Royal Brompton and Harefield hospitals

NHS

What to expect when someone is dying
A guide for relatives and friends

You have been given this information because your relative or friend is very unwell and may die in the coming hours or days. This information describes some of the changes that can occur when someone is at the end of their life. Please speak to the medical team if you have questions or concerns.

Recognising dying

The process of dying is different depending on the cause. It is not always possible to:

- know for certain that someone is in the last hours or days of life
- know exactly when someone will die
- know exactly what changes will occur when someone dies

We aim to provide the best information we can based on our knowledge and experience of caring for people who are very unwell.

Caring for the dying person

We aim to provide the highest possible quality of care for people at the end of life. Our care addresses the physical, emotional, social, and spiritual or religious needs and wishes of each person.

We will discuss the issues as honestly as possible, to make sure the opinions of the person (if possible) and their relatives or friends are included when planning care.

Caring for you

We recognise that this can be an upsetting and stressful situation for relatives and friends. We want you to feel supported during this difficult time.

The medical and nursing teams will aim to update you each day and welcome your views and any questions you have. Please ask them about any worries or concerns you have.

Changes that can occur

Food and drink. Close to death, appetite might be reduced and sometimes people no longer want to eat or drink. Your relative or friend will be helped to eat or drink if they want to. Nurses will offer regular mouth care to make sure their mouth and lips are kept clean and moist. They might be given food or fluids through a feeding tube, or a ‘drip’.

This will be reviewed and discussed by the medical team. The best interests and wellbeing of your relative or friend will always be at the forefront of our care.

Breathing changes. It is common for breathing to become more shallow and sometimes irregular or noisy. This might cause a rattling sound, as normal swallowing and coughing is limited. It can be upsetting to hear this change in breathing, but we believe it rarely distresses the person who is dying. Medicine can be used to help reduce this. Changing the person’s position might also help.

Restlessness and agitation. People sometimes become more restless or agitated in the last few hours or days of life. This has many possible causes, such as physical discomfort from pain, constipation or difficulty passing urine. The nursing and medical teams will monitor these symptoms closely.

Restlessness can also be caused by emotional distress. Some people find it useful to talk to a trusted professional, close friend or spiritual or religious leader.

At times the person might seem disorientated or confused. Sitting with someone and offering quiet reassurance can have a calming effect. Familiar things, soothing music, holding a hand or light massage can be of great comfort to them.

Incontinence. Loss of muscle strength can mean loss of control of the bladder or bowels. The nurses aim to keep your relative or friend clean and comfortable. Please do talk to a member of staff if you have any concerns.

Fluctuating consciousness. People are likely to spend more time sleeping at the end of life, and will often be sleepy (drowsy). They might become unresponsive and drift in and out of consciousness.

It is normal for someone who is dying to become less interested in what is going on around them, but this does not mean they no longer hear what you say to them. Do not feel that you need to stop communicating with them. Being present and speaking softly can be a great comfort to them, and to you.

Changes to the skin. The person’s skin might feel cold to touch, especially the hands, feet, ears and nose. This is due to reduced blood circulation. The skin might change colour, appearing mottled and patchy. These changes are a normal part of the dying process and are not painful.

Coming to hospital

If you need to find accommodation nearby, please ask the nurse in charge for information.

You will also be directed to refreshments and facilities that are available in the hospital.

Useful contacts

Palliative care team

If you want to speak to a specialist nurse about your relative or friend's symptoms, please ask your nurse to contact the palliative care team

Chaplaincy

If you or your loved one would like any spiritual or religious support, please ask your nurse to contact the spiritual care team. You are welcome to visit the chapel or multi-faith prayer room.

Sacred spaces

Harefield Hospital

- the Chapel: the first floor of the building opposite the main entrance, next to the Concert Hall. It is available to all at any time of the day or night.
- the new Prayer Room is halfway along the ground-floor corridor to the right of the main reception desk, on Maple Ward. It is a particularly appropriate space for Muslim prayer.
- the Sanctuary (Multi-faith Room) is halfway along the ground-floor corridor to the left of the main reception desk. The room is locked overnight, a key is available from our security team.

Royal Brompton Hospital

- the Chapel is on Sydney Wing (level 2), next to the stairs leading to the cafeteria. It is available to all at any time of the day or night.
- the Multi-faith Prayer Room is on Sydney Wing (level 2), opposite the Cashiers Office. Open 7am to 8pm. The security team can provide access to the room outside these hours.

If you need help or advice about any service or department at our hospitals, and feel unable to talk to those people responsible for your care, call the Patient Advice and Liaison Service (PALS) on 020 7349 7715 or email gstt.rbhh-pals@nhs.net. This is a confidential service.
Royal Brompton and Harefield hospitals are part of Guy's and St Thomas' NHS Foundation Trust.

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