

What to Expect when somebody close to you dies



Guidance to support health professionals give the right information at the right time

Cheshire and Merseyside
Palliative and End Of Life Care Network

Experiencing the death of a loved one can affect every aspect of a person's life and well-being, and can have far-reaching implications in the immediate period following death and long into the future. It is often a time of great uncertainty and confusion, particularly in the hospital setting, where there is a vital need for clear, sensitive communication and support to ease distress.

The Cheshire and Merseyside Palliative and End of Life Care Network asked bereaved relatives about their experience before and after the death of their loved one. They said having more information on what to expect as their loved one deteriorated and died would have helped. This guidance has been developed in response to their feedback and aims to support staff in acute hospitals to provide the essential information for patients and their families in a timely and pro-active way. This project is the work of the People's Voice subgroup, a group of dedicated and valued patient and carer representatives, who devoted their time, passion and enthusiasm to share their own experiences of losing a loved one in the hospital setting, both positive and negative, to underpin the development of this guidance.

As health care professionals, we may feel we understand the needs of our patients and their families and carers in the last few days of life. What we have learnt most from this workshop is that the little things matter the most in providing comfort, reassurance and practical support. Some kind words of understanding, a willingness to help and even just a few minutes of our time can make all the difference to a carer's experience, which they carry on in their memories, even years after their loss. The breadth of questions and thoughts that pass through the mind can be overwhelming – emotional, spiritual at times, but often very practical concerns that we may not consider. The guidance is therefore divided into three sections – the face to face conversations that carers expect when death is approaching and into bereavement, the facilities available in hospital to support them, and the written information provided for them to read, share and discuss at a later time.

Timing of information is crucial, and the feeling of the group was that we are often late in our offers of explanations and written information. Preparation is key to reducing the fear of watching a loved one die, and therefore communication about what to expect when somebody close to you dies should start at the point of recognition of dying. The group therefore considered what information and services should be offered before death, at the time of death on the ward, and then afterwards during a visit to the bereavement office.

We hope you will find this guidance of value in developing your services.

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On behalf of the

Transform Acute Hospitals and **People's Voice** subgroups of the Cheshire and Merseyside Palliative and End of Life Care Network.

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WRITTEN INFORMATION: *To help relatives know what to expect*

Easy to read and in plain English; simple wording; avoiding medical terminology; sensitive but clear language and explanations; clear reference to specific timeframes.

Written information should include what to expect:

Before death

- Likely conditional changes as death approaches - conscious level, breathing, skin and circulation
- Possible symptoms and signs of distress and how they will be managed
- Food and drink in the last hours/ days of life
- Information on syringe drivers and medications
- Information on organ and tissue donation/ post mortem/ coroner referral if likely/ requested
- Chaplaincy contact details
- Information on facilities for carers (see below)
- Information on talking to children about dying
- Site map
- Information on Trust facilities

At time of death

- Contact numbers and opening hours for the bereavement office and how to make appointment
- Written Information on obtaining the Medical Certificate of Cause of Death (MCCD)
- List of funeral directors if required and advice on choosing one/potential costs/ financial assistance
- Organ and tissue donation leaflet if appropriate
- Post mortem/ coroner information if required
- Contact details for the ward if there are questions/ concerns
- Chaplaincy contact details

After death

- Grief reactions and how to cope – normal vs abnormal grief reactions and when to seek help
- Signposting to bereavement counselling (local or national services) if required
- Information about who to inform and ‘tell us once’ services
- Post mortem/ coroner information
- Information on talking to children about dying
- How to make complaints/compliments
- **Avoid sending generic ‘friends and family’ survey to bereaved families**
- Forewarn of the possibility of bespoke hospital bereavement survey
- Trust condolence cards

FACILITIES/SERVICES: *To help relatives/carers have an improved experience*

Provision of quiet, private areas on the ward for carers/ families of dying patients and the recently bereaved; manage expectations of families – busy environment and staff, some noise is expected;

Before death

- Side room if possible and desired
- Quiet space/ relative room – preferably off ward
- Washing facilities
- Showering facilities
- Sleeping facilities – in relatives room or in patient's room if desired
- Advice on overnight accommodation elsewhere
- Mobile phones – permissions to use; advice on where to charge; emergency chargers available on request
- Car parking – free if possible or reduced rate passes; advice on locations to park out of hours
- Chaplaincy/ spiritual support room and service
- Volunteer service to support if needed
- Carer's food and drink – advice on what's available on ward or in hospital, rules re takeaways
- Visiting times

At time of death

- Bereavement bag for patient belongings
- Bereavement symbol on ward to ensure awareness that a patient has recently died
- Volunteer service to support if required
- Free car park pass to leave hospital

After death

- Bereavement office away from ward areas (avoids carers returning to ward areas)
- Appointment system for bereavement office
- Dedicated free bereavement office parking
- Clear signposting to bereavement office from within and outside hospital
- Non-clinical visiting facilities (see attached)
- Trained staff available to support visits
- Signposting to bereavement counselling if required

FACE TO FACE COMMUNICATION: To help relatives understand what to expect

Staff should be experienced and trained in appropriate communication skills; staff should avoid using medical terminology; ensure information is understood; give written information to disseminate to other carers; offer further opportunities to discuss

Verbal information should include what to expect:

Before death

- Current clinical condition and likely physical changes including timeframes and plan for review
- Likely symptoms and possible signs of distress and how will be managed
- Patient and carer preferences for care (e.g. Advance Care Plan) and facilities available for carers
- Clarification of nominated carer contact details and plan for contact at time of death if absent (by phone/ in person)
- Plan for hydration and nutrition in the last hours and days of life
- Managing fear/ distress/ spiritual needs
- How carers can help to care for their loved one
 - Comfort measures – touch, hearing, environment
 - Moving positions
 - Mouth care, food and drink
- Explanation of medications and syringe drivers if appropriate
- Cultural/ religious needs at the time of death; advice re clothing, jewellery
- Potential for post-mortem/ coroner referral if appropriate

At time of death

- Proactive sensitive discussion and explanations of immediate steps to be taken (if appropriate)
 - Last offices (including offer for carer to help if desired)
 - How long carers can (or should) stay with their loved one until transfer to mortuary
 - Removal and collection of jewellery and personal belongings
 - Clothing required for funeral directors
 - Process of verification
 - Process of transfer to mortuary
- Need for post mortem/ coroner referral if appropriate
- Organ/ tissue donation process if appropriate
- Advice on issue and collection of the Medical Certificate of Cause of Death (MCCD) including timeframes
- Advice on visiting the body in the mortuary
- Advice on bereavement office processes
- Offer of further clinical discussion if questions/ concerns

After death

- Proactive contact regarding delays to issue of the Medical Certificate of Cause of Death
- Proactive offer of clinical discussion if on-going questions/ concerns
- How to register the death
- Signposting to bereavement counselling if required
- Post mortem/ coroner information if appropriate
- Forewarn of hospital bereavement survey