When someone may be dying
Care in the last hours or days of life
Information for relatives and friends

Note to Staff:
Please give to the relative or friend following the discussion of the care plan. Also consider issuing “End of Life Care: The Facts”

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What is this leaflet about?

We have explained that there has been a change in the condition of your relative or friend. We believe that they may now be dying and in the last hours or days of life.

This leaflet provides key information about the changes you may see in someone who is dying and our commitments to you at this difficult time.

We aim to give the highest quality of care to patients who are at the end of their life. We encourage you to be involved in discussions so that you can understand the reasons why care decisions are being made.

Every person is unique and the dying process is sometimes unpredictable. If your relative or friend’s condition improves then we will review and change the plan of care appropriately.

All care will be reviewed regularly by the medical and nursing staff. If, after a discussion with the doctors and nurses, you do not agree with any decisions we make, you can ask for a second opinion.
Communication

We have provided this leaflet, as we know that it is sometimes difficult to remember everything that is said. We hope you find the information helpful. There is space near the end of this leaflet for any notes or questions you want to write down.

Keeping everyone updated is our priority. The ward should hold telephone numbers of nominated relatives or friends and it be agreed how and when we should contact them.

Care of those who may be dying is very important to us and we only have one opportunity to get it right. Please do not hesitate to ask any questions that occur to you in the coming hours or days, no matter how insignificant you think these may be or how busy the staff may seem. Everything may be very unfamiliar to you and we are here to explain, support, and care.
Medication

Medicine that is not helpful at this time may be stopped and new medicines may be prescribed. Medicines for symptom control will only be given when needed and at the right time. To keep side effects at a minimum, the smallest dose possible to help the symptom will be used. Medicines are often given by injection and use of a pump called a syringe driver may also be suggested. If a syringe driver is required, we will explain this to you.

Care and comfort

We will make sure that any care needs of your relative or friend are met at this time. Please let us know if, for whatever reason, you feel those needs are not being met.

You can support care in important ways such as spending time with your relative or friend, sharing memories and news, or even assisting in care should you wish to do so.
Understanding the changes that may occur before death

The time from the recognition of dying to the time of death is very difficult to predict. It may be a matter of hours or days or even longer. You may have anticipated this news for some time now or this may be very new to you. Even when the person who may be dying is settled and comfortable, it can be difficult for their relatives and friends to watch and be around them at this time.

Dying patients often spend increasing time sleeping and will often be drowsy. Eventually they may lapse into unconsciousness, and may remain this way for a surprisingly long time. When death is very close, there may be changes to breathing, skin colour, and temperature. Please speak to us if you are concerned.
Reduced need for food and drink

Good mouth care is important at this time to keep your relative or friend’s mouth clean and comfortable. We will explain to you how we provide mouth care and may ask you if you would like to help give this care.

Loss of interest in and reduced need for food and drink is part of the normal dying process. When a person stops eating and drinking this can be hard to accept, even when we know that they are dying. They will be supported to eat and drink for as long as possible.

If they cannot take fluids by mouth, fluids given by a drip may occasionally be used. Fluids given by a drip will only be given where it is considered helpful and not harmful. This decision will be explained to you and, if possible, to the dying person.

The Last Days of Life Documentation

Care of the dying person is supported by the ‘Last Days of Life Documentation’. This ensures the care is individualised and is focussed on relieving their symptoms, maintaining comfort and meeting their physical, psychological, social and spiritual needs. Our aim is that the dying are peaceful and comfortable at the end of their life, and that any relatives and friends are well supported.
Comfort Packs

If your relative or friend is in hospital, comfort packs are available on each ward and include essential supplies that can help make your own stay more comfortable. Please ask us for one.
Our commitment

We will:

- clearly identify the doctors and nurses responsible for caring for your relative or friend
- identify those people that the patient wishes for us to share information with and those to be involved in discussions about care
- ensure you have the opportunity to discuss, should you wish, the medical condition, the treatment options available, and your preferences about the care your relative/friend receives
- communicate with you regularly
- listen carefully to your comments and concerns
- regularly assess your relative or friend to ensure that comfort and dignity are maintained
- endeavour that any prescribed medication is:
  - reviewed regularly
  - prescribed promptly to ensure good symptom control
  - given in the smallest doses appropriate for the symptoms, and only for as long as the patient needs it
• where appropriate seek advice from the Specialist Palliative Care Team – sometimes known as the Macmillan Team

• if your relative or friend is able to swallow safely, they will be supported to eat and drink

• ensure that, if your relative or friend is not able to eat and drink, the medical team have discussed whether giving fluids via a drip would be helpful or harmful

• provide emotional and practical support to the patient’s friends and family

• respect and seek to meet any cultural, spiritual and faith requirements of your relative or friend

• if wished, contact the chaplaincy team to offer or suggest ways emotional/listening/spiritual support can be given to you/your loved one during this time. You don’t have to ‘be religious’ to be offered this support. (You can, if you wish contact chaplaincy direct through the numbers at the end of the booklet)
Space for your notes

Please use this space below to list any questions you may want to ask the doctors and nurses:
Further information and support

If you feel you need extra support or would benefit from further discussion, please do not hesitate to speak to one of the following people:

If your relative or friend is in Hospital:
- A member of the ward Nursing or Medical team

If your relative or friend is at Home:
- The GP
- District Nursing team

Contacting the Chaplaincy Team

If you would like to contact the hospital chaplaincy team direct with a **non-urgent** message, you can call them on:
York Hospital  01904 725579 or 01904 725678
Scarborough Hospital  01723 342500

An answer machine is available for you to leave a message

If you need to call the hospital chaplaincy team urgently, please ask a member of staff to bleep the on call chaplain, or contact switchboard (see information overleaf).
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Contact Information

The Hospital Switchboards:

Scarborough Hospital  Tel: 01723 368111

The York Hospital  Tel: 01904 631313

York Hospital Specialist Palliative Care Team  Tel: 01904 725835

York Community Specialist Palliative Care Team  Tel: 01904 724476

Scarborough Hospital Specialist Palliative Care Team  Tel: 01723 342446

St Catherine’s Community Specialist Palliative Care Team, Scarborough  Tel: 01723 356043

Ward Contact No.:

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Other Information or Contact Numbers:

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Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact: York Hospital Palliative Care Team, The York Hospital, Wigginton Road, York, YO31 8HE, or telephone 01904 725835.

Teaching, training and research

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

Patient Advice and Liaison Service (PALS)

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email pals@york.nhs.uk.

An answer phone is available out of hours.