Important things to remember:

- Any leaflet should only be used as an accompaniment to a face to face conversation in a private area or quiet room by a competent member of staff.
- Ideally the Nurse In Charge should be proactive at the start of each day in identifying any patients who are at end of life and appoint a named member of staff who will take responsibility for talking to the family and giving the appropriate level of information as required at the appropriate time.
- To be used in conjunction with the dual standard Bereavement Specification (B1) and 'What to expect when someone is dying' (WTE1)

Points to consider when developing your leaflet:

- Ensure public consultation;
- Make the font size easy to read and use plain and clear language; no acronyms;
- Ensure leaflet is accessible for all abilities: www.abilitynet.org.uk for more tips
- Use bullet points or flow chart format for an easy guide to follow;
- Avoid unnecessary wasted space;
- Be consistent when considering who the information is written for; don't switch from carer to patient to professional perspective mid-document.
- Include information on bereavement survey if the Trust has one

People's Voice consider it important for three levels of information be available, as guided by the family or by the circumstances:

- Level One may be used in expected deaths where the family requires this information
- Level Two will be a requirement in all deaths
- Level Three will be for anyone who requires further detailed information.

Despite a national drive to support more patients to die in their own home, in reality the many of the population will spend their final weeks, days and hours of life in a hospital setting. A few may express a preference to remain in hospital at the end of their life, but for many dying in hospital comes at the end of a period of acute illness and sometimes intensive treatment.

It is often a time of great uncertainty, emotion and fear for many families and carers. We therefore have an essential duty to provide timely, proactive information, facilities and support, and ensure our bereavement services make this period of transition and distress as smooth as possible.

Timely access to information and resources is essential and many bereaved relatives expressed a wish that staff had been more proactive in exploring end of life and bereavement wishes, and offered information prior to death to help them better prepare.

The Network Transforming End of Life Care in Acute Hospitals Group and the People's Voice Group, worked closely together to produce this guidance, ensuring the views of bereaved relatives were at its core. People's Voice held a focus group to make some recommendations on the information that should be included.

Other resources available:

- Network recommended Bereavement Specification (B1)
- Network recommended 'What to Expect' specification (WTE1)

This guidance should be used in conjunction with B1 and WTE1



North West Coast Strategic Clinical Networks

Bereavement Literature in the Trust setting

Guidance to reviewing literature that supports bereavement care in Acute Hospitals



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

Dr Julie Raj Sharon Bird Chair Chair

On behalf of the

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

Level One: Days/hours before death Information relevant to those days/hours before death (**Optional**: as guided by the relatives, or by the circumstances of illness/death)

Explain About:

Why the patient is thought to be at the end of their life

Any expected medical changes i.e. breathing/ skin/consciousness/agitation

Visiting when end of life is near (is it unlimited?) **Ask about:**

Observing any religious or cultural customs prior to death

Prompts to guide conversations relatives may like to have:

Does the patient:

- ♦ Have an Advance Care Plan (ACP)?
- Have an advance decision to refuse treatment (ADRT)?

Do you know:

- Their preferences and wishes?
- If they would like to wear their jewellery?
- What they would like for their funeral?
- A Have they made a will?
- Do they carry a donor card?

Practical processes

ONLY IF THE FAMILY AGREE

- Collection of the *MCCD and why there may be delays (e.g. Post-mortem)
- Mortuary information
- Registering the death
- Oremation/burial papers
- Collection of remains

Refer to Level Two for details to include

Pastoral support / multi-faith prayer room Advice on bereavement counselling services; include common feelings experienced

Ensure that all departments are **clearly** marked on a hospital site map. Include opening times, contact names, telephone numbers and how to make an appointment (include in Level Two)

Level Two: Bereavement leaflet Summary of information necessary soon after death

Detailed information regarding the cause of death and events at point of death - e.g. exact times, people present .

Advice on arranging *MCCD and cremation/burial papers:

- Where is collection?
- Who should collect ?
- ♦ ID required
- Appointment times, opening hours, contact details
- Documents required to arrange a burial or cremation (i.e. Form 4, and Form 5 to be signed by two medics)
- Collection of remains
- Advice if the Coroner is involved and if PM required.

Pro-active communication about release of *MCCD Include why delays may happen (e.g.

Coroner's PM). Consider a standalone leaflet.

Bereavement / mortuary team:

- Contact details and opening hours; offices clearly marked on site map
- Making an appointment
- Viewing the deceased
- Dedicated parking; clearly marked on site map

How to register the death:

Who Can and should do this

What Information and ID is required Where Registry Office and location

When Timeframe and appointment details

Collection of personal items. See Bereavement Specification (B1) for advice on property bags.

Pastoral support / multi-faith prayer room Advice on bereavement counselling services; include common feelings experienced

*MCCD: Medical Certificate Cause of Death

Level Three: Detailed information Further, more detailed information that may be required post-death

(as guided by the bereaved)

For more detailed information consider signposting to national guidance, or in-house if available.

National (for example):

Sue Ryder, Macmillan, Cruse, Marie Curie, Dementia UK, NHS Choices.

How to tell children about a death: signpost to relevant literature that will support this if not available in-house.

Advise on:

- Emotional / spiritual advice
- ♦ Grief counselling
- Bereavement support

Include useful web links and signposting to support services with contact telephone numbers when possible.

Advise on:

- 'Mail Preference Service' and 'Telephone Preference Service' to stop spam mail or telephone calls
- DWP/Benefits contacts if needed
- Withdrawing from a Care Home, if this was the point of referral

Advise on liaison with authoritative bodies: e.g.

- ♦ Registrar
- ♦ Police
- ♦ Coroner
- ♦ GP
- Social Worker