

WHO definition of palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Helping hand

- Accept the ill persons feelings, and be prepared to go over them over and over again.
- Be prepared for sharp mood swings in mood and outlook.
- Recognise your own feelings, try and sort out useful ones from the ones that are not so useful
- Encourage the ill person to talk about their feelings, and try to be open and honest about your own
- Show that you want to listen and understand it is a way of giving support
- If it is difficult for them to talk to you, encourage them to find someone else they can open up to.
- Encourage the ill person to draw strength from their own past experiences, thinking back to a difficult situation and how they dealt with it.
- Avoid the temptation to rush in and take over, work out how best you can help

“Palliative care (from Latin *palliare*, to cloak) is any form of medical care or treatment that concentrates on reducing the severity of disease”

www.healthline.com



General reaction process

- Shock and disbelief
- Denial
- Anger and grief
- Fear

Helping hand cont'd

- Don't make decisions for the ill person; let them take the lead in what they want to do.
- Being there is more important than doing things
- Rushing around may make you feel better, but the ill person may prefer your company for a couple of hours
- Get more information, people under this kind of stress find it very difficult to take in information, so it may help if you can answer their questions, and make informed decisions about their treatment and care.

Short term care options

Regular	Sitter or care attendant - few hours care.
Live-in help	Constant care within individuals home
Day Services	Day care away from the home
Residential	A few days, weeks or permanent care / nursing
Holiday	Specialist homes with care on site

Medical and nursing care

G.P.	hour care at home for registered patients.
Macmillan Nurse	Emotional support, advice regarding illness
District	Nursing care at home advice
Marie Curie	Trained cancer nurses and help at home
Carer / PA	Daily personal care (non nursing tasks)
Physiotherapist	Treatment and exercise for mobility and advice
Specialist nurse	Unique to the illness or condition

Long term care options

Regular	Sitter or care attendant - few hours care.
Live-in help	Constant care within individuals home
Day Services	Day care away from the home

Possible questions after diagnosis

- Can you be sure that the illness is terminal?
- What are the options?
- What treatment is available and what is the purpose of the treatment?
- What can be done to help fight the disease?



- How will the illness develop – what symptoms can the person expect?
- Will there be a lot of pain?
- How much time will they have to be in hospital?
- Will they need extra help at home if the illness gets worse?

Living with the illness

Pain	Although many people are afraid that a terminal illness will mean pain, this is not necessarily so.
Loss of appetite	People who are ill often have little or no appetite, encourage smaller more frequent meals when they please.
Nausea / vomiting	Has many causes. Symptoms can usually be relieved by medication, or changing prescription.
Constipation	This is a common problem in ill people caused by lack of appetite, exercise or medication.
Incontinence	This often happens at the later stages of the illness.
Pressure sores	The skin over the bony parts of the body such as heels and base of spine begin to break down, causing pressure sores.
Smells	Changing bedding, clothes, emptying commodes and bedpans as soon as possible can help.
Confusion	Often occurs in the final stages of a terminal illness, but can happen earlier.
Other problems	Indigestion, diarrhoea, cough's, cramps, swelling, breathlessness, sleeplessness, sweating, heartburn, an unpleasant discharge.

Fear

We are all afraid of dying, and almost everyone goes through a period of being afraid during a terminal illness.

- For some people this happens at an early stage in the illness
- For others, this fear may surface or become more difficult to ignore as the illness progresses
- It is not cowardly to be afraid of dying. It is part of our natural instinct for self-preservation
- Because we live in a society where dying and death are outside most people's experience, it is very difficult to acknowledge these feelings.
- It is also very difficult to listen and give comfort to someone who is afraid of dying

Approaching death

In the final stages of a terminal illness the changes to the body are visible and take away the uncertainty

Death is inevitable however some people never accept they are dying



Empathy

Most people find it difficult to know how to help and support someone who is facing death.

It may help to try and think about how you might feel if you were in the ill person's place.