Providing care through the final days

Responsibilities of a family caregiver when their loved one reaches the end of life largely depend on where the person with cancer is receiving care. For instance, having constant care from nurses at an inpatient hospice would mean that the family caregiver can have fewer responsibilities as compared to a home setting. Nevertheless, if your loved one is under the care of hospice services, the hospice care team will ensure his or her comfort as much as possible, no matter where he or she is cared for. Read more about palliative care and hospice services at <u>https://singaporehospice.org.sg/</u>

People reaching the end of life usually become weaker and more tired. It is not always possible to predict exactly how long more a person will live, but there are some common signs and symptoms that can indicate that the end is nearing.



Knowing what to expect and what you can do allows you to plan better and feel less anxious.

The following are some common symptoms that your loved one may experience, and suggestions on what you can do. Remember that **symptoms vary across individuals and not everyone will experience them**.

What happens

Sleeping excessively

This change is normal and is partly due to chemical changes in the body and brain.

What you can do

- Hold his/her hand, speak softly into the ears to assure them of your presence.
- Continue to talk to your loved one; never assume they cannot hear you even if they do not respond to you. Hearing is the last sense to be lost.
- Gently reposition your loved one regularly to prevent pressure sores if he or she is unable to turn on his or her own.

Decreased interest in food & drinks This is part of the normal dying process. Your loved one does not require many calories at this stage.	 Offer desired foods and drinks in small amounts via teaspoons or syringe if your loved one is still alert Do not force or insist if he/she does not want to eat, as doing so will increase discomfort. Clean and moisten the mouth periodically to maintain oral hygiene and enhance comfort.
Unable to control urine & bowels This is an expected part of the dying process.	 Be supportive and understanding Keep bed and clothes clean, and change bed pads often, if you are providing care at home. Put on a diaper for your loved one and change it when necessary. Use barrier cream to prevent skin from coming into contact with excretions.
Coolness of Limbs Limbs may be increasingly cool to touch as blood flows to the vital organs. The face may be pale and the soles of the feet and legs may turn a purple-blue mottled colour.	 Cover your loved one with just enough blankets to keep him or her warm.
Confusion or restlessness Confusion about people and surrounding things may occur. Some may appear restless, displaying repetitive movements such as pulling at the bed linen or their clothing. This may be due to many reasons (e.g. chemical changes in the body).	 Identify yourself when you speak. Speak softly, naturally and clearly. Use simple words or short phrases. Provide reassurance. You do not have to correct the confusion, as doing so may increase distress. Orientate him/her to the day of the week, hour of the day.

	 Do something that you think will calm your loved one. E.g. lightly massage the hands or forehead, play soothing music or prayers at a low volume. Maintain a pleasant room atmosphere. Avoid using glaring bright lights. The doctor may prescribe some medications for your loved one, to calm him or her down.
Changes in breathing pattern Your loved one may breathe with his/her mouth open as muscles become more relaxed. Breathing may be irregular, shallow or may stop for periods of 10 to 30 seconds. This usually does not disturb the dying person.	 Raising the head of the bed or turning your loved one onto his/her side may help, but this is not necessary as it is part of the normal dying process.
Gurgling throat secretions Loud gurgling sounds from the throat are usually due to the inability to swallow saliva. This normally does not cause discomfort.	 Avoid deep suctioning as it can cause discomfort. If you are providing care at home, elevate the head using pillows or turn your loved one onto his or her side to help reduce the gurgling sounds. Place a small towel at side of mouth to allow phlegm to flow out. The doctor may prescribe some medications for your loved one, to help dry up excessive secretions.

Help with caregiving

Caring for a loved one at the end of life can be challenging, especially if you prefer to provide care at home. Aside from hospice homecare services, some people choose to engage additional assistance so that they are able to cope better at home. This

can come in the form of private nursing, or other home help services. Speak to your loved one's healthcare or hospice care team if you need more information on help with caregiving at home. If your loved one is a patient with NCCS, you may call +65 6436 8417 or +65 64368088 to book an appointment to speak to an NCCS medical social worker if necessary.



When death occurs

When death occurs, the person will be unresponsive, breathing will stop, the heart will stop beating and the eyes will be fixed in one direction. Muscles will relax as well.

It is normal for family and caregivers to feel a sense of shock and unpreparedness, even when death is expected to occur. There is often no immediate rush to notify the doctor or nurse. Many people find comfort and peace in having a quiet moment with their loved one, after they passed on. If you feel that you are unable to cope with the loss of your loved one, individual counselling and bereavement support groups are available in NCCS. You may call **+65 6436 8417** or **+65 64368088** to book an appointment with an NCCS medical social worker, to find out more about how they can help you.

Useful resources

Singapore Silver Pages - End-of-life Care: Caring for your loved one near the end https://www.silverpages.sg/caregiving/End-Of-Life%20Care

Singapore Hospice Council - Caregiver Resources https://singaporehospice.org.sg/caregiver/

Private nursing agencies http://www.healthnetcafe.com/directory/nurse_agencies.html

Home help services https://www.aic.sg/for-seniors-and-caregivers/all-about-caregiving/care-services

The above contents are made available as part of TEMASEK FOUNDATION-ACCESS (Accessible Cancer Care to Enable Support for Survivors) PROGRAMME, a holistic care programme to support cancer patients during their care and recovery journey.

The contents have been approved by the Cancer Education Information Service, National Cancer Centre Singapore (NCCS), for people with cancer and their families and caregivers. However, this information serves only as a guide and should not be used as a substitute for medical diagnosis, treatment or advice. For specific medical conditions, please seek expert medical advice from your healthcare team.

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