



Opening the door to improved outcomes

Improved health and wellbeing through collaborative working across
Cheshire, Merseyside, Lancashire & South Cumbria

Clinical Advisory Forum

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Bereavement Specification

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Background

- Network commissioned Care of the Dying Evaluation (CODE)
- National Care of the Dying Audit
 - Majority of people will die in acute setting
 - Huge variation in experience and facilities
 - Information often lacking

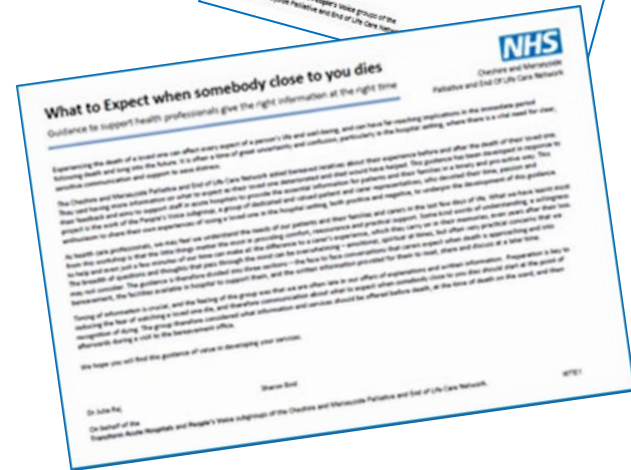


Background

- Hospital Transform Group – transforming palliative and end of life care in Acute Trusts
 - The experts
- People's Voice Group
 - The real experts
- Focus workshops December 2016
- Bereaved relatives survey
- Websites and information leaflets

Process

- Development of two standards:
 - Dual Standard Bereavement Specification (B1)
 - What to expect when someone close to you is dying (WTE1)



What to Expect when someone close to you is dying

- Information - too little, too late
- Over-reliance on impersonal information leaflets
- A lack of explanation of the normal dying process
- Challenges of disseminating information to wider family

What to expect

- 3 sections:
 - Face to face discussion
 - Written information – for wider family and to refer back to
 - Facilities

- 3 time frames:
 - as death approaches
 - at the time of death
 - afterwards

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

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

Bereavement Specification

- Recognises the challenges faced by hospitals
- Minimum standard vs Gold standard
 - Websites and resources
 - Advice and signposting
 - Facilities
 - Mortuary processes
 - Education and training for staff

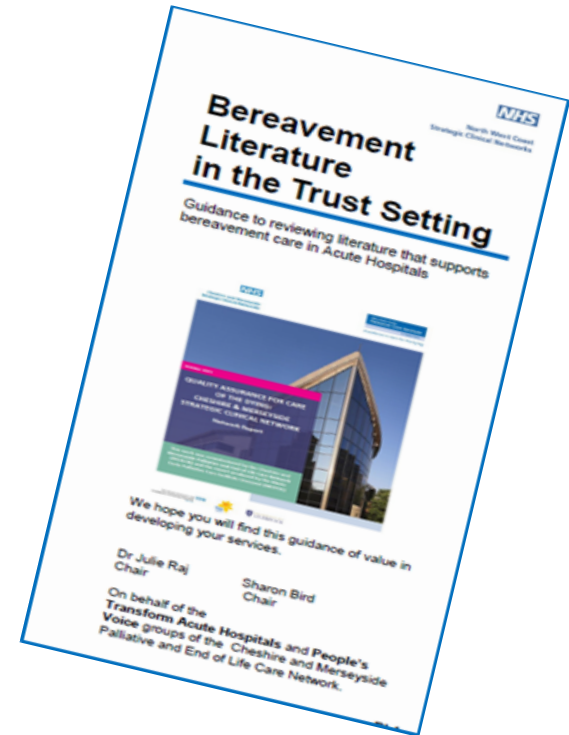
Bereavement Specification

- Making the processes as straightforward as possible – one stop where possible
- Proactive in explaining processes and delays
- The little touches matter
- Bereavement feedback

- Our bereaved carers are our patients of the future

Follow Up

- People's Voice, through subsequent workshops, developed some recommendations for bereavement literature
- Ratified by both the Hospital Transform and the Education Strategy Network Groups
- To be used in conjunction with the bereavement and WTE standards



Resources

- Dual standard bereavement specification (B1)
- What to expect when someone close to you is dying (WTE1)
- Bereavement literature recommendations (BL1)
- Network CODE report

Where to find resources:

There is a resource pack for every attendee and further copies can be requested from the NWC Network:

Kathryn.davies16@nhs.net

Or download from the Palliative and End of Life Care section of www.nwscnsentate.nhs.uk

What we hope to achieve

- All Trusts within Cheshire & Merseyside to review their audit findings and bereavement services and implement some service improvements using the Network recommended guidance
- Share best practice across the North West Coast
- Ensure palliative and end of life care blah

Any Questions

