

## End of Life Care

'At the End', 'Finishing Up' or the 'Terminal Phase' refers to the last days of life, when a person is actively dying (Palliative Care Expert Group, 2016).

There are things that can help us to prepare as someone approaches the last few weeks and days of life. Having information can help to make choices. People vary in what they know, understand, and believe about dying and death. They also differ in what they want to know.

Each individual should choose how informed about dying and death they want to be (CareSearch, 2017).

People who are end of life may prefer to be cared for, and die at home.

Or, they may not want to be cared for at home, but to spend their final days in a hospice or hospital.

The choices of the person at the end must be respected and supported by family, friends and carers as much as possible (CareSearch, 2017).

Many people at the end may have documented their choices in an Advance Directive or Advance Care Plan, or they may have discussed their wishes with carers or family.

Possible changes that may be seen in a person as death approaches may include:

- Increased periods of sleep
- Increased bed rest requiring further care by professionals and/or family
- Changes in their thought processes eg, confusion, hallucinations
- Decreased response to conversation and touch - becoming less responsive/semi-conscious
- No longer wishes to eat and/or has difficulty swallowing
- No longer needs fluids – some thirst is common and mouth care can alleviate this
- Has reduced, or no urine output and may be incontinent – urine will be dark and concentrated
- Changes in their breathing pattern due to decreased function of muscles
- Rattly breathing due to secretions pooling in throat and loss of muscle function that clears the throat
- Pale or mottled (bluish) skin, cold hands, and feet (in the last hours of life)
- May require pain relief – which can be administered in a variety of ways however a syringe driver is common at the end – this neither hastens nor postpones the dying process – as the illness is the cause of death.

(Palliative Care Expert Group, 2016).



## Vision and Hearing Information

Unless vision or hearing has been directly affected by their illness the person at the end of life will have the same vision and hearing as they have had before the illness. Therefore, it is important to talk to the person and explain what is happening.

### Support that may be needed at the end-of-life includes:

- Awareness and understanding of the persons Advance Care Plan or Advance Directive
- Culturally sensitive care
- Emotional counselling
- Follow up appointments with the palliative care team to review care plans and changes to care plans
- Discussion about any medication changes
- Additional at-home supports (if the person wishes to die at home)
- Support to write an action plan of what will happen once the death has occurred
- Contacts of all the people needed in regard to after-death care, eg, family and friends to be contacted; doctor, funeral supports, governmental organisations to coordinate notifications of death.

An expected death is not an emergency. There is no need to call for the police or for an ambulance.

Family/carers may however, want to call a friend or family member to be with them. Ring the community nurse or the doctor to let them know what has happened.

A doctor will need to come and certify the death. (If the person was expected to die this is not urgent).

A doctor may have seen the person recently. If so, and they die at home during the night, it is possible to wait until morning to call the doctor. Family/carers may want to spend quiet time with the person who has died before ringing anyone (CareSearch, 2017).



## References:

CareSearch (2018). At the End Factsheet. Accessed Jan 2021 at:  
[https://www.caresearch.com.au/Caresearch/Portals/0/Fact-Sheets/CareSearch\\_FactSheet\\_At-the-End.pdf](https://www.caresearch.com.au/Caresearch/Portals/0/Fact-Sheets/CareSearch_FactSheet_At-the-End.pdf)

CareSearch (2020). End of Life Symptoms. Accessed Jan 2021 at:  
<https://www.caresearch.com.au/caresearch/tabid/3431/Default.aspx>

Palliative Care Expert Group. (2016). Therapeutic Guidelines; palliative care (4th ed.). Melbourne: Therapeutic Guidelines Limited.

