

Patient Information Leaflet

Cancer

Title: **Palliative & End of Life Care at Milton Keynes University Hospital**



As a teaching hospital, we conduct education and research to improve healthcare for our patients. During your visit students may be involved in your care, or you may be asked to participate in a clinical trial. Please speak to your doctor or nurse if you have any concerns.

Chief Executive: Joe Harrison
Chair: Alison Davis

You have been given this leaflet to help you understand the changes that happen with your loved one, when coming towards the end of their life.

The dying process is individual to every person and every person will be treated with their best interests in mind.

This leaflet may have content that might be difficult to read, it uses clear and sometimes explicit words to explain what intervention to expect for the dying person and those who are important to them.

What is Palliative Care?

Palliative Care is the care of patients with life-limiting illnesses, irrespective of diagnosis or disease. The purpose of Palliative Care is to achieve the best quality of life for patients and families. This might be over a period of days, weeks, or months and sometimes years.

What is End of Life Care?

The term 'end of life' refers to someone who is in the last few days or weeks of life, where there is no treatment available to reverse any complications or there is no medical intervention that will change the outcome for the dying person.

Milton Keynes University Hospital takes pride in working together with medical teams, specialist teams and services outside of the hospital, providing a high standard of End of Life care for the community of Milton Keynes.

If you are unsure about the contents of this leaflet, or what is happening to your loved one, please ask a member of the ward team.

The staff are here to help you and want to deliver the best care for their patients.

The Palliative & End of Life Care Team will:

- Give advice about symptom control including advising on drug and non-drug treatment.
- Support with any changes in the dying person's condition and help with difficult decision-making.
- Provide emotional support for you and those important to you in order to help manage your loved one's deterioration.
- Discuss holistic needs including religious, Spiritual, and cultural aspects of care. Offer Chaplaincy services for people of any faith or none.
- Offer the opportunity to have honest, clear conversations regarding the stages of dying, what happens at the point of death and after the death has occurred.

The Palliative & End of Life Team strives to put the patient's best interests at the heart of any decision making. This may include involvement of people who are important to the patient, their family, carers, and clinical staff.

Milton Keynes University Hospital uses a system called eCARE to record patient data. Those patients deemed End of Life, will have a specific care plan called the 'End of Life Care Plan' which is initiated by the Doctors. This document supports guiding clinicians into good decision-making and is reviewed regularly by the Palliative & End of Life team and/or the ward team.

Nurses document their care intervention every four hours, including mouth care, symptom assessment and ongoing support.

End Of Life Care sign and symbol:

We have dedicated purple signs with two hands holding as a symbol which can be displayed on a side room door or pegged to curtains if patient is in a bay to highlight with wider team members that patient is at End Of Life to ensure additional awareness, sensitivity and care is in place.

There are common changes which usually indicate that a person is dying.

These can include:

- More sleepy, less wakeful periods
- Wishing to be cared for in bed
- Less need for food and fluid
- Swallowing becoming less effective
- Colour of the skin can change
- Sometimes there may be secretions in the chest that make a bubbly noise and breathing may change.

Very occasionally, patients who are thought to be dying can improve. Should this happen, your loved one will be re-assessed and managed appropriately for their needs.

Even if your loved one is unable to respond, they may still be able to hear you and know you're there. It can help to speak to them, play their favourite music, and let them know what you're doing, especially if you're touching them or giving care. This may feel strange as they cannot respond, but it can be comforting for both of you.

If you would like to be part of the care for your loved one, the ward will guide and support you in this.

To give you extra privacy at this difficult time, ward staff will try to arrange for your loved one to be nursed in a side room, if this is your wish. However, sometimes this is not always possible. If a

side room is not available or it is your wish for your loved one to remain in the main ward area, please close the curtains, if that helps you feel more comfortable.

Visitors are able to arrange to spend time with their loved one, through arranging this directly with the ward; however, it is encouraged to keep numbers to a small amount. Should you wish to stay overnight; the ward can supply you with a mattress or comfy chair and bed linen. Please feel free to bring in your own comforts e.g., pillows, music, pictures, or anything else that makes this difficult time as normal as possible.

On the ward there is a 'comfort kit' that is available to make your experience as comfortable as possible.

Care after Death

For some people of certain religions, particularly those of Muslim or Jewish faith, it is important to be buried as soon as possible after death. If this, is you or your loved one, please let the ward doctors know as soon as possible as this will allow us to try to accommodate this.

There may be questions that you might think of and have not been addressed in this leaflet, such as 'How long do we have? What will dying look like? and Should I be here when death happens? If there are any questions that you have, that might feel sensitive or emotional, **please talk with the ward team or The Palliative Team.**

Please ensure that the ward have your correct contact number with times when you wish to be contacted.

Please ensure that the ward see any important documents associated with your loved ones wishes and needs at this time.

Advance Care Plan

Lasting Power of Attorney

Advanced Directive

PACT document

If you have any concerns or comments about your loved one or the treatment that they are receiving please raise this with the ward staff in the first instance. You can also speak with the Palliative End of Life Team.

The **Palliative and End of Life Care Team** are available:

Monday – Friday between **8:00am and 4:00pm**

Weekends between **8:00am – 4:00pm**

They can also be contacted via the ward staff

Palliative Care Team: 01908 996 553
answer machine service available out of hours

Milton Keynes University Hospital Bereavement Team: 01908 996155

Details regarding Registering the death of your loved one will be available in the Bereavement Pack you will receive from the Bereavement Team

Samaritans: 116 123 or email: jo@samaritans.org response provided within 24hrs

MIND: 0300 123 3393 text 86463

We are constantly working to improve our service

Your feedback is welcome on anything that has been good during your care and any areas that you feel need improving.

Please use the QR code to access our online survey or complete the attached comments form and return to the manager of the ward.