



## COVID-19 disease and end of life care in hospital

Information for families and carers

### What to expect when you have been told your family member or friend is likely to die from COVID-19 disease

Have doctors and nurses explained to you that there has been a serious change in your family member or friend's condition? Are they concerned that your loved one is entering the last hours or days of life as a result of COVID-19?

The following information may help you during this uncertain time.

#### Things to know when visiting your loved one

Visiting people with COVID-19 disease is more complicated than usual due to the risk of infection. The number of visits allowed, and the duration of each visit may also be affected.

If you are feeling unwell with a fever or new respiratory symptoms (e.g. sore throat, shortness of breath or cough) it is important you speak to a doctor or nurse before visiting.



#### Personal Protective Equipment (PPE) is important

When visiting your loved one, you must wear Personal Protective Equipment (PPE). PPE is essential for your own safety and those around you. For example, visitors may be asked to wear a mask before entering health facilities.

Even with PPE, if the risk of the virus transmission is too high, you may not be able to enter your family or friend's room. This can be very upsetting. The staff may be able to arrange phone or video calls so you are still able to talk with your family or friend. There may be a window to their room through which you can see them even if you cannot go into the room.

PPE includes a full-length plastic gown or apron, gloves, a facemask, glasses or a face shield. You will be instructed how to correctly put on and take off PPE. You will also be instructed when you are required to clean your hands during this process with hand sanitiser or soap and water.

#### Feel free to ask questions

This is a worrying and emotional time. The doctors and nurses will ensure the correct contact details are being recorded so you can be updated on your family member or friend's condition.

If you have any questions, no matter how big or small, or how busy the staff may seem, please ask the nurses and doctors on the ward to talk with you.



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

Respecting each person's wishes regarding their care is important. These may include cultural or spiritual needs. If you know your family member or friend has an Advance Care Directive or has discussed their wishes previously, please share this information with the staff.

If your family member or friend is at home with COVID-19 disease and they are not going to recover, in some circumstances it may still be possible for them to stay at home to die. This may be dependent on the services available in your area and how well care can be managed in the home.

Caring for someone at home with COVID-19 requires careful planning. The doctors and nurses will spend time with you to help you understand all aspects of your family member or friend's care and your role in providing this. The team will also need to ensure essential equipment is in place and that you are taught how to give medications if necessary for your family member or friend's comfort.

### Remember to care for yourself

This is a tiring and stressful time that sometimes raises upsetting emotions including anger, grief or distress. Managing all the information and decisions, as well as dealing with other family members' needs, can also bring additional distress. Talking with nurses or a social worker may help. Pastoral care workers can also support you for any spiritual or religious needs.



### What to expect when a person is nearing death

It is often difficult to know exactly when a person is likely to die. This is often a question that people ask but everyone is different. Sometimes people with COVID-19 disease change very quickly. Some of the changes you might see are:

- **Restlessness and confusion:** A person may become increasingly confused and restless. This can take the form of moaning, calling out or even trying to get out of bed. In order to ensure people are as safe and comfortable as possible, the doctors may recommend regular sedating medications to reduce their restlessness. Please talk with staff if you have any questions or concerns.
- **Breathlessness, changes in breathing pattern and noisy breathing (or "rattles"):** Many people with COVID-19 disease experience breathlessness. At the end of life, small doses of morphine are regularly prescribed to reduce the sensation of shortness of breath. Other changes you might see at this time include pauses between breaths and "rattly" breathing. While such changes may be distressing to watch, they are not distressing to the person.
- **Fevers:** Many people with COVID-19 disease experience persistent high fevers. The nurses caring for your family member or friend will provide cool washes and other medications such as paracetamol, as required.
- **Reduced need for food and drink:** As people become more unwell, they tend to be less and less interested in food and drink. This is often worrying for families but it is very unlikely to be distressing to the person.
- **Sleeping more:** As people become weaker, they tend to sleep more and usually become unconscious. This is a normal part of the dying process and may occur regardless of whether or not people are requiring medications to help manage symptoms. It is important to remember that even if a person is unable to respond to you they can still hear you, so a gentle, familiar voice either in person or by phone will be comforting.

Above all, the aim of hospital care at this time is to ensure your family member or friend is as safe and comfortable as possible. The doctors and nurses will ensure medications are available to relieve symptoms such as pain, shortness of breath and restlessness if these occur. Remember if you have any questions around any aspects of care, please do not hesitate to ask.

### For more general information on COVID-19, visit:

<https://www.health.nsw.gov.au/Infectious/covid-19/Pages/default.aspx>

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