

# FAMILY/CARER INFORMATION REGARDING CARE IN THE LAST DAYS OF LIFE

The doctors and nurses will have explained to you that there has been a change in your family member or friend's condition. They believe that the person you care about is now dying and in the last hours or days of life. The following information might help you during this time.

You and your family member or friend will be involved in discussions regarding the plan of care with the aim that everyone understands the reasons why decisions are being made. If your family member or friend's condition improves, then the plan of care will be reviewed and changed as needed.

## Communication

**Asking questions:** We understand that this is a worrying and emotional time. The doctors and nurses will ask you for your contact details, as keeping you updated is a priority. If you have any questions, no matter how big or small you think they may be or how busy the staff may seem, please speak to them. If you would like to see a social worker please ask the staff.

## Helping staff to respect your family member or friend's wishes about their care

**Knowing personal wishes, cultural or spiritual needs:** We would like to respect any specific personal wishes regarding care. We will also try to help arrange any specific cultural or religious needs you and your family may have. Please let us know if there is anything we can do.

**Personal wishes about where care is provided:** Some people are clear where they would like to spend the last days of their life. If your family member or friend may want to be moved, please ask staff about this now. The doctor will need to assess if this is possible or not. Do they wish to go home? (This includes going home to Residential Aged Care.) Moving to a local hospital closer to home or family may also be an option. Sometimes care in a Palliative Care Unit may be offered if symptoms, like pain, are difficult to control.

**Comfort:** Comfort is very important. Please let the staff know if you feel the person is not comfortable. You can support the care given to your family member or friend in important ways such as spending time with them, sharing memories, bringing news of family and friends or simply holding their hand.

**Medication:** There may be frequent changes to medications so that a person will be as comfortable as possible. Medication to help control problems that may occur, like pain or breathlessness, will only be given when they are needed, and just enough that is needed to help.

**Caring for yourself:** Caring for someone who is dying can be a tiring and stressful time. It may bring up upsetting emotions including grief or distress. Managing all the information and decisions, as well as dealing with other family members, can also bring additional distress. Talking with nurses, a counsellor or social worker may help. Pastoral care workers are available to help support you and for any spiritual or religious needs.

## Changes which may occur before death and suggestions for caregivers

**Reduced need for food and drink:** You may notice that food and drink are no longer tolerated. This is normal and a person will be kept comfortable if their lips and mouth are kept moist with lip balm and moist mouth swabs.

**Keep the lips and mouth moist with lip balm and swabs moistened in water. Ask the nurse if you can give small sips of water, or ice chips on a spoon if the person is still able to swallow.**

**Sleeping more:** A person often sleeps more and may not wake up easily. They may have a short time when they are mentally clear before going back to sleep again.

**Restlessness and confusion:** A person may become increasingly confused and restless. This can take the form of moaning, calling out or trying to get out of bed. Medicines may be able to help keep a person comfortable. Please talk with staff if you have any concerns.

**Having someone familiar close by often helps, particularly at night. Keep voices low and calm and have soft lighting.**

**Breathing and increased secretions:** Changes in the breathing pattern are common, including a pattern where several deep breaths are followed by a pause in breathing. Saliva and mucus can collect and can cause a 'rattling' sound. Changes in breathing and the sound is not usually distressing to the person who is dying. It is often more distressing to the carers.

**Medication may be given to help dry these secretions. Repositioning a person may also help.**

**Circulation:** A person's hands and feet can become cool, mottled and appear slightly blue in colour. The person is usually comfortable and unaware of these changes.

**There is no need to treat any of these changes. Although the person may feel cold to touch, they will often not tolerate many blankets. Use light blankets and keep the room a comfortable temperature.**

**Personal care and turns:** Turning or moving the person on the bed may help prevent pressure areas, soreness and stiffness from lying in one position for too long and it is important that nurses continue to do this. Mouth and eye care are also important to keep a person comfortable. Sometimes a tube (catheter) is inserted into the bladder to relieve the feeling of a full bladder, but for most people urine flow decreases or stops.

**Understand that turns are still needed, even when it may disturb a person.**

## Knowing how long a person has left to live

Most family members and close friends want to know exactly how long the person will live. It is impossible to accurately predict how long someone will live for. Some people will stop waking up a few days prior to dying, however, others may die quite suddenly or even remain awake to some extent right up until they die.

## Contact Information