Where can I find more information?

Every person is different and has different needs. It is important to know what care and support is available and how to receive it.

<u>palliativecare.my</u> – is a website where you can find more information and links about palliative care in Malaysia and the following resources available to download:

What can I say – What can I do? when someone I know is living with a life-limiting condition – strategies for making a difference to help you help someone you know who is living with a life-limiting condition.

Now what? understanding grief – information about grief and bereavement.

Facts about morphine and other opioid medicines – information on the facts and myths about medicines used in palliative care.

Asking questions can help – a booklet with a list of questions you may wish to ask when you are seeing a member of the palliative care team. This question list helps you get the information you want about palliative care and your illness.

About the process of dying – a brochure that guides you through what happens when someone is dying.

Advance care planning – A brochure to guide you as you complete an advance care plan so that your wishes for care at the end of life are known.

<u>hospismalaysia.org</u> – is the website of Hospis Malaysia, a leading palliative care provider in Malaysia.

palliative care guidelines.scot.nhs.uk/
This website contains reliable guidelines for professionals and patients about palliative care.

malaysianoncology.org/ - The Malaysian Oncology Society website provides useful and up to date information pertaining to cancer development in Malaysia and other resources.

<u>cancerlinkfoundation.org</u> – The Cancerlink Foundation website provides information and resources for cancer patients and families. For more information on key palliative care contacts in Malaysia, refer to:

Website : palliativecare.my

Email : info@hospismalaysia.org

Tel : 603-9133 3936 (Hospis Malaysia General Line)

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Find out more about the support and services that are available at: palliativecare.my

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What kind of care is available?

Quality care at the end of life is specialised care and support that recognises the unique needs of a person who has a life-limiting condition, and their family and carers.

In some parts of Malaysia, specialist palliative care is available either in hospitals or provided by community palliative care services.

The goal is to improve quality of life for patients, their families and carers by providing care that addresses the many needs patients, families and carers have such as physical (including treatment of pain and other symptoms), emotional, social, cultural and spiritual.

The aim is to help the person live as well as possible. Support is also offered to help family and carers manage during the patient's illness and in bereavement.

As a person receiving care, the patient is an important partner in planning their care and managing their condition. Family and carers also have an important role in this area. When people are well informed, participate in treatment decisions and communicate openly with their doctors and other health professionals, they help make their care as effective as possible.

Care planning is an important process in ensuring the patient's wishes, in relation to care, are met. Patients should speak to their doctor about anticipating their changing needs through advance care planning.

Discussions about appointing a substitute decision maker may also be important.

My first reaction was "but we don't need palliative care". I feared what this meant. I felt more comfortable when I realised that palliative care was much more than just nursing a dying person – it was about holistic support and understanding, ensuring that my husband could still "live" as best he could in the time he had left. I know my family would not have coped nearly as well physically and emotionally without it.

What is specialist palliative care?

A small number of people experience severe or complex problems as their condition advances. These people may be referred to a specialist palliative care service where a team of specialist professionals will work to meet their needs.

Alternatively, the patient's general practitioner may seek advice from a specialist palliative care service on the patient's behalf.

Can I still have active treatment for my illness?

Yes – treatment aimed at curing illness can often be continued. The focus of care is maintaining quality of life and meeting the needs of the person, their family and carers.

Who provides care?

Care can be provided by a number of different health professionals, depending on:

- the needs of the patient
- the resources and needs of the family and carers.

Many health professionals may be involved in delivering care and generally they will work as part of an interdisciplinary team. A care team may include:

- general practitioners
- specialist palliative care doctors and nurses
- specialist doctors oncologists, cardiologists, neurologists, respiratory physicians
- nurses
- allied health professionals pharmacists, occu pational therapists, physiotherapists
- social workers
- grief and bereavement counsellors
- pastoral care workers
- · volunteers.

Who should I talk to about palliative care?

You can talk about your needs with your doctor or regular care team. You can also refer to a comprehensive list of palliative care providers in Malaysia to find a service that provides care in your area.

Where can I receive care?

Care can be provided in:

- the home
- a hospital
- an aged care home
- · a hospice.

Most people with a life-limiting condition prefer to receive care at home, but this will depend on many factors, including:

- the nature of the illness
- how much support is available from the person's family and community
- whether the person has someone who can care for them.

If I am in pain, how will it be eased?

Not everyone with a life limiting condition will experience pain. If patients do experience pain, in almost all cases it can be relieved.

There are many pain management medicines that can be given in different ways – tablets, liquids, injections, patches. There is also a wide range of medicines and other treatments that can be combined to improve pain relief.

Some complementary therapies, such as massage, acupuncture or aromatherapy can also be helpful in relieving pain.