and bring family/friends back home
- Let them talk about their fears; if they wish, with a non family member so privacy is maintained.
- Let them know that they are not a nuisance and they should not feel guilty about anything.
- To have someone of your relative's faith to perform any final rites if they request for it.
- Financial matters such as drawing up a will and so on, should have been attended to earlier. If you haven't, get a lawyer to assist now.
- Continue to offer fluids regularly to quench their thirst. Food too if possible. Don't be concerned if they refuse food and drink. Just offer again some time later. Keep a supply of ice cream, yoghurt and other soft foods if they have difficulty swallowing.
- Positioning and movement – do consult the medical team on whether you can move your loved one to relieve pain or discomfort, and avoid sore areas.

- Continue to provide medication as instructed.
- Attend to toileting if needed. Have a supply of incontinence pads or see whether a urinary catheter can be fitted.

Fears of Dying

Your relative may have fears about dying; of moving into the unknown such as:

- Pain
- The process of dying
- Losing their faith
- Losing control over their bodily functions (incontinence, etc)
- Having been a burden to you
- Possible judgment after death based on their beliefs
- Dying alone or in an unpleasant manner
- Being buried or cremated alive

Understanding what they're going through will help you comfort them during their final moments.

At the time of death, you may wish to sit by your loved one's bedside. Their breathing may become noisy and their body restless. These changes are part of the process of dying and are not signs of distress. They may slip into a coma and never recover.

You will know that death has occurred once the medical team informs you or there is no breathing and no pulse.

At this moment, it's alright to just sit down and gather your thoughts or cry. Do allow yourself time for it to sink in. It would be good to have friends and family around at this time.

Once you are composed, you or someone else should start looking into funeral arrangements.

*Be near me when my light is low...
And all the wheels of being slow.*

– Alfred Lord Tennyson

CHAPTER 7

DEALING WITH PRACTICAL AND PERSONAL AFFAIRS

It would be better if certain personal and financial matters of the deceased had been decided before. For instance, where to be buried, writing a will and so on. This traumatic period is probably not the best time to be managing all of these affairs after your loved one's passing.

If you're not sure what needs to be done, seek advice. There are many professional people and counsellors who can point you in the right direction.

You can also speak with your religious leaders. They are likely to have information and contacts who can give you further information.



NOTIFICATION & REGISTRATION OF DEATH

If your relative has passed away at home, you will need to notify the relevant parties. Contact the medical team so they can certify the death and cause of death and issue a medical certificate. Then you should notify the nearest police station to get a death and burial certificate issued.

You should have important information such as:

- The time, date and place of death
- The deceased's full name, date and place of birth
- Their residing address
- Their Identification Card (IC)
- Personal details of their spouse if appropriate.

You may also wish to inform any relatives, friends and so on about the death and funeral services. This would include making phone calls and placing a newspaper advertisement if needed. Then come arrangements for a wake either at a funeral house or at home. There is also the funeral itself.

Nowadays, most undertakers are able to handle these matters for you. Get in touch with a reliable and sensitive undertaker who will be able to manage many of these matters for you.

You may wish to look into some of these matters yourself, but having these things managed by an unrelated third party will allow you to focus on other personal matters such as to attend to your own feelings, be with family members and perhaps prepare a eulogy or look into any unfulfilled requests by your loved one.

The undertaker would also look into the preparation of the body for burial. You may choose to get involved (selecting the attire, etc) or just stand by and watch. It's completely up to you.

If the death has occurred overseas, contact the relevant Malaysian embassy, high commission or consulate. They will assist you in all matters, including registering the death and transporting the body home.

FINANCES

There is the matter of finances such as medical and funeral bills to settle and insurance claims to make (if relevant).

It would be better to have all these prepared in advance before your loved one's passing. Have them ready, including phone numbers of whom to contact.

Some matters such as insurance claims may have to be handled within a certain time frame. Please check the relevant policy or contact your insurance agent for more information. Others such as perhaps medical and hospital bills can be made in staggered payments.

You may also wish to look into any pension and welfare payments that your loved one was receiving. According to the Pension Act 1980, government pension of a deceased husband can be passed to the wife.

There may be other welfare funds or Employee Provident Funds (EPF) or tax rebates that are due to the deceased or should be remitted to beneficiaries. Contact your family lawyer or accountant to assist in legal and financial matters. Or contact the nearest EPF, Inland Revenue Board (IRB) and Social Security (SOCSO) office.

For more information, kindly refer to the following Malaysian legislation:

- Married Women and Children (Maintenance) Act 1950 (Revised 1981)
- Inheritance (Family Provision) Act 1971
- Pensions Act 1980, Pensions Regulations 1980 and Employees' Provident Fund
- Employees Social Security Act 1969, Regulations and Rules (505(0))
- Income Tax Act 1967 (as amended)
- Employment Provident Fund Act 1991

IS THERE A WILL?

A will is extremely important to ensure that your loved one's possessions are distributed as intended according to his/her wishes.

Often times, families have fought over a deceased's estate or have been 'robbed' of assets due to issues arising over the absence of a will. Wealth may end up in hands that the deceased would not have wanted.

Writing a will can be easily done by your loved one in the presence of an independent witness. An independent witness is someone who is not a beneficiary or is married to a beneficiary. An executor should also be named – someone who will execute the will's instructions. An executor can be a beneficiary in the will.

It's better to engage a lawyer or a professional will writer to ensure the will is written to satisfaction and assets are distributed as intended.

They can also advise accordingly if there are complications i.e. a vested party in the will has passed away.

Follow your honest convictions, and stay strong.

– William Thackeray



CHAPTER 8 PRACTICAL TIPS

How can you get others to assist you in this difficult time? In this chapter, we outline some ideas that have been useful to many cancer carers.

The tips and suggestions in this book are meant to address generic or common situations that carers may face. Expect to adapt these to your own unique experience.

This chapter summarises tips provided throughout this book as well as suggests other ideas.

HOW CAN I INVOLVE OTHERS?

- Ask for help with transport and chores
- Get friends to look for information on cancer from books, the Internet, etc. Get them to speak to doctors as well.
- Don't have negative people around your loved one. Tell them what and what not to say.
- Get a friend and family member to sit by your loved one's bed to chat and keep them company.
- If they can't visit, ask them to send uplifting letters, cards and presents from time to time as these would be welcome.
- Often, people want to help, but don't know what to do. Make a list of things to be done and ask your friends to help with the listed items.
- Ask for help with meal preparation and cooking.
- Get a close friend or two to be the news disseminator. In this way, you don't have to constantly update everyone.
- Get them to accompany you and your loved one during hospital visits. The extra hands, eyes and ears will be useful.
- Ask them if they know any other cancer carers or those who have beaten the disease.
- Ask them to help contact your loved one's employer to explain the situation.



HOW CAN FRIENDS & FAMILY HELP?

- Bring food over.
- Offer to take the carer out or even the cancer patient if possible.
- Show empathy not pity. Avoid false reassurances. Show concern but don't become a busybody just wanting to find out what is going on.
- Don't persistently call the carer or the family. Persistent calling and asking can be annoying.
- Tailor responses to suit the patient, not what you think is right.
- Useful things you can bring to the hospital include:
 - Books, magazines, reading material
 - Flowers, food, tissues
 - Earplugs for sleeping
 - Toiletries
 - Alarm clock
 - Thermos flask
 - Games
 - DVDs, CDs
 - Chewing gum
 - Clothing items
- Be sensitive when visiting. Leave when it's time to go.
- Accept that the patient may say No to your offers.
- Help with the other family members (children, etc).
- Look after their pets.
- Offer to find out about welfare and domestic assistance.
- Record a video. It's a great way to preserve the memories of a terminally ill cancer person.
- Say sorry if you need to for closure.
- Offer support and prayers. They are usually welcome.

*If you do not hope, you will not find what is beyond
your hopes.*

– St. Clement of Alexandria

CHAPTER 9

STORIES OF HOPE

Jessy Tai, 48 years old
Breast Cancer patient; housewife

I will never forget the day of my diagnosis, 4th October 2007. It was my husband who first noticed the lump and we rushed to the hospital the next day to seek consultation. We didn't wait any further, opting to do a mammogram and a biopsy on the very same day.

The next two days were torturous as we waited for the results. I thought I had braced myself, but when the word "cancer" was pronounced, my guard broke and I cried like I had never cried before.

But one determined sentence from my husband, gave me the courage to fight my cancer. "No matter what, I will do anything to have you cured!"

And so our battle with breast cancer began with an immediate mastectomy. I wasn't worried that losing my breast would make me less beautiful; I know my husband loves me for who I am. Beauty is not just skin deep, it's more than that.

In time of adversity like this, I still feel like the luckiest, most loved and blessed woman on earth. My husband and children have been nothing but pillars of strength, faith and hope for me. When I was just recovering from the surgery and going into chemotherapy, my husband's constant encouragement, hugs and caresses kept me going on. Not only that, he cooked meals for me and the family each day before he went to work. My children wrote encouraging notes and cards for me daily.

Our friends were also tremendously supportive, always offering to help in ways that they could. One of them did some research over the Internet and printed out a book on living with cancer for me. Get-well cards poured in, pronouncing their support when I was down. They really inspired me to get well and continue to live life.

I can't wait to fully recover and to do things that I love again like line dance and going out with my family. With love and care from my family and friends, I know I will!

Leong Kok Ong, 58 years old
Husband of Jessy Tai; caregiver and lecturer

I was at work when Jessy called to break the news; the biopsy results confirmed our fear that the lump in her breast turned out to be cancerous. I was numbed with her sobbing momentarily, but I told her I would have her cured at whatever cost.

When we were advised for Jessy to undergo a mammogram, I was not perplexed at the fact that she would lose her breast at all. I heard stories of women who did not want to have their breasts removed for cancer, fearing that their husbands would leave them. This may be a reason why many women keep mum about their conditions which lead to fatality. I reassured Jessy that I loved her for who she is, not merely her physical beauty. Thankfully, she agreed to undergo the mastectomy.

From the day Jessy was diagnosed with cancer, I knew I had to takeover the caregiver role from her. As a wife and mother, Jessy has been terrific in taking care of me and the children. Faced with big shoes to fill, I was determined to do as much as it took to help her fight and recover from this ordeal. Together, we sought advice and help from doctors and organizations such as BCWA for information on cancer, its treatment and recovery process. We also spoke to some cancer patients so that we could learn from their experiences. They were very helpful and supportive; they even visited us to give moral support and encouragement.

It is never easy caring for your loved one suffering with a potentially terminal disease. All along when I reassured her and gave her encouragement to stay strong, I was also encouraging myself. In a way, we needed to be strong for each other in order to fight this battle. The children were wonderful and supportive, always writing her encouraging notes. Friends were also very kind in extending comforting words and help in whatever they could.

My experience has shown me that emotional and moral support is a very important part of caring for a patient. When a patient feels loved, he or she will naturally have the fighting spirit, to get better and to look forward to live.

Margaret Lee

***BCWA Volunteer, cared for her late sister, Joyce Lee
founder of Johor Bahru Breast Cancer Support Group***

Life has taught me many things. I am a volunteer at the Breast Cancer Women's Association (BCWA), an organization that supports and guides women who are breast cancer survivors, family members of breast cancer patients, related professionals and interested persons.

My sister was diagnosed with 3rd stage breast cancer. The news stamped our lives with fear and anxiety. My sister on the other hand took it with stride and began her battle against cancer, learning about her disease and even becoming a member of the Breast Cancer Welfare Association (BCWA). After the surgery, she had chemotherapy and was put on medication. Her regular check ups showed she was healing and doctors were happy with her progress. She was in the teaching profession but due to treatment she went on long medical leave. She was so dedicated to her students that even during treatment she would drive to her students' home to give free tuition classes for poor students.

Four years later, the family moved to Johor Bahru as her husband was relocated to Singapore for work. There, she founded the Johor Bahru Breast Cancer Support Group to provide support to other women cope with the diagnosis of breast cancer.

8 years later, she had a recurrence of the tumour and this time it had spread to her brain. My sister and her family moved back to Kuala Lumpur as her husband's work required him to be in Malaysia. I immediately offered to care for her. Her husband continued to care for her and their 3 children who were still schooling, work and to manage the household and finances. It was without hesitation that I chose to give up my corporate job for a consultancy position to help out and care for my sister.

I helped my sister with regular chores like managing the home and her medication. I would also read to her during bedtime and she also liked listening to her children's day at school. The highlight of her day would be spending time with her children, talking or even just watching TV together. Her husband took care of her every night, once he was back from work. We would hold her hand or caress her hair when she was sleeping and at times she would smile in her sleep. We fought hard, but God called her home to be with Him. We bade farewell to her in April 2002.

My sister's battle with breast cancer, the support she received from BCWA and especially her own compassion in supporting other women diagnosed with breast cancer through her Johor Bahru Breast Cancer Support Group, inspired me to become a member of BCWA volunteering my time and service in her memory. I suppose my decision to care for my sister involved some sacrifice, but I felt it was worth every second I shared with her. We always had a strong emotional bond as sisters and the time we spent together only made our bond even stronger.

Love is an attitude. Love is good will for the gain of another. When we put others' interests before our own, we learn to love, serve and sacrifice. When she passed away, all her loved ones were by her side. She knew she was loved.

CHAPTER 10

Lists of Radiotherapy & Oncology Centres In Malaysia

Penang

Pantai Mutiara Hospital

82, Jalan Tengah Bayan Baru
11900 Pulau Pinang
Tel : (604) 643 3888

Mount Miriam Cancer Centre

Jalan Bulan, Fettes Park Tanjung Bungah
11200 Pulau Pinang
Tel : (604) 890 7044

Loh Guan Lye Specialist Centre

19& 21, Jalan Logan
10400 Pulau Pinang
Tel : 604-238 8888

Gleneagles Medical Centre

1 Jalan Pangkor
10050 Pulau Pinang
Tel : 604-2276111

Hospital Lam Wah Ee

Jalan Tan Sri Teh Ewe Lim
11600 Pulau Pinang
Tel : 604-657 1888

Perak

Ipoh Specialist Centre

26, Jalan Raja Dihilir
30350 Ipoh, Perak
Tel : (605) 241 8777

Kelantan

Hospital Universiti Sains Malaysia

Kubang Kerian, Kota Bharu
16150 Kota Bharu
Tel : (609) 765 1700

Pahang

International Islamic University Malaysia

Bandar Indera Mahkota
52000 Kuantan
Tel : 609-5716 402

Selangor

Sime Darby Medical Centre

1, Jln SS12/1A Subang Jaya
47500 Selangor
Tel : (603) 5630 6270

Sri Kota Medical Centre

Jalan Mohet Klang
41000 Selangor
Tel : (603) 3374 5531

Damansara Specialist Centre

119, Jalan SS20/10 Damansara Utama
47400 Selangor
Tel : (603) 7722 2692

Wijaya International Medical Centre

1, Jalan 215, Section 51,
Off Jalan Templer, 46050 Petaling Jaya
Tel : 03-76207979

Wilayah Persekutuan

Tung Shin Specialist Hospital

102, Jalan Pudu
55100 Kuala Lumpur
Tel : (603) 2072 1655

Pantai Medical Centre

8, Jalan Bukit Pantai
59100 Kuala Lumpur
Tel : (603) 2296 0888

Prince Court Medical Centre

39 Jalan Kia Peng
50450 Kuala Lumpur
Tel : 603-2160 0000

Gleneagles Oncology Centre

286, Jalan Ampang
50450 Kuala Lumpur
Tel : (603) 4255 2758

Universiti Malaya Medical Centre

Jalan Universiti Kuala Lumpur
Tel : (603) 7956 4422

**Hospital Universiti Kebangsaan
Malaysia**

Jalan Yaacob Latif,
Bandar Tun Razak, Cheras
56000 Kuala Lumpur
Tel : (603) 9170 2130

Hospital Kuala Lumpur

Jalan Pahang
50586 Kuala Lumpur
Tel : (603) 2292 1044

Negeri Sembilan**NCI Cancer Hospital**

PT 137/7 Jalan BBN 2/1
71800 Negeri Sembilan
Tel : (606) 850 0999

Melaka**Mahkota Medical Centre**

3, Mahkota Melaka Jalan Bendahara
75000 Melaka
Tel : (606) 281 3333

Hospital Pantai Ayer Keroh

2418-1, KM 8,
Lebuh Ayer Keroh
75450 Melaka
Tel : 606-231 9999

Johor**Johor Specialist Centre**

39B, Jalan Abdul Samad
80100 Johor Bahru
Tel : (607) 223 7811

Hospital Sultan Ismail

Taman Mt Austin
81100 Johor Bahru
Tel.: 607 356 5004

Sarawak**Sarawak General Hospital**

Jalan Tun Ahmad Zaidi Adruce
93586 Kuching, Sarawak
Tel.: (608) 220 8069

Sabah**Sabah Medical Centre**

P.O Box 13393 Kingfisher Park,
Kuala Inanam
88838 Sabah
Tel.: (608) 842 4333

CHAPTER 11

Support Groups

For added support and advice, you may wish to contact the organisations mentioned below. Some have state branches or town chapters which are closer to you.

Amanita

Amanita is committed to helping women restore their appearance and self-confidence after breast surgery, with several stores in Malaysia specializing in post-surgery supplies for breast cancer patients and survivors, such as prostheses, lingerie, bras, swimwear and wigs. Amanita also offers nutritional advice, counselling and workshops on topics such as lymphedema and exercise.

Lot 1.06, 1st Flr, The Ampwalk,
218, Jalan Ampang,
50450 Kuala Lumpur
Tel : +603 2162 8215
Fax : +603 2163 6172
Email : info@amanita.com.my

Breast Cancer Resource Centre

Tel : 03-7949 2639

Breast Cancer Welfare Association (BCWA)

The BCWA is a self-help support group. Its members are breast cancer survivors, family members and friends of breast cancer patients, related professionals and volunteers who help provide psychological and emotional support, information and education.

5th Floor Bangunan Sultan Salahuddin
Abdul Aziz Shah, 16 Jalan Utara
46200 Petaling Jaya,
Selangor Darul Ehsan
Tel : 03-7954 0133
Fax : 03-7954 0122
Email : bcwa@tm.net.my /info@
breastcancer.org.my

Cancerlink Foundation

The Cancerlink Foundation provides care and support to cancer patients. Among its projects are the home-stay program based in Petaling Jaya, which provides free lodging for cancer patients and their family members, food and transport to the hospital for treatment. Counselling is available and entry is determined through hospital references.

13, Jalan Utara,
46200 Petaling Jaya,
Selangor Darul Ehsan
Tel : 03-7956 9499 / 7957 9310
Fax : 03-7957 9310
Email : cancerkl@tm.net.my

Cancerlink Foundation Perak branch

60A, Lintasan Perajurit 6,
Ipoh Garden East,
31400 Ipoh, Perak
Tel : 05-255 9906
Fax : 05-255 6164

**Cancerlink Foundation
Penang Branch**

2U, Lorong Delima 17,
Island Glades,
11700 Pulau Pinang
Tel : 04 659 3692
Fax : 04 565 2052

**Cancerlink Society of Malaysia
Kelantan branch**

B 1882, Lrg Sekilau 32,
Taman Pacific, Jalan Haji Ahmad,
25300 Kelantan, Pahang
Tel : 09-515 8539
Fax : 09-515 8539

College of Radiology

A society of professionals dedicated to being the national authority on radiology, clinical oncology and allied sciences by providing education, training, promoting research and to work with healthcare providers and educate consumers on the benefits and risks of therapeutic and imaging procedures.

College of Radiology
c/o Department of Biomedical Imaging
University Malaya Medical Centre
59100 Kuala Lumpur,
Tel : 03-7949 2093
Fax : 03-7958 1973
E-mail :
secretariat@radiologymalaysia.org
<http://www.radiologymalaysia.org>

Hospis Malaysia

Hospis Malaysia is a charitable organisation established in August 1991 to address the need to develop and provide professional Palliative Care services to those who live within the Klang Valley. Their service help provide a more balanced, humane, equitable and economical approach to meeting the needs of people with life-threatening illnesses, their loved ones and caregivers.

No. 2 Jalan 4/96,
Off Jalan Sekuci
Taman Sri Bahtera
56100 Kuala Lumpur
Tel : 03-9133 3936
Email : info@hospismalaysia.org
<http://www.hospismalaysia.org>

Hospis Klang

03-3324-2125
Email: hospisklang@myjaring.net
www.hospisklang.org

International Union Against Cancer

International Union Against Cancer is a non-profit, non-governmental association of 262 programmes in 84 countries. One of its many programmes is Reach to Recovery International (RRI), a breast cancer support network which links breast cancer support groups all over the world.

<http://www.uicc.org>

IIUM Breast Centre

International Islamic University Malaysia
Jalan Hospital
25150 Kelantan,
Pahang
Tel : 09-5163799 / 09-5132797
Fax : 09-5178548

Johor Bahru Breast Cancer Support Group

Tel: 07-335 7211

Kasih Hospice Care Society

74, Jalan 14/29, Section 14
46100 Petaling Jaya
Selangor
Tel : 03-7960 7424
admin@kasih-hospice.org
<http://www.kasih-hospice.org>

Kelantan Family Planning Association (breast cancer support)

4261-F, Jalan Kebun Sultan
15350 Kota Bharu
Tel: 09-743 2407 / 09-748 3323

Matahari

Lorong Maxwell 2, Jalan Maxwell
Off Jalan Tun Abang Haji Openg
93000 Kuching, Sarawak
Tel: 08-241 1137

Malacca Breast Cancer Support Group

2A, Jalan M8, Bukit Baru,
Taman Merbuk,
75450 Melaka
Tel : 06-284 8888

Majlis Kanser Nasional (MAKNA)

No. 26-3, Jalan 10/55A
Taman Setiawangsa
54200 Kuala Lumpur
Malaysia
Tel : +603 4256 9178 / 79
Fax : +603 4256 9203
Email : makna@makna.org.my

Malaysian Breast Cancer Education Project (MBCEP)

The MBCEP grows out of a need for Malaysian women and their families to have chance to gain knowledge about breast cancer. The project is a collaborative effort between Cornell University (CU) NY, USA and the Universiti Putra Malaysia (UPM), Malaysia.
<http://www.breastcancermalaysia.org>

Malaysian Oncological Society (MOS)

MOS is a medical society consisting of oncologists, physicians and surgeons. Its mission is to provide continual education, updates and expert advice to fellow doctors and the public, in the interest of improving the level of care for cancer patients.

Malaysian Oncological Society
Unit 13-01, Amcorp Service Suites
Menara Melawangi,
Pusat Perdagangan Amcorp
18, Jalan Persiaran Barat,
46050 Petaling Jaya, Malaysia
Tel/Fax : 03 - 7960 0177
Email : secretariat@malaysiaoncology.org,
info@malaysiaoncology.org
www.malaysiaoncology.org

National Cancer Registry, Malaysia

The National Cancer Registry (NCR) is supported by The Ministry of Health (MOH) to collect information about cancers in Malaysia, which will enable us to know the incidence of cancer and to evaluate the risk factors and treatment available in the country. This information is useful in assisting MOH as well as non-governmental and private organisations in raising awareness on cancer and improving treatment for patients.

<http://www.crc.gov.my/nrc>

National Cancer Society of Malaysia

The National Cancer Society of Malaysia is dedicated to preventing cancer, saving lives from cancer and improving the quality of life of those living with cancer through patient care and education.

66 Jalan Raja Muda Abdul Aziz
50300 Kuala Lumpur
Tel : 03-2698 7300
Fax : 03-2698 4300
Email : contact@cancer.org.my
<http://www.cancer.org.my/>

The Society also has branches in Penang, Ipoh (Perak), Seremban (Negeri Sembilan) and Johor Bahru (Johor) and Sarawak.

Pahang Breast Cancer Support Group

7352, Taman Rotan Tunggal,
27600 Pahang
Tel : 09-355 6895

Penang Breast Care Society

c/o Mount Mariam Hospital, Jalan Bulan,
Fettes Park, Tanjong Bungah
11200 Penang
Tel : 04-890 7044
Fax : 04-657 0959 / 04-890 1583
Email : penangbreastcare@yahoo.com

Persatuan Pink Champion Perak

c/o Sumithra Surgical Clinic,
Suite 217 Hospital Pantai Putri,
126 Jalan Tambun,
31400 Ipoh, Perak
Tel : 05-548 4333 ext 3821 / 3822
Fax : 05-545 8168

PRIDE Foundation

PRIDE Foundation (Pink Ribbon Deeds) is a charity body that aims to enhance awareness efforts and improve accessibility to treatment and care of breast cancer at all levels of society. Its incorporation is a tribute to the late Datin Paduka Seri Endon Mahmood's courage, resilience and strength in her fight against breast cancer. PRIDE is committed in its efforts to create a positive environment where knowledge, treatment and support on breast cancer are readily available to everyone.

7th Floor, Wisma KLIH
126, Jln Bukit Bintang
55100 Kuala Lumpur,
Tel: 03-2144 9932 / 9952
Fax: 03-2145 2445
E-mail: info@pride.org.my

Sabah Family Planning Association Breast Cancer Support Group

Jalan Kebajikan, Kota Kinabalu, Sabah
Tel : 088-245 209 / 088-222 703

Sarawak Breast Cancer Support Group

C/o. klinik Satok
22F Lorong 12, Jalan Rubber
93400 Kuching, Sarawak
Tel : 08-241 4994
Fax : 08-225 0910

Segamat Breast Cancer Support Society

34, Jalan Nagasari 7,
Segamat Baru,
85000 Johor

Terengganu Rakan Cakna Persatuan Perancangan Keluarga Terengganu

12-G, Jalan Engku Pengiran Anom 2
20300 Kuala Terengganu, Terengganu
Tel : 09-622 1763

Online Resources

There are also foreign-based organisations which provide useful information on dealing with cancer and how to be a carer. These offer you the opportunity to learn from others across the world who also may be carers like you.

American Cancer Society

The American Cancer Society (ACS) is a nationwide community based voluntary health organisation. Headquartered in Atlanta, Georgia, the ACS has state divisions and more than 3400 local offices.

<http://www.cancer.org>

Cancer Information Network

The Cancer Information Network is a non-commercial site founded to provide support and information to cancer patients and their caregivers. It is founded on the belief that pro-active patients who educate themselves to take an active role in decisions regarding their therapy can affect their outcome in a positive way.

<http://www.cancerlinkusa.com/support>

Cancer Support Association Australia

The Cancer Support Association of Western Australia Inc was formed in 1984 by a small group of individuals who share the common bond of either had or have cancer, or having a loved one with cancer. Over the years, this need for a cancer support group was broadened to include a greater choice of wellness and healing strategies and to provide timely access to quality information, enabling a more

inclusive and holistic approach to cancer care.

<http://www.cancersupportwa.org.au/>

CancerHelp UK

CancerHelp UK is a free information service about cancer and cancer care for people with cancer and their families. We believe that information about cancer should be freely available to all and written in a way that people can easily understand.

<http://www.cancerhelp.org.uk/>

European Cancer Patient Coalition

The European Cancer Patient Coalition has been established to represent the views of cancer patients in the European healthcare debate and to provide a forum for European cancer patients to exchange information and share best practice experiences.

http://www.cancerworld.org/CancerWorld/home.aspx?id_stato=1&id_sito=9

Leukaemia Society of America

The Leukaemia & Lymphoma Society is the world's largest voluntary health organisation dedicated to funding blood cancer research, education and patient services. The Society's mission: Cure Leukaemia, lymphoma, Hodgkin's disease and myeloma and improve the quality of life of patients' and their families.

<http://www.leukemia.org>

National Childhood Cancer Foundation

CureSearch represents the combined efforts of the Children's Oncology Group

(COG) and the National Childhood Cancer Foundation (NCCF), two organisations united by a common goal: finding a cure for childhood cancer.

<http://www.curesearch.org>

Ovacom (UK Ovarian Cancer Support Network)

Ovacom is a UK-based support group for all those concerned with ovarian cancer, involving sufferers, families, friends, carers and health professionals. It aims to: share personal experiences, link sufferers, provide information on treatments, screening and research and raise awareness of the condition.

<http://www.ovacom.org.uk>

People Living With Cancer – ASCO

People Living with Cancer, the patient information website of the American Society of Clinical Oncology (ASCO), is designed to help patients and families make informed healthcare decisions.

The site provides information on more than 85 types of cancer, clinical trials, coping, side effects, a Find an Oncologists database, message boards and much more.

<http://www.plwc.org/portal/site/PLWC>

The Lymphoma Research Foundation of America

The Lymphoma Research Foundation of America (LRF) is the United States' largest lymphoma-focussed voluntary health organisation – devoted exclusively to funding lymphoma research and providing patients and healthcare professionals with

critical information on the disease. LRF's mission is to eradicate lymphoma and serve those afflicted by the disease.

<http://www.lymphoma.org>

The Cancer Index

This is a list of useful websites providing up-to-date and authoritative on cancer information. The sites cover a wide range of topics that would be helpful to patients, carers, healthcare professionals, family members and so on.

<http://www.cancerindex.org/>

Willow Breast Cancer Support (Canada)

Willow Breast Cancer Support & Resources Services provides timely access to information, compassionate support, facilitator training and psycho-social education to people with breast cancer, their families and friends and healthcare professionals.

<http://www.willow.org>

References:

1. What Can I Do To Help?; Deborah Hutton, short books, UK, 2005
2. Caring For Someone With Cancer; Toni Battison, Age Concern Books, UK, 2002

Websites:

American Cancer Society

<http://www.cancer.org>

Malaysian Oncological Society (MOS)

www.malaysiaoncology.org

National Cancer Registry, Malaysia

<http://www.crc.gov.my/nrc>

National Cancer Society of Malaysia

<http://www.cancer.org.my/>



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