

What to expect when someone is dying

A guide for carers, families and friends of dying people

If you are caring for someone who is in the last stages of life, or who may be soon, this booklet is for you. It is designed to help prepare you for what to expect in the very last days and hours of a person's life & what to do afterwards.

The final days of life are precious days, often remembered in detail by those who live on, and the priority is to achieve a peaceful and comfortable death with the right level of support for you and the person you are caring for.

You may wonder what the dying process involves – what actually happens in the very last days and hours of a person's life? The process is unique to every person and it is not always possible to know for sure or predict exactly when a person will die.

This is a guide only, if you are unsure about anything or symptoms are escalating please speak to a member of the nursing staff or medical team who will be able to talk to you about your concerns.

Sometimes interventions are needed to manage symptoms. If you have concerns please call the North London Hospice on: **0800 368 7848** (freephone) or your local District Nursing Service.

Changes in the last days of life

There are certain bodily changes that signify a person is likely to be close to death. It is normal that these signs can come and go over a period of days. The information below may reassure you that many of these changes are not unusual. We also suggest how you can help.

Signs a person may be dying	Is there anything I can do to help?
<p>The person may sleep more and be difficult to wake at times. They may drift in and out of consciousness and some become completely unconscious before they die.</p>	<p>They may have less energy to take part in what is happening around them but it does not necessarily mean they are no longer hearing what you say to them.</p> <p>You could let them know you are there by holding their hand, reading to them or playing their favorite music.</p>

The person's appetite is likely to be reduced and they may have difficulty swallowing. They may no longer wish to eat or drink because the effort to try is too much and they have little desire or need for food and drink. Eventually, the person will stop eating and drinking and will not be able to swallow anything including medications safely. Therefore if they cough or choke frequently please discuss this with your nurse.

It can be hard to accept this but it is a normal part of the dying and giving food or fluid artificially usually leads to more discomfort.

If they are conscious and alert enough and wish to eat or drink, you can offer sips so long as they can swallow safely. If so you can give comfort to a person with a dry mouth by offering small servings of favorite foods or drink through a straw or from a teaspoon or offer ice chips.

If they can't swallow safely you can moisten lips and apply lip balm. We try to minimise oral medications in this situation, but are able to give medications that are most important for comfort by injection. Hospice staff will explain this to you in more detail.

They may become confused about time or may not recognise familiar faces. They may become restless, pull at bed clothes, have visions of people or things that aren't there. They may develop a fixed stare.

Speak calmly. You may remind the person of the day, time and who is in the room. Simply sitting with the person may help to calm them down. Leave a soft light on in the room and keep their surroundings calm. Provide reassurance and avoid physical restrictions where possible. Even if the person cannot respond, they may be able to hear so offer reassurance.

<p>They may lose control of their bowels or bladder. This happens as muscles relax. As they eat and drink less they may have fewer bowel movements and pass less urine which may go darker.</p>	<p>You can speak to the nurses about equipment that may help such as incontinence pads or a catheter.</p>
<p>The persons skin may feel cold and change colour as their circulation slows down. Their hands or other body parts may swell a little.</p>	<p>These changes are all normal parts of the dying process. You do not need to warm them up but doing so may help you feel more comfortable.</p>
<p>The persons breathing may change and become irregular with long pauses between breathes and even stops for short periods of time. Sometimes the persons breathing may make a rattly noise. This is likely to be because they are unable to absorb or swallow the normal secretions which collect at the back of the throat.</p>	<p>There is no need to become alarmed about changes to breathing patterns. It causes no distress to the patient. The "rattly" noise does not usually make them uncomfortable as they are often unconscious. Turn the person on their side or raise the head off the bed. Sometimes medication can be given to help – ask the nurse or call the hospice.</p>

The persons final moments

Sometimes it can be difficult to identify the exact moment when someone has died. There may be one or two last gasps a minute or so after what seemed like the last breath. This can feel like a profound moment, even when death is expected. You may feel suddenly overwhelmed by emotions or you may feel calm. You may wish to be alone with your loved one or you may wish to call family and friends.

Signs that someone has died:

- Breathing stops
- Heartbeat and pulse stop
- Eyes may be open or closed
- A 'last sigh' or gurgling sound may be heard
- There is no sign of life

Try not to call 999 for an ambulance. Call your GP's surgery and a doctor will come to verify and certify the death and support you. If the GP is closed please call 111 to arrange an out of hours GP to visit to verify death. They will also remove any medical equipment from the patient. (If the patient has not been seen by a doctor in person or by video/visual consultation 28 days prior to death, the Medical Certificate of the Cause of Death (MCCD) can still be issued but the death must be referred to the coroner)

If you are uncertain what to do, please call North London Hospice on **0800 368 7848**.

You may feel shocked or numb when someone dies even if its expected. Don't feel like you have to do anything. You can just sit with the persons body for a while. You may experience different emotions at this stage. Consider contacting someone close to you for support.

You may want to help wash and clothe the person's body. At home if you contact the undertaker they will arrange to collect the body and offer advice on the next steps.

When you are ready and the death has been verified contact a funeral director of your choice. There is no rush to do this if you wish to spend some time with the person who has died. Many people sit and talk or hold the individuals hand. It's important to take care of yourself looking after your own wellbeing.

You may wish to inform the care agency, district nurse and North London Hospice.

How to register a death

Before registering a death, a doctor will need to prepare a Medical Certificate of Cause of Death after discussing it with a Medical Examiner. You will be informed as soon as this has been done but this does not usually cause any delay to funeral arrangements. The registration of death must take place at the office covering the area in which death occurred, within 5 days (unless the registrar says you can take longer than this).

The following people are able to register a death:

- A relative, usually the closest one.
- Someone who was present at the death.
- Someone who is arranging the funeral with the undertaker.

In order to register the death, the registrar will need the following information about the deceased:

- Medical certificate showing cause of death
- Date and place of death
- Full name and where applicable, maiden name
- Date and place of birth
- Full name of spouse (whether deceased or living)
- Their usual address
- Occupation (of the deceased and their husband, wife or civil partner (if applicable))
- Date of birth of their surviving husband, wife or civil partner (if applicable)

- If the deceased was getting a pension or benefits from the government

It is helpful but not essential to take the deceased's

- Birth certificate
- NHS medical card
- Passport
- Marriage or civil partnership certificate (if applicable)

The registrar will charge a fee for each copy of the death certificate. You might need several copies - for the will to be carried out, any pension claims, insurance policies etc. You may want to purchase more copies of the death certificate at this time, as the price increases considerably if you need more later on.

For more information, go to www.gov.uk/after-a-death or you can call **North London Hospice on 0800 368 7848**

Tell Us Once

This service allows you to inform local and central government services, (such as pensions, benefits etc) of the death in one go, rather than contacting them all individually. If you want to use this service please mention it when making your appointment to register the death.

Registry Contact Details

If a death takes place within the London Borough of Barnet contact:

Barnet Register Office Open: Mon-Fri, 8.30am—5pm Hendon Town Hall Sat, 9am—4pm The Burroughs, London NW9 6BG Sun, 9am-1 pm

You must make an appointment prior to visiting by calling 020 8359 6400

For cultural reasons, if you urgently need a Certificate for Burial or Cremation (green form) on a Bank Holiday, a limited service runs between 9am-10am.

In this instance, contact the out of hours team on 020 8359 2000. For more information see www.barnet.gov.uk or call 020 8359 6400

If a death takes place within the London Borough of Enfield, contact:

Enfield Register Office 020 8379 1000 1 Gentleman's Row, Mon-Fri , 9am-5pm Enfield EN2 6PS (For sat nav: EN2 6QQ)
Closed on the second Tuesday of every month from 12pm
You must make an appointment prior to visiting by calling 020 8379 1000

For cultural reasons, if you need a same day burial notice at the weekend or on a Bank Holiday, telephone 020 8379 1000. You will need a copy of the medical certificate showing cause of death from the doctor. For more information see www.enfield.gov.uk

If a death takes place within the London Borough of Haringey, contact:

Haringey Register Office 020 8489 2605

Civic Centre, Mon- Fri, 9.30am-4:30pm

High Road, Wood Green

London N22 8LE (For sat nav: N22 9SB)

Closed on the first Thursday of every month from 1pm

To avoid delays, it is recommended that you make an appointment. It is possible to walk in without an appointment, but you must arrive before 3pm and be prepared to wait.

For cultural reasons, if a weekend or Bank Holiday funeral is required, contact the out-of-hours number 020 8489 0000.

You will be given contact details for the on-call registrar.

For more information see www.haringey.gov



North London Hospice

Serving the boroughs of Barnet, Enfield and Haringey
North London Hospice, 47 Woodside Avenue, London N12 8TT

T 0800 368 7848 (Freephone)

E nlh@northlondonhospice.co.uk

www.northlondonhospice.org



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