

Care at the End of Life – A leaflet for families and friends

Please be aware that this is updated advice during the COVID-19 outbreak

Introduction

This leaflet is for the family and for close friends of someone who is nearing the end of their life in hospital. It includes information on how the person who is dying will be cared for and how you, their family and friends will be supported.

All our staff are committed to providing the best possible care to the person who is dying, respecting their privacy, dignity, choices and confidentiality.

Visiting

At East Sussex Healthcare NHS Trust we have always tried to support patients nearing end of life to be with their family or friends, if this is their wish. We know that this is precious time. However we are currently living in exceptional circumstances. We will continue to support visiting where possible for patients nearing end of life, but ask that this is now reduced to one family member (or friend) each day. We ask that you confirm visiting arrangements with the relevant Ward Matron.

There may be times when visiting will need to be suspended for safety reasons. We know that this will be so hard for so many families. We know that this decision brings great responsibility, but our staff will care for your loved one with compassion and respect at all times. Our staff will be with your loved one for you. We will share your messages and we will do our very best to support you to communicate and be with your loved one through virtual visiting on mobile devices.

Sometimes a person can deteriorate unexpectedly. The ward staff will do their best to contact you, day or night, if that is your wish.

The Last Days of Life

When a person is dying it is important that we focus our care on their comfort and dignity. The doctors and nurses will assess the individual needs of the dying person and identify the main priorities for their care, ensuring they are supported and kept comfortable. It is difficult to predict exactly what will happen or how fast a person will deteriorate, but the needs of the dying person will be reviewed regularly.

In the last days the dying person is likely to become weaker, sleep more and require extra care from nursing staff. Their need for food and fluids can reduce. Fluids given in a drip may no longer be appropriate as this may increase symptoms. Moistening lips and regular mouth care can maintain comfort for the dying person.

What should I do before I come into hospital?

Where will the procedure take place?

The person who is dying may no longer be able to take their tablets. If they require medication to keep them comfortable, then it can be given by injection or through a small pump known as a syringe driver.

Sometimes a person's breathing changes as their condition deteriorates. Occasionally their breathing can become noisy. This is usually not distressing to the person who is dying, but changing their position or giving medication might help.

For most people, the final moments of life are peaceful, with a gradual slowing and irregularity of breathing before it ceases.

What Can you do to Help?

Please do let the nursing staff know what is important to your loved one. If possible share a special picture or verse or words of comfort with the staff.

You can send a personal message using a dedicated email: esht.patientmailbox@nhs.net

If your loved one has a smart phone please ensure they have the charger and let the ward team know so that they can support you with keeping in touch. We will also try to support you with keeping in touch with 'virtual visiting', using an iPad to make a video call. Please ask the ward team for more information.

When a Person Dies

If you have not been able to visit due to visiting restrictions or because you are in self isolation, the doctor or nurse will contact you by telephone. If you do not wish to be contacted in the night, please do let the ward team know this. After a short while a member of the hospital team will verify that the person has died. The nursing staff will then attend to the personal needs of the person who has died, before they are transferred to the hospital mortuary.

Unfortunately during this COVID-19 outbreak it will not be possible to support a visit to see your loved one after they have died, through the Bereavement Office. Please check with your Funeral Director if a visit will be possible, but please be aware that guidance from Public Health England may change. You will be asked to ring the Bereavement Office after 10am on the first working day following the death, when a Bereavement Officer will give you advice and support about the next practical steps to be taken regarding registration and funeral arrangements.

Funeral Directors can be contacted immediately following a death, who will support and advise you of their own procedural arrangements during this time. During this COVID-19 outbreak the death registration procedure has changed to keep everyone safe. The Bereavement Office will electronically send the Medical Certificate completed by the doctor to the East Sussex Registration Service.

After you have been advised to do so by a Bereavement Officer, ring the central Registry Office number on 0345 6080198 to make an appointment to register the death. You will not be attending in person but a Registrar will call you to complete this by phone and the

Death Certificates will be posted to you. When you ring for the appointment the Registrar will guide you through this process in more detail. Unfortunately during this COVID-19 outbreak families are not being invited in to the hospital to see a Bereavement Officer; however they will help and support you in any way they can on the phone following the death of your loved one.

This is an extremely difficult and anxious time so please do not hesitate to contact the service with any questions or concerns you may have. If we are unable to answer anything, the correct information or person will be found for you whenever possible.

Helpful contacts

- The ward team Tel: 0300 131 4500 hospital switchboard and then ask for the relevant ward
- Hospital Chaplaincy Team
Tel: 0300 131 4500 hospital switchboard and ask for the Duty Chaplain
- Supportive and Palliative Care Team:
Tel: EDGH 07813430421
Tel: Conquest 07788415014
- Bereavement Office:
Tel: 0300 131 4500 hospital switchboard and ask for the office at the relevant hospital.

Your comments

We are always interested to hear your views about our leaflets. If you have any comments, please contact the Patient Experience Team – Tel: 0300 131 4731 (direct dial) or by email at: esh-tr.patientexperience@nhs.net

Hand hygiene

The Trust is committed to maintaining a clean, safe environment. Hand hygiene is very important in controlling infection. Alcohol gel is widely available at the patient bedside for staff use and at the entrance of each clinical area for visitors to clean their hands before and after entering.

Other formats

If you require any of the Trust leaflets in alternative formats, such as large print or alternative languages, please contact the Equality and Human Rights Department.

Tel: 0300 131 4434 Email: esh-tr.AccessibleInformation@nhs.net

After reading this information are there any questions you would like to ask? Please list below and ask your nurse or doctor.

Reference

The following clinicians have been consulted and agreed this patient information:
Jayne Winter (Macmillan Lead Nurse Supportive and Palliative Care Team)

The directorate group that have agreed this patient information leaflet:

Macmillan Lead Nurse Supportive and Palliative Care Team

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