



**Royal Berkshire**  
NHS Foundation Trust

# Communication booklet for:

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Consultant: \_\_\_\_\_

This booklet is designed to support communication for patients at the end of life, their families, carers and those important to them, and the team looking after them.

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We understand this may be very unfamiliar to you. Please let us know if there are any questions that occur to you, no matter how insignificant you think they may be, or how busy we may seem to be. We want to provide the best care we can.

Please speak to the named nurse responsible for your relative's care or request to speak with a doctor. Or if you prefer please write down any questions or queries and these will be answered as soon as possible.

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Date	Comment	Name and contact number



## Information for relatives

As the end of life approaches it can be difficult to estimate how much time is left, but this may be as short as hours or days. We will do our best to make sure that \_\_\_\_\_ is as comfortable as possible.

It can be difficult to take lots of information on board at a time like this but we will do our best to explain things to you clearly. If you have any questions or just want to talk things over with one of the doctors or nurses, let us know.

It can be a difficult time when someone you love is close to dying. Anxiety is often increased by not knowing what to expect. Although it is difficult to give exact details of how someone will die the following information describes some of the typical features of the dying process.

## How long?

This is a very difficult question to answer. There are occasions when a person who is thought to be dying lives longer than we expect, and vice versa. It is impossible to accurately predict when death may occur but certain changes take place during the days leading up to death, which may indicate that the dying process has begun.

## Reduced need for food and drink

As the body system shuts down, the desire to eat or drink becomes less important and there will come a time when food and fluids are no longer needed. The need for replacement, i.e. by a drip, is not normally necessary and the mouth can be kept clean and moist by good mouth care.

## Changes in breathing

When death is approaching, the breathing pattern may change. Sometimes there are long pauses between breaths or the breathing may become fast and shallow. As the body becomes less active, the demand for oxygen is reduced. Occasionally, a rattle or 'bubbly' noise,

caused by a build-up of mucous, may develop but does not cause the person distress. Changing their position or medication may help.

### Skin changes

The face, hands, arms and feet may become cool to touch and look blotchy or mottled. This is because there is now less blood circulating to these parts of the body.

### Withdrawing from the world

This is a gradual process. More time is spent sleeping and the person will often be drowsy when awake. This lack of interest in one's surroundings may be accompanied by feelings of tranquillity.

Eventually, the person will lapse into unconsciousness and may remain in this state for a surprisingly long time, in some cases many days. We believe people are still able to hear so do touch and talk to them. Even if the person is unable to respond, the contact will be of great comfort to you all.

### Care plan

At this time, medical treatments or investigations which are thought to be unhelpful are stopped, e.g. antibiotics or blood tests. Taking tablets and other medications usually becomes difficult as it becomes harder to swallow safely so these are stopped if not needed. Instead, the main focus of care is to keep your loved one comfortable. Sometimes a care plan is used which can help to guide ward staff in the provision of care; this includes guidance on managing symptoms, spiritual and religious considerations and identifying things which may be important to the person or family at this time.

### Managing symptoms

Medications prescribed for comfort can be given if the person is experiencing discomfort or restlessness. These are usually very effective and if required frequently, can be given by means of a small infusion, which runs slowly over 24 hours.

## Comfort

We will offer help with personal care regularly; however we recognise that it is important for you to have time and space just to be together. This is sometimes a difficult balance to achieve so please let us know if we need to do things differently for whatever reason. Feel free to share as much of the physical care as you want or if you prefer, support by spending time together, sharing memories and news of family and friends.

## Facilities

The ward welcomes 24 hour open visiting for those wishing to be with their loved one at this time. However, please consider that you may become exhausted over time and resting at home may help you cope both physically and emotionally.

We can offer meal vouchers to be used in the hospital restaurant – alternatively there are various areas around the hospital where you can obtain food, drink and provisions. For those driving to and from the hospital, we can provide a free parking permit.

## Tissue donation

Most people will already have made the decision about whether or not they would want to be an organ or tissue donor after their death. This is often done through registering on the National Organ Donor Register. The majority of people who have died are able to donate tissue up to 48 hours following their death and it may be possible for their relatives to give consent to do this. If you think that this is something that your loved one had expressed as a wish in life, please speak to a member of staff or contact a specially trained nurse from NHS Blood and Transplant, who will give you more information about tissue donation. They can be contacted via pager on 0800 432 0559. Alternatively visit <http://www.nhsbt.nhs.uk>

## Spiritual support

Everyone is an individual who during life will have experienced things that are important and meaningful to them. These may be of particular importance to your loved one and of comfort to you at this time e.g. a favourite piece of music or personal items. Your loved one may have a specific religious tradition or belief and you may want to consider support from the hospital chaplain.

The Hospital Palliative Care Team will often be involved and can give advice on managing symptoms and provide emotional support for you and your loved one. Please ask a member of the ward staff if you would like this support; alternatively they can be contacted on 0118 322 7826.

We understand this may be all very unfamiliar to you. Please let us know if there are any questions or concerns you may have, no matter how insignificant you think they may be, or how busy we may seem. We want to provide the best care we can.

## Patient Relations

Patient Relations is an impartial, confidential and friendly service that can guide you through the different services at the Trust. They can help you with on-the-spot advice and support and can give you practical information at a time when you are feeling confused and anxious. Patient Relations can be contacted on: 0118 322 8338 or ask a member of staff, the receptionists or the switchboard to contact them.

This document can be made available in other languages and formats upon request.

Please contact us on 0118 322 7826 or email [palliative.care@royalberkshire.nhs.uk](mailto:palliative.care@royalberkshire.nhs.uk)

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The care we are providing is in line with the following principles:

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Priorities for care in the last days and hours of life  
(Leadership Alliance for the Care of Dying People):

When it is thought that a person may die within the next few days or hours:

1. The possibility is recognised and communicated clearly, any decisions and actions taken are in accordance with the person's needs and wishes, and these are regularly reviewed and revised accordingly.
2. That sensitive communication takes place between staff and the patient, their family, carers and those identified as important to the patient.
3. That the patient and those identified as important are involved in decisions about treatment and care to the extent that the patient needs and wishes.
4. The needs of the patient's family and others identified as important to the patient are understood, respected and met, as far as possible.
5. That an individual plan of care, which includes nutrition, pain control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion

For more information about the Trust please visit  
[www.royalberkshire.nhs.uk](http://www.royalberkshire.nhs.uk)

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