



What to expect when someone is in their last days of life

Guidance for families and carers



This leaflet has been jointly developed by:

- Wirral Hospice St John's
- Wirral Community Health and Care NHS Foundation Trust (WCHC)
- Wirral University Teaching Hospital NHS Foundation Trust (WUTH)
- Claire House Children's Hospice

Being with someone in their last days of life can bring great comfort in the future, but it can also be daunting and emotional.

This booklet provides information that aims to reassure you and encourage you to ask questions of the healthcare team supporting you.

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The dying process - what to expect

The dying process is unique to each person, but there are some common changes that happen. Most of the time the person is not in any pain, and the changes are just a normal part of dying.

Supportive films about dying

These short information films by palliative care doctor and author Kathryn Mannix are helpful and supportive. Scan the QR codes or search the film titles online.

Dying is not as bad as you think

How dying is a process and one that is much gentler than we imagine.



Dying for beginners: What happens when someone is dying

A short, animated video guiding you gently on a journey through the process of dying.



Sleep

A person may sleep more and might be difficult to wake. Try not to be discouraged if there is little response - this may be due to weakness, not lack of appreciation that you are there.

Simply being together can be a great comfort to both of you. Plan conversations for when they are more alert. Carry on speaking to them, hold their hand, read to them, or play their favourite music.

They may drift in and out of consciousness and may remain in this state for a long time (in rare cases many days).

Appetite and swallowing

Someone at the end of life has less need for food and drink. Offer small servings of favourite food or drink, as the effort of eating and drinking may become too much. Continue as long as they are conscious and can still swallow without coughing or spluttering.

If they have a dry mouth, you can help them by:

- Offering drink through a straw or from a teaspoon.
- Cleaning the person's mouth - use a soft, baby-sized toothbrush slowly and gently, to help keep their mouth moist and clean.
- Placing ice chips in their mouth whilst they are awake.
- Applying lip balm.

You can ask your nurse for advice on mouth care.

Breathing

As people become less active towards the end of their life, they need less oxygen. Breathing may become shallower, there may be long pauses between breaths, or they might take a deep breath - a natural response to draw more oxygen into the body.

They will be unaware of fluid gathering at the back of their throat, which may make a rattling or gurgling sound as they breathe, a bit like snoring. This doesn't mean they are in distress or need oxygen.

If breathing becomes very loud it may be that healthcare staff can help with re-positioning, or they may suggest medication to reduce fluid in their chest or throat.

Anxiety can cause their breathing rate to increase a little. Breathlessness can be frightening but sitting with them so they know you are there can help.

Pain

Some people may experience pain. There are many medications that can help manage pain or discomfort. If you think they are in pain or uncomfortable in any way, please tell a healthcare professional.

Restlessness

Some people may become restless in the last days of life. They may appear confused and not recognise familiar faces, or see or hear people or things that are not there, such as pets or people who have died. While this can be upsetting, it is not a sign that they feel differently about you. Restlessness can be caused by medication, chemical balance in the brain, or from drifting in and out of sleep.

Just sitting with the person can help to calm them down.

You can also help by:

- Speaking clearly and calmly and offering reassurance.
- Gently reminding them who you are.
- Keeping the surroundings calm with few changes in noise level and a soft light on.
- Trying not to correct them if they say something wrong, or insist on them getting things right.

Being with someone who is restless or agitated can be stressful and tiring. Take turns with another person if possible.

Agitation could also be a sign of constipation or difficulty passing urine. Ask your healthcare team if you have any concerns.

Bladder and bowel function

When someone is very ill, they may not know when they need the toilet and can pass urine or faeces without warning. Or they may get a full bladder or become constipated.

Healthcare staff will suggest appropriate padding or a catheter (a long thin tube that can be put into the person's bladder to drain urine). They can also show you how to keep their bed clean and comfortable. The amount of urine will decrease or stop, and there will be fewer bowel movements. If you are concerned about how often or not they are passing urine or faeces, please ask the healthcare team.

How someone looks and feels

The person's hands, feet, ears and nose may feel cold. The skin may also become pale, mottled and blue, or patchy and uneven in colour. Sometimes a person's hands or other body parts may swell, due to reduced circulation - this is normal.

For some, changes to metabolism can cause their breath, skin and body fluids to have a distinctive smell, similar to nail polish remover, which can be quite strong.

What happens when someone dies

When someone dies

- They will be entirely unresponsive.
- Breathing stops, but occasionally after death there may be a 'last sigh' or gurgling sound.
- Heartbeat and pulse stop.
- Their eyes will be fixed in one direction and may be open or closed.

If you are at home when the person dies

You will need to call the Community Nurses or Right Care Hub (see contact details at the end of this booklet).

They will arrange for a healthcare professional to visit you and verify the death.

If the person has an oxygen mask or nasal tube, you can turn this off and remove it. Please do not remove any other devices or turn the bed off. The community nurses will remove devices such as syringe drivers, needles or catheters. If you have an adjustable bed, you can put it flat.

If you want to move them, wipe their face and hands, or perform faith practices, you can do this. You may want to talk to them with other family or friends, or contact a faith leader.

Once a death has been verified at home you can contact a funeral director who will collect them from your home and take them to the funeral home. Funeral directors can do this at any time of the day and will have a 24-hour phone line.

The person verifying the death or the funeral director can advise you on the next steps and provide further information. Useful information can also be found on the Gov.UK website: **www.gov.uk/when-someone-dies**

If you are in a hospital or hospice

Please use the call bell and staff will support you. When you are ready to leave, speak to staff about taking the person's belongings or discuss when they could be collected.

Registering the death and further support

Staff that confirm the death will advise you of the next steps and support available to you, including bereavement support.

Useful resources and contact information

Contact information

Community Nursing Team

Find the contact number in the folder provided to you.

You may wish to record this here

If you are unable to find this, contact the Community Nursing Right Care Hub below.

Community Nursing Right Care Hub

7 days a week, 24hrs a day

Tel: **0151 514 2222 option 1**

Wirral Palliative Care Advice Line

7 days a week, 24hrs a day

Tel: **0151 343 9529 option 1**

Hospice at Home (if you are receiving their support)

7 days a week, 7.30am - 7.00pm

Tel: **0151 482 8984**

Claire House Rapid Response Team

(if you are receiving their support)

7 days a week, 24hrs a day

Tel: **07717 888 604**

Equipment returns

If you have been caring for someone at home, equipment that has been loaned to you can be returned by contacting Medequip:

Tel: **0151 203 0404**

Email: **wirral@medequip-uk.com**

Medication returns

Store any leftover medication safely until you can take it to a pharmacy to be disposed of correctly. If you cannot return medication to a pharmacy, please give it to a community nurse when they visit.

Space for your thoughts...

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Space for your thoughts continued...

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