

Caring for someone at the end of life at home: some practical information

This resource is for people caring for someone at the end of life at home. The aim is to help you to know what to expect and how you can support a person who is dying. Your GP, Public Health Nurse and/or Community Nurse can provide advice on medications and other supports that can help.

The information here has been adapted from the "What you can do to practically care for someone who is in their last days and hours of life" document developed by the HSE National Clinical Programme for Palliative Care. Some information has also been adapted from the Helix Centre and NHS End-of-life Care Toolkit for Carers at Home.

Breathlessness and cough

Breathlessness and cough can be distressing and can make it difficult to communicate. If the person you are caring for is experiencing this, try to give them time and space to respond. Do not force the person to talk. It might be helpful to talk calmly and reassuringly, to open a window to allow fresh air in or a fan may be useful. If possible, sit the person up with pillows, rather than lying flat. This can help to relieve the sensation of not being able to breathe. Before someone dies their breathing often becomes noisy. Some people call this the 'death rattle'. Try not to be alarmed by this. It is normal and happens because of a build-up of secretions as well as the muscles at the back of the throat relaxing. There are medicines that can be given to help if it is a problem.

Pain

Not everyone experiences pain when they are dying, but some people do. If they are less conscious, they may grimace or groan to show this. It is a good idea to check the person's position in bed to see if this can also help. They may be too weak to move, and this can cause discomfort. You might be aware if they have any areas that are known to hurt, for example a bad back. This can be useful to remember when helping them to re-position. There are also medicines that can be given to ease pain.

Agitation or restlessness

Some people can become agitated and appear distressed when they are dying. This can be frightening. It is important to try to find out the cause of any restlessness. Having a full bladder or bowel can be a cause. This can be relieved by using a catheter to drain urine or by giving medicines to help the person open their bowels. The GP and nurse(s) can help with this. If it is not either of these, you can try to reassure the person by talking and/or sitting with them. Touch can be effective too. If you are comfortable, you could hold the person's hand. There are also medicines that can be given to help.

Feeling sick or nauseous

Sometimes people can feel sick or feel like vomiting when they are dying. If the person is vomiting, and is unable to sit up, you can try to help the person turn on their side. This helps to protect their airway. There are medicines that can be given to help relieve this.

Eating and drinking



As the person's body gets weaker the body uses less energy so wanting to eat or drink less is part of a natural process. When a person is dying, they often lose their desire to eat or drink and eventually their ability to swallow. Weight loss can happen quickly. This can be difficult to watch because we equate food with health and offering food as an act of love. However, hunger and thirst are rarely a problem at the end of life. You can offer a variety of soft foods and sips of water with a teaspoon or straw if the person is awake. Remember to allow the person to refuse this too. When offering food and drinks, help the person to sit up first to avoid choking. If the person coughs after eating or drinking it is better to stop as their swallow may be too weak. When a person is no longer able to swallow some people ask about fluids through a drip or other routes. At the end of life this offers little, if any, benefit as the body cannot process the fluid like a healthy body can. As a result, it can be harmful.

Mouth care

At the end of life having a dry mouth can be a problem. This may be linked to the use of certain medications and the person breathing through their mouth, but it doesn't mean that the person is thirsty. It is important to keep lips moist with a small amount of un-perfumed lip balm to prevent cracking. You can regularly wet the inside of the person's mouth and around their teeth with a moistened toothbrush. When doing this, check for sore areas and white patches on the tongue, gums and inside the cheek. If this happens tell the person's GP or nurse(s) as it can be treated easily.

Going to the toilet

Towards the end of life, a person may lose control of their bladder and bowel as muscles relax. It is normal to expect someone at the end of life to go to the toilet less as they eat and drink less. Contact the GP or nurse(s) if the person has not passed urine for 12 hours or more. Regular washes and changing incontinence wear can also help someone feel more comfortable, as well as a using a catheter to drain urine in some cases.

Washing

Sometimes it may be too disruptive for the person to have a full wash. Just washing hands, face and bottom can feel refreshing. To help the person with a bed bath, use two separate flannels. One flannel can be used for the face and top half of the body and one for the bottom half. Start at the top of the body, washing the person's face, arms, back, chest, and tummy. Then, wash their feet and legs. Finally, wash the area between their legs and their bottom. Rinse off any soap completely to stop their skin feeling itchy. Dry their skin gently but thoroughly. Expose only the parts that are being washed and cover the rest of their body with a towel. This helps the person stay warm and helps to maintain their dignity.

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Communication and environment

When nearing the end of life, people often sleep more, and they may drift in and out of consciousness. Try to imagine what the person you are caring for would want. Provide familiar sounds and sensations, a favourite blanket for example, or piece of music. Keep the environment calm by not having too many people in the room at once and by avoiding bright lights. This can help to reduce anxiety even when someone is unconscious. Even if the person cannot respond, it is important to keep talking to them. People can most probably hear right up until the time that they die.



Looking after yourself

Caring for a dying person can be exhausting both physically and emotionally. Remember to take time out to eat and rest. Where possible, try to share the care with other people. Remember it is OK to leave the person's side to have a break. It might be useful to see the tips included in this resource: **www.hospicefoundation.ie/wp-content/uploads/2020/04/Caring-for-Someone-nearing-end-of-life-at-Home-during-Covid19.pdf**

Useful resources and information

Here are some useful websites that provide support and information. The Irish Hospice Foundation Care & Inform Hub has resources and information, including leaflets on bereavement, grief and loss and a resource "Caring for someone, nearing end of life, at home during the COVID-19 crisis". These resources, and more are available on: **www.hospicefoundation.ie/covid19careandinform/**

Other resources include:

- Family Carers Ireland **www.familycarers.ie/coronavirus-covid-19-information-advice/**
- The HSE has information about caring for someone with COVID-19, including a list of do's and don'ts and information about living with other people **www2.hse.ie/conditions/coronavirus/self-isolation-and-limited-social-interaction.html**

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