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**Patient Information**

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# Information

If you need this information in large print, easy read, on audiotape or in another language please call 0800 7838058 or e-mail [pals@dchft.nhs.uk](mailto:pals@dchft.nhs.uk)

If you wish to obtain a list of the sources used to develop this information leaflet please call 0800 7838058 or e-mail [patient.info@dchft.nhs.uk](mailto:patient.info@dchft.nhs.uk)

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## Information for relatives and friends of those approaching end of life

This leaflet is designed to ensure you are fully informed about the care of your family member or friend towards the end of their life.

It is likely that you have recently spoken with a doctor and /or nurse who feel that your family member or friend is in the last hours or days of life.

Whilst the end of life is often viewed as an extremely difficult time for those involved, it is also a very important part of life and needs careful planning and care delivery to ensure the experience is as comfortable as possible for all those involved.

### Communication

The key to good end of life care is effective communication between all those involved, including the patient, family, friends, doctors, nurses, and other professionals. As with any situation, when people know what is happening and have an opportunity to talk, they feel more in control and comfortable with the situation. Along with discussions between people about the care of someone approaching the end of life, it is helpful to have a written plan of care so that everyone involved can be kept informed of the current situation, ensuring things don't get missed and that care is consistent. This written plan is called "Achieving Priorities of Care". Please feel free to read the document at any time and ask a member of staff if there is anything that you don't understand or that concerns you.

In order that we can keep you as up to date with the care as possible, it is vital that we have the correct contact telephone numbers and information on when you are happy for us to contact you. Please ensure the ward nurses have this information now.

### Comfort and Medications

As people approach the end of their life, they sometimes require extra medication to help manage any unpleasant symptoms they are experiencing. These symptoms might include pain, nausea, restlessness, agitation and confusion.

The nurses will administer appropriate medications and assess how well they work, giving different doses or more frequently to achieve the best response. Medications can be given in a number of ways including medicines, tablets, injections and syringe driver devices depending on the needs of the patient. It is also likely that many medications your family member or friend has been on, maybe for a number of years will be stopped at this stage as they will not be of benefit and maybe difficult to take. If you think your family member or friend is experiencing any unpleasant symptoms, or you are concerned about any medications being omitted please talk to the nurse or doctor so they can come and address the problem.

Spending time with your family member or friend is important to both of you / all of you so please talk to the nurses about visiting arrangements and any worries or concerns you have about this.

Your family member or friend may feel very tired at this stage in their life, so try not to be concerned if they sleep more and do not join in so much with conversations. It is likely that your presence with them and gentle conversation will be comforting to them.

## **Minimising interventions**

When someone is in the last hours/days of life, it is important that we do not cause them unnecessary disturbance or distress. As part of the care planning process, the doctors and nurses will decide which interventions are essential and which can be stopped. For example, it is unlikely that your family member or friend will require things like blood tests, blood pressure and temperature but important that their position is changed periodically to ensure they do not develop sore skin.

## **Reduced need for food and drink**

People approaching the end of life are supported to eat and drink for as long as they wish. However, as time goes on, their need for food and drink reduces. This can be of particular concern to family and friends but please be assured this is normal and struggling to make or encourage people to eat and drink at this time can be distressing for them. Food will be made available if they want it. If your friend or relative's mouth seems dry or they tell you they are thirsty, providing a drink to sip through a straw or beaker or using a sponge stick soaked in water may provide comfort to them.

If your friend or relative has difficulty swallowing (dysphagia) a speech and language therapist may work with them and with you to develop compensatory strategies (which may include modified diet and/or fluids) that will allow them to eat orally for as long as possible.

In some cases, a drip may be used to provide fluids which the doctor will explain to you although this is not common.

## **Your involvement in the care of your relative/friend**

As an important person to your family member or friend who is approaching the end of their life, we would encourage you to be involved in their care. Please talk to the nurses about how much you would like to be involved.

Being involved in the care of your relative or friend as they approach the end of their life is important to us. We want to make this important time of theirs lives as comfortable and peaceful as possible for them and also support you at this difficult time.

Please talk to the nurses or doctors if there is anything you are concerned about regarding the care of your relative/ friend.

## **Staff caring for your relative/friend**

There are likely to be a number of doctors and nurses caring for your relative or friend. We will endeavour to ensure the same staff are involved where possible as this promotes continuity of care for both you and your relative/friend. However this is not always possible. The nurse responsible for the care of you relative should introduce themselves to you early in on their shift. However, if you are unsure who is in charge, please speak with a member of staff.

## **How to contact us**

You can telephone the ward at any time of day or night. The contact numbers are

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## **Your feedback**

We appreciate you are likely to be feeling very sad and emotional at this significant time; however your feedback on the care that we provide is very important to us.

We would therefore be very grateful if you would take a few moments to complete the questions overleaf and provide any comments that you have regarding this time.

Thank you.



**Please complete the questions as well as you can and hand to a member of staff.**

**Please add any comments on the back of this page.**

1. Did you feel fully informed about the care of your family member/ friend throughout this time?

*Yes / No*

2. Did you feel the doctors and/or nurses attended to the needs of your relative friend effectively?

*Yes / No*

3. Did you feel the doctors and/or nurses attended to the needs of your relative friend quickly enough?

*Yes / No*

4. Did you feel you were included in discussions regarding the care of your relative/ friend?

*Yes / No*

5. Did you feel you could approach the nurses/ doctors freely?

*Yes / No*

6. Did you feel listened to?

*Yes / No*

7. In your opinion, did you think your friend or relative was comfortable and not distressed most of the time?

*Yes / No*

8. Did you feel comfortable that your relative/ friend died in hospital?

*Yes / No*

9. Is there anything that we could have done better?

10. Is there anything that we did particularly well?

**Thank you for taking the time to share your experience with us.**

