



When a person dies:

guidance for professionals on developing bereavement services

In collaboration with



**National End of Life
Care Programme**
Improving end of life care

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Foreword

The care of people in the last few days of life, and the availability of care and support for people who are bereaved, is an essential component of good end of life care. The immediate period following a death can be a very difficult time for people who are bereaved, and many struggle with the need to handle administrative details around registering the death, notifying the relevant authorities, and making the necessary funeral arrangements. It is imperative that people are provided with comprehensive, trustworthy and easy to understand information, in addition to practical and emotional support that makes this time as trouble free as possible.

The need to review services relating to death and bereavement was made clear in the reports to the inquiries at Bristol Royal Infirmary and Royal Liverpool Children's Hospital in 2001. In response, the Chief Medical Officer recommended that all NHS Trusts should provide support and advice to families at the time of bereavement. *'When a Patient Dies: Advice on developing bereavement services in the NHS'* (DH 2005) was developed to support Trusts to put these services in place.

Since the publication of *'When a Patient Dies'*, there have been a number of significant developments that have relevance for bereavement care. These include legislative changes, such as the introduction on the Mental Capacity Act 2005, and large scale policy changes and more specific policy developments, particularly the new direction set out in the White Paper *'Equity and Excellence: Liberating the NHS'* (DH 2010) and publication of the *'End of Life Care Strategy'* (DH 2008).

'Liberating the NHS' highlights the importance of giving people choice about the care they receive, and how they need to have access to care and information to make this choice a reality. The importance of bereavement services was highlighted in the *'End of Life Care Strategy'*, which set out recommendations to support delivery of high quality care for all people approaching the end of life, and their families and carers.

It was recognised in the *'End of Life Care Strategy- First Annual Report'* (DH 2009) that whilst the strategy touched on the needs of people who are bereaved, more needed to be done to expand on the issues related to bereavement. A multi-agency Bereavement Working Group was consequently established to inform a programme of work on bereavement, and to support its delivery.

Following recommendations from the working group, this revision to the *'When a Patient Dies'* guidance has been developed to take into account these policy and legislative changes.



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Introduction

Statutory organisations have a responsibility to ensure that information and practical and emotional support is available to people who are bereaved. Voluntary organisations and volunteers also offer important services to people who are bereaved. This guidance is to support statutory and voluntary organisations to develop services for this important group.

“People who experience bereavement need to have their loss recognised and acknowledged by professionals.”

The manner in which professionals and volunteers respond to those who are bereaved can have a long term impact on how they grieve, their health and their memories of the individual who has died.

For families and carers, bereavement can be associated with poorer mental and physical health, and increased use of health services (*Recognised, valued and supported: next steps for the Carers Strategy*) (HM Government 2010). Effective links between staff, both within and between sectors, are important to ensure a consistent service is offered to people who are bereaved.

The information within this guidance describes the essential elements of high quality care and services for people who are bereaved and offers examples of how they may be delivered. It covers the days before an individual's death, the time of death, and the days following death.

This document is intended to be viewed in conjunction with the revision by Cruse Bereavement Care and the Bereavement Services Association of the 2001 document by the London Bereavement Network entitled *'Standards for Bereavement Care in the UK'**. Currently in development, this will provide guidance on the commissioning of services to meet longer term bereavement needs. *'Guidance for staff responsible for care after death (last offices)'* (2011) published by the National End of Life Care Programme also provides valuable guidance for care in the immediate period following death.

NHS Trusts, community providers and commissioners will wish to consider the advice contained in this and associated documents when developing their own policies and services relating to bereavement.

The original guidance *'When a Patient Dies'* (2005) was focused on NHS Trusts, though there was recognition that the information it contained could be applicable to some extent in other care settings. Given the increasing emphasis on supporting community-based care, including at the end of life, this revised guidance provides more specific advice for community-based services.

The document is structured around the care pathway approach, following the dying person and people who are bereaved through their experience of care. It also includes chapters on workforce and commissioning.

* The London Bereavement Network no longer exists. The guidance will be renamed 'National Guidance for Bereavement Services' as part of its revision.

The bereavement care pathway

The Department of Health's End of Life Care Strategy (DH 2008) advocates a whole systems approach to commissioning and providing services based on an end of life care pathway. The final steps of the pathway ('Care in the last days of life' and 'Care after death') incorporate bereavement care.

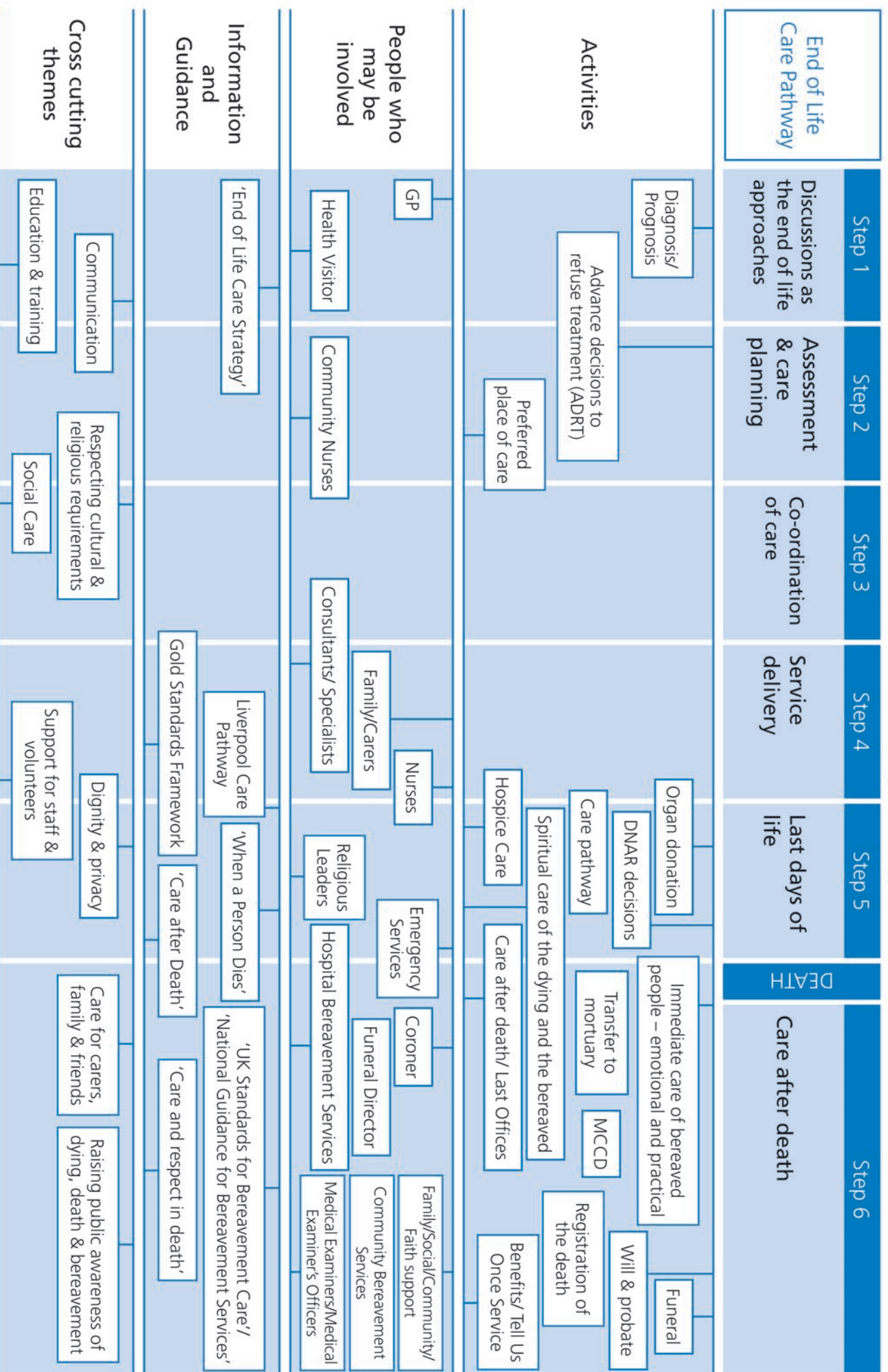
Adopting a similar approach, the 'Gold Standards in Bereavement Care' project, a joint project between Cruse and the Bereavement Services Association, has developed a bereavement care pathway that details the different elements of bereavement care and what is required to meet bereavement needs (see figure 1). Similarly, the Association for Children's Palliative Care have produced an *'Integrated Care Pathway for Children and Young People with Life-Threatening or Life-Limiting Conditions and their Families'*.

Commissioners and providers of services may wish to utilise these care pathways when developing local bereavement services. The pathways could be used to determine and resolve any gaps in current services, as well as ensure an effective transition between acute services and those that meet longer term bereavement needs. For any organisation developing a bereavement service, it is valuable to include people who have experienced bereavement. It is important that bereavement is not considered in isolation from other areas of care.

Many statutory, independent and voluntary organisations will be involved in providing bereavement services and care. They will need to work closely with commissioning colleagues to ensure the provision of high quality services is maintained, possibly through a local bereavement forum. A bereavement forum could be used to identify opportunities for integrated working and share good practice. Whilst each locality may have a range of different organisations and professionals that could be involved in developing bereavement care services, the following partners are suggested as a guide:

- Acute Trusts – bereavement co-ordinators/directors, palliative care specialists (medical and non-medical), chaplains, nurses
- Anatomical pathology technicians
- Medical examiners
- Commissioners – leads for end of life care and bereavement
- Community health professionals – GPs, health visitors, district nurses, allied health professionals, school nurses, practice nurses
- Local authorities – bereavement co-ordinators and social workers
- Hospice staff – medical and non-medical
- Care home staff
- Voluntary organisations – both employed staff and volunteers, including those that specialise in bereavement care for adults, children, young people and people with learning disabilities
- Faith and non-faith community leaders
- Mental Health Trusts – psychologists, learning disability specialists
- Ambulance Trusts – service co-ordinators and ambulance staff
- Funeral directors
- Coroner's office – coroner and coroner's officers
- Police
- Prisons
- Hostels
- Registrars of births and deaths
- Carers organisations
- Citizens Advice Bureaux

The bereavement care pathway



Care Quality Commission

The Care Quality Commission (CQC) is the independent regulator of health and adult social care providers in England. Under the Health and Social Care Act 2008 all providers of regulated activities, including NHS and independent providers, have to register with the CQC and meet a set of essential requirements of safety and quality.

The 16 registration requirements reflect the essential levels of safety and quality of care that people should be able to expect, and are built around the main risks inherent in the provision of health and adult social care services. The requirements include:

- Respecting and involving service users
- Obtaining consent to care and treatment
- Co-operating with other providers
- Safeguarding service users from abuse.

The regulated activities that are most likely to relate to bereavement care are:

- Personal care
- Treatment of disease, disorder or injury

The CQC is responsible for developing and consulting on its methodology for assessing whether providers are meeting the registration requirements and published its Guidance About Compliance in March 2010. This guidance is not itself enforceable, but providers must have regard to it in complying with the registration requirements and it must be taken into account by the CQC when any decision about registration is taken.

Initial registration is the start of a more responsive system that enables the CQC to check continuously and monitor whether services are meeting essential standards. The system brings together a wide range of information from people who use the services, inspections, data sets (e.g. mortality and infection rates) and information from partner bodies. This is all contained in a Quality and Risk Profile for each provider. This is constantly updated and acts as a prompt for action, such as inspection.

Further information on regulated activities and Quality and Risk Profiles can be found on the CQC website: www.cqc.org.uk.

Organisational leadership

It is important that the executive team within a statutory organisation recognises the significant impact that its services can have on people who are bereaved. Ideally, this will be through identification of an executive leader to ensure that corporate responsibility for providing bereavement care is met. Voluntary organisations may also wish to follow this model.

Additionally, it is recommended that each statutory organisation and independent care provider identifies a lead person for bereavement care, responsible for directing and co-ordinating bereavement services. In some organisations, such as acute Trusts, additional bereavement co-ordinators may need to be identified from several departments, for example oncology, accident and emergency, intensive therapy units, children's services and midwifery. These bereavement co-ordinators will need to liaise closely with the bereavement lead. Voluntary organisations may also wish to follow this model.

Whilst the following responsibilities would normally be undertaken by the identified lead on behalf of their employing organisation, many of the responsibilities could be fulfilled by considering a joint approach to working across all care settings. This would have the benefit of providing seamless services for people who are bereaved, as well as achieving economic benefits through the reduction in duplication. Identified responsibilities may include, but are not limited to:

- Co-ordinating services across the organisation and acting as the lead person for working with partners across the whole system
- Ensuring that the needs of people who are bereaved are reflected in all policies that relate to bereavement care. Policies should consider the specific needs of different groups including adults, children and young people who are bereaved, people who lack mental capacity, people with learning disabilities, people's religious and cultural preferences and where death is expected, sudden or traumatic, for example by suicide, murder or misadventure
- Working with colleagues to performance manage and monitor bereavement care, in accordance with national and locally agreed quality outcomes, including the monitoring of service quality from the perspective of people who are bereaved
- Co-ordinating the development and implementation of bereavement information across the organisation, including information for people who are bereaved, professionals and volunteers
- Co-ordinating the development and implementation of training and education programmes for professionals and volunteers within the organisation
- Co-ordinating professional supervision and support networks for staff and volunteers involved in bereavement care
- Co-ordinating, developing and partaking in applicable research projects.

Chapter One:

Principles of bereavement services

- 1.1 It is recommended that commissioners and providers of bereavement services adopt the following overarching principles to underpin the development of bereavement services, whether this is for an expected death, a sudden or traumatic death, a parent whose child has died or a child who is bereaved. The principles will be expanded upon further in this guidance document.
- 1.2 **Personalised care** - keep the person who is reaching the end of life, their family and carers, at the centre of all bereavement service provision. Promote choice and control for the individual and ensure that the individual and their family and carers are continuously included in the care planning process.
- Requires accurate, timely, clear and detailed information to be offered to individuals, and their families and carers, to ensure that informed choices may be made
 - Sensitive, honest and clear communication is essential between professionals, individuals, families and carers if personalised and timely care is to be achieved.
- 1.3 **Legal rights** - ensure that an individual's legal rights are protected at all times. All legislation should be adhered to when commissioning and providing bereavement services, particularly:
- The Mental Health Act 2007 –this replaces the Mental Health Act of 1983, and confers responsibility for mental health care on to a broad range of professionals and describes the legal circumstances under which an individual may be sectioned
 - The Mental Capacity Act 2005 – this assumes that all people have capacity until proven otherwise and people should receive support to help them make their own decisions. This safeguards the interests of people who lack capacity
 - The Equality Act 2010 – this safeguards against discrimination
 - The Health and Social Care Act 2008 – this identifies the legal responsibilities of what health and social care organisations are expected to provide
 - Data Protection Act 1998 – this details the legal responsibilities of organisations if they have access to personal information on individuals
 - The Criminal Justice Act 1988 – this determines criminal law
 - The Births and Deaths Registration Act 1953 – this governs death certification and registration
 - The Coroners Act 1988 and The Coroners Rules 1984 (as amended)
 - The Coroners and Justice Act 2009 – this governs death certification and provides the legislative framework for coroners in England and Wales if and when implemented
 - The Human Tissue Act 2004 – this covers England, Wales and Northern Ireland. Through the Human Tissue Authority it regulates the removal, use, storage and disposal of human tissue for scheduled purposes. Consent is the underpinning principle of the legislation
 - The Health and Safety at Work Act 1974 – this governs the general duties employers have towards employees and members of the public, and employees have to themselves and each other.

1.4 Dignity and respect - bereavement services are encouraged to embrace the principles of dignity and respect in care, which includes, but is not limited to, providing an environment that promotes privacy at all times. Additionally, respecting and meeting personal, spiritual and faith beliefs is important to meet the holistic care needs of individuals, families and carers. Working collaboratively with hospital chaplaincy leads and community based faith and non-faith leaders will be vital in ensuring these needs can be met.

- Organisations may wish to adopt the principles of dignity in care as outlined in the *'Dignity in Care'* campaign (DH 2007, www.dignityincare.gov.uk) and in *'Essence of Care - Benchmarks for the Fundamental Aspects of Care'* (DH 2010)
- Dignity and respect includes providing an appropriate physical environment for care. The King's Fund, as part of their Enhancing the Healing Environment (EHE) Programme, has worked with a range of NHS Trusts and other organisations to deliver improvements in the physical environments of end of life care services. Principles of the programme can be applied across all care settings. The King's Fund has published a guidance document *'Improving the patient experience: Environments for care at the end of life'*, which can be found along with details of the EHE programme at: http://www.kingsfund.org.uk/current_projects/enhancing_the_healing_environment/index.html.
- In tandem with this, the National End of Life Care Programme has published *'Route to Success in end of life care –*

Achieving quality environments for care at the end of life', which is available at: www.endoflifecareforadults.nhs.uk/publications/routes-to-success-achieving-quality-environments-for-care-at-end-of-life

1.5 Family and carers are partners in care - recognise the significant contribution that families and carers of people facing the end of their life make to meeting the needs of that individual, from diagnosis through to the terminal phase of illness, at the time of death and following death.

- Whilst the needs and wishes of an individual who is reaching the end of life are of paramount importance, the family and carers of each individual should be recognised as an essential part of the end of life care team and be fully involved in the planning and delivery of care. Where an individual lacks capacity to give consent to the involvement of family members or carers, the provision of care should be in line with the Mental Capacity Act (2005) to ensure that the individual's best interests are served.
- Ensure that the rights of carers to have a Carer's Assessment are protected in accordance with the Equal Opportunities Act (2004), which places a duty on local authorities to inform carers, in certain circumstances, of their right to an assessment of their needs.

1.6 Equality - The Equality Act 2010 contains an integrated public sector equality duty, requiring public sector bodies and organisations carrying out public functions to have due regard of the need to eliminate discrimination, advance equality of opportunity and foster good community relations.

- Statutory health and social care organisations, and other organisations carrying out functions of a public nature, must be able to demonstrate their compliance with the public sector equality duty in exercising their functions, including in reconfiguring or withdrawing bereavement services.
- The Department of Health's standard equality analysis template (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123180) can be adapted to help local organisations evidence their compliance with the public sector equality duty.

1.7 Recognising the need for bereavement care and support - ensure that bereavement services recognise and incorporate the three components of bereavement support, as identified in *'Improving Supportive and Palliative Care for Adults with Cancer'* (NICE 2004). Although the original NICE guidance related to the care of adults with cancer, these three components can be applied to all adults and children who are bereaved, regardless of the cause. The three components are:

1. Grief is a normal reaction to bereavement. Some people who are bereaved may lack an understanding of grief so accessible information should be provided on grieving and how to access support services, including services for children and young people if required.
2. Some adults, children and young people who are bereaved may require some direct support over and above that which family and friends can provide. This support may include,

but is not limited to, community health and social care services, voluntary groups, self-help groups, spiritual and faith groups, getting directly involved with fund raising activities, access to internet support, and may or may not include some professional support.

3. A smaller number of people who are bereaved will require more intense, specialist support, usually involving access to professionals. Early recognition and referral is essential. This component includes provision for meeting the specialist needs of people with learning disabilities, children and young people who are bereaved.

1.8 Skilled workforce - as detailed in the End of Life Care Strategy, it is important that bereavement care is provided by a workforce that has the relevant skills and knowledge to undertake that care. It is equally important that professionals and volunteers have access to supervision and support to undertake their role.

Providing quality care to people who are bereaved can be part of any professional's or volunteer's role and responsibilities. It is important that bereavement care is not perceived as the domain of specialist bereavement services alone.

Chapter Two:

Information provision: general guidance

- 2.1 The confidentiality of an individual who is approaching the end of life should be maintained by professionals and volunteers at all times. Information about an individual should only be shared with family members and carers with that individual's permission, or where the legal right to disclose information has been confirmed by professionals. When sharing information individuals, families and carers should be treated as equal partners with professionals and volunteers.
- 2.2 Information needs to be communicated sensitively to people who are expecting or have experienced bereavement, at a time that is appropriate for them. It is important to acknowledge that not all individuals, families and carers will wish to receive all the available information and needs may vary within the same family or carer group. Some may choose not to acknowledge the approach of the end of life, although this can change over time. Professionals and volunteers will need to listen and watch what an individual, family member or carer is communicating to determine what, when and how information should be imparted.
- 2.3 Whilst written information is important, it is there to consolidate, not replace, verbal communication with people who are, or are about to be bereaved. Information needs to be clear, accurate, detailed and accessible. This means developing information that is available in a variety of formats that meets the needs of all people, including people who have learning disabilities, a sensory impairment, and people that require information in a language other than English. Information also needs to be sensitive and relevant to different cultures and faiths. Information that is sensitive and age appropriate to the needs of children and young people, including young carers, can also be required. It is recommended that representatives from all groups of people, including people requiring information in a specific format, are involved in the development of this information to ensure that it is fit for purpose.
- 2.4 Statutory organisations are required to offer and make available interpreters and translators, including British Sign Language interpreters. Statutory organisations currently have access to these services and it is important that professionals avoid using written information as a sole replacement for engaging these services. Interpreters and translators need to be included in staff supervision and support networks.
- 2.5 The following are examples of the different types of format for information, which could be made available by organisations:
- Face to face contact with professionals and volunteers involved in end of life and bereavement care
 - Internet access to information and support
 - Telephone helplines and voice recorded information
 - Written information including Braille, large print, easy read and specific for children and young people
 - Information prescriptions, which can be offered to people with a long term condition or social need. This can be done from either the Information Prescriptions Service or other local/ bespoke systems. Some patients or their carers may wish to create their own information prescription. The

prescription provides relevant and reliable information that assists people to make choices and maintain their independence. Further information can be found at www.nhs.uk/Planners/Yourhealth/Pages/Information.aspx

- 2.6 Examples of useful sources of information can be found in Appendix 1 of this guidance.

Chapter Three:

Bereavement care in the days preceding death

3.1 When a death is expected it is important for bereavement care to commence before an individual dies, often at the point where information regarding diagnosis and/or prognosis is communicated to individuals, their family and carers. The way in which a diagnosis and prognosis is communicated to people can have a significant impact on bereavement, so relevant professionals engaged in communicating this information need to be skilled and experienced in doing so.

Care of the individual in the days preceding death – impact on bereavement

3.2 Even when a death is expected it can be difficult to determine the point at which an individual is reaching the last days of life. It can be important to the family and carers that they are made aware, if possible, that death is imminent as they may have certain needs. For example, they may wish to arrange for someone to stay with the individual who is dying at all times until death occurs. Similarly, family members or carers who live some

Good Practice

The Dying Matters coalition

The Dying Matters coalition is working to help all professionals, generalists and specialists alike, to have confident conversations about dying, death and bereavement with people at any point. This spans from diagnosis of a condition that is life-limiting until the time of death, across all settings. Dying Matters produces and disseminates a range of leaflets and resources which give practical advice on how to start a conversation about dying, death and bereavement. The coalition has worked with GPs to increase their confidence, with positive effect, and learning can be shared across settings.

The coalition aims to ensure that more of the general public are assisted to have open and regular conversations about death, dying and bereavement because:

- When individuals have talked about their wishes in advance, professionals will be more equipped to plan for and meet those wishes in a timely manner. This is particularly important for people diagnosed with dementia and neurodegenerative conditions
- Talking more has an impact on the grieving process. People who are bereaved may cope better with bereavement if open conversations have taken place leading up to an individual's death, and wishes were known about and met
- More people will be able to talk to and support friends, colleagues and family members who have been bereaved, which may have an impact on the level of bereavement support needed.

Visit www.dyingmatters.org for further information.

distance away may wish to travel to be present at the time of death. There are a number of tools and pathways that can assist professionals to identify and provide care when an individual may be reaching the last days of life. Some examples are:

- The Liverpool Care Pathway (LCP) – this is an established tool used to support care in the last hours or days of life when death is considered imminent. Its purpose is to ensure that dying patients receive appropriate interventions, including medication, to control their symptoms and to eliminate any distress they might experience by receiving treatment or tests that are no longer beneficial to them. The LCP can be used in a variety of settings including acute Trusts, care homes and hospices. Visit www.mcpil.org.uk to access the LCP.
- The Gold Standards Framework – for use by general practitioners and community teams to help care for people in the final year of life within their home. Visit www.goldstandardsframework.nhs.uk for further information.
- Preferred Priorities of Care (PPC) – this is a tool by which individuals can specify where and how they would prefer to be cared for at the end of their life, and it is transferable between different care settings. Visit www.endoflifecareforadults.nhs.uk for further information.

Mental capacity

- 3.3 Some individuals, for example people with dementia, may lack mental capacity to make decisions as their disease

Good Practice

Providing a resource pack to support the LCP for families and carers in last days of life - NHS Gloucestershire

An LCP resource pack has been developed as part of a county-wide bereavement protocol to support community nurses in delivering standardised care to families and carers who are bereaved. This pack is utilised at the point the multi-disciplinary team decides to place an individual on the LCP.

It provides useful information to families and carers in the form of leaflets about

the LCP, what to do after a death, bereavement and a contact card explaining standardised follow-up. It also includes useful tools for the nurses including an LCP guidance sheet, a prompt sheet and a bereavement documentation tool.

The resource pack provides an easy and simple way to document follow-up, calls and visits. It helps to signpost families and carers to appropriate care and support services such as Cruse, or professional counselling.

For further information contact Georgina.King@glos.nhs.uk.

progresses and the end of life is approaching. Lack of mental capacity may also apply to a family member or carer. Knowing how to communicate sensitively and appropriately to people in these circumstances, whatever the cause of their lack of mental capacity, is of particular importance for professionals and volunteers. The bereavement needs of people who lack mental capacity to make decisions are as significant as they are for people with capacity.

3.4 Some individuals may wish to make an *'advance decision to refuse treatment'* in the event that they lack the mental capacity to make those decisions themselves at a later date. The Mental Capacity Act 2005 was introduced to *'enable and support people who lack mental capacity'* and it sets out the conditions under which an advance decision can be made.

3.5 There are five statutory principles within the Mental Capacity Act (2005), which are:

1. A person must be assumed to have capacity unless it is established that they lack capacity
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success
3. A person is not to be treated as unable to make a decision merely because s/he makes an unwise decision
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his/her best interests
5. Before the act is done or the decision is made, regard must be had to

whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

3.6 All professionals caring for an individual at the end of life need to be aware of the Mental Capacity Act (2005) and how to apply it. Organisations will need policies relating to the Act and may wish to consider its inclusion on induction training programmes. The General Medical Council has produced guidance on decision-making at the end of life, including how to handle issues around capacity, which may help inform this process (*'Treatment and care towards the end of life: good practice in decision making'* GMC 2010). Further information can be found in *'The Mental Capacity Act Code of Practice'* (Department of Constitutional Affairs 2007) or at <http://www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet12> and <http://webarchive.nationalarchives.gov.uk/+http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf>

3.7 Additional resources for staff around aspects of the Mental Capacity Act (2005) have been made available by the National End of Life Care Programme, which has produced guides on advance care planning (*'Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff'* 2011 - <http://www.endoflifecareforadults.nhs.uk/publications/pubacpguide>) and advance decisions to refuse treatment (*'Advance Decisions to Refuse Treatment: A Guide for Health and Social Care Professionals'* 2008 - <http://www.endoflifecareforadults.nhs.uk/publications/pubadrtguide>).

Good Practice

Information on mental capacity targeted at end of life care - National Council for Palliative Care

The National Council for Palliative Care has produced two documents relating to mental capacity which offer useful summary guidance on the Mental Capacity Act (2005) and its implementation:

- *'Good decision-making – the Mental Capacity Act and end of life care'*
- *'The Mental Capacity Act in practice: guidance for end of life care'*

Visit www.ncpc.org.uk/publications for more information.

NHS Continuing Healthcare (CHC) Fast Track

- 3.8** Enabling an individual to die in their chosen setting can have special significance for some families and carers and where this does not occur it can have a prolonged detrimental effect on how people experience bereavement.
- 3.9** In the event that an individual is admitted to hospital during the days or weeks preceding death, it is important that this is not seen as the final option if the individual's choice is to die at home, which may be a care home, or elsewhere in the community.
- 3.10** If an individual has not already been assessed as needing Continuing Healthcare, the NHS CHC Fast Track tool can be used to assess an individual's continuing health needs in order to facilitate rapid discharge to the community and put an appropriate care package in place. The family and carers' views will be central to the decision making process as some may feel their ability to care at home is limited for a variety of reasons. The NHS CHC Framework and Fast Track tool can be located on the DH website at www.dh.gov.uk.

Consent for body, organ and tissue donation and post mortem examination

3.11 The Human Tissue Act 2004 established the Human Tissue Authority (HTA), which regulates activity in relation to the removal, storage, use and disposal of human tissue. Consent is the fundamental principle of the legislation. Consent is required from an individual for the removal, storage and use of tissue for scheduled purposes under the Act.

3.12 These purposes include anatomical examination research and transplantation amongst others. Individuals are also able to appoint a nominated representative to act on their behalf after death. If consent or refusal has not been determined prior to death, then a person in a 'qualifying' relationship with the individual immediately before their death may give consent. However, consent for full body donation for anatomical examination or public display can only

be consented to by the individual in life and in writing. Further information on scheduled purposes and qualifying relationships can be found at www.hta.gov.uk.

- 3.13** If the death needs to be reported to the coroner, the coroner must agree before any donation can take place. Where a death is unexpected or sudden the coroner does not require consent to carry out a post-mortem examination for the purposes of determining the cause of death. However, the reasons for the post mortem examination and the process should be explained to relatives.
- 3.14** All post-mortem examinations must be undertaken on premises licensed by the HTA. All bodies stored for post-mortem examinations must be stored on licensed premises. Post-mortem examinations should be carried out in accordance with the HTA relevant Codes of Practice. Written policies and procedures should be in place within any organisation that undertakes post-mortem examinations, or is responsible for the disposal of human tissue. The Human Tissue Act 2004 and the HTA Codes of Practice could be used as a base for developing local policies and procedures.
- 3.15** It is preferable for individuals to have considered body, organ and tissue donation prior to death. Discussion on these matters with individuals, families and carers needs to be initiated in a sensitive and timely manner, and Trusts will wish to consider using professionals with specialist skills in this area to facilitate the discussion and provide information, such as Specialist Nurses in Organ Donation and National Tissue Donor Co-ordinators (the latter is relevant for community staff).

Good Practice

The Human Tissue Authority codes of practice

The Human Tissue Authority has produced the following codes of practice for use by professionals:

- Code of practice 1: Consent
- Code of practice 2: Donation of solid organs for transplantation
- Code of practice 3: Post mortem examination
- Code of practice 4: Anatomical examination
- Code of practice 5: Disposal of human tissue
- Code of practice 7: Public display
- Code of practice 9: Research

Visit www.hta.gov.uk for copies of the codes of practice.

Families and carers may require written information, time and privacy to discuss and consider body, organ and tissue donation and specialist skills may be required when families and carers cannot reach agreement.

- 3.16** Acute Trusts should have a written policy on early notification of potential donors and on consent for donation, post mortem examination and the disposal of human tissue. Statutory organisations and care homes will also have to address the issue of consent around the disposal of human tissue. Staff need to be made aware of when and how to implement the policy. Organisations could consider using the HTA Codes of Practice as the basis for the policy.

Care of the family and carers in the days preceding death

- 3.17 Ensuring that an individual's wishes are respected and carried out in relation to end of life care may be particularly important to the family and carers. For this reason, any changes to an individual's care plan need to be discussed and agreed with the individual, family and carers prior to any changes being undertaken, wherever possible and where confidentiality permits.
- 3.18 If it is not possible for an organisation to facilitate all of an individual's wishes in the last days of life, the reasons need to be sensitively and openly communicated to the individual, family and carers, and alternatives discussed and negotiated if possible. In some situations, the wishes of an individual differ from those of the family and carers. Here sensitive communication and clear information will be needed to support the individual, family and carers. The skills of chaplaincy services, patient advisory liaison services, the voluntary sector and faith and non-faith leaders could be utilised at this time.
- 3.19 Whenever possible, any specific wishes in relation to resuscitation should be discussed by professionals with families and carers. Discussion should include explaining to families and carers what to expect if they choose to witness a resuscitation attempt. If possible, a member of staff should stay with the family and carers if they do choose to witness a resuscitation attempt. Statutory organisations and independent care providers will need to have in place policies that relate to resuscitation and the recording of

people's wishes in relation to resuscitation.

- 3.20 During the days preceding death, family and carers may wish to be with an individual at all times, including overnight. Organisations should consider supporting overnight stays with the provision of private facilities and adopting a flexible approach to the numbers of people permitted to be with the individual at any one time.

"They wouldn't let us be there overnight. I just wanted to let her know I cared, to hold her hand."

"Only two people could stay with her. How could we choose which of her children could stay and which had to go?"

- 3.21 Ideally an individual in the days preceding death should have access to a single room, which would allow family and carers to stay overnight if appropriate, support flexibility of numbers and accommodate the needs of children and young people. Single rooms also provide privacy for all concerned, including other individuals being cared for in the same facility. Where single room accommodation is not available, which may mean some restrictions, tactful negotiation will be required with members of the family, carers and others in care who may be sharing the same room. See also paragraphs 1.4 and 4.3.

- 3.22 If families and carers are not present, they may wish to be kept continuously updated of any changes in the individual's condition. To facilitate communication it is recommended that

organisations establish a lead contact person within the family or carer group that professionals contact in the first instance if change, or death, occurs. This information would need to be kept up to date and easily accessible to all staff.

3.23 The role of chaplaincy services to provide pastoral care to individuals, families and carers during the days preceding death can be vital. Guidance on meeting the spiritual needs of individuals in hospitals is set out in *'Meeting the Religious and Spiritual Needs of Patients and Staff in the NHS'* (DH 2003). Chaplaincy services not only have the capacity to meet the spiritual and faith needs of individuals, families and carers but they are also equipped to provide emotional support as well as contribute to the assessment of bereavement needs. Chaplaincy services can also provide direct links with faith leaders and support networks within the community setting and vice versa. Individuals, families and carers need to be made aware of the pastoral support services available to them, irrespective of faith and non-faith beliefs.

3.24 Organisations, including care homes, hospices and the voluntary sector, should consider having processes in place to ensure that information on pastoral services is available and they may wish to develop direct links with local faith and non-faith leaders. Further information on meeting the spiritual needs of individuals, families and carers in end of life care can be found in *'The Missing Piece: Meeting People's Spiritual Needs in End of Life Care'* (National Council for Palliative Care 2010).

Assessment of bereavement needs

3.25 Assessing the bereavement needs of families and carers is a continuous process and can commence before the death of an individual, in some situations long before. Assessing bereavement needs is complex as each person will experience grief in a different way. Assessing bereavement needs is not solely dependent on the use of formal assessment tools, as it often involves recognising how family and carers are coping on a day-to-day, hour-by-hour basis, and being responsive to their need for information and support.

3.26 The majority of people will find that other family members, friends and support networks will provide sufficient support when they are bereaved, whilst some will require more intensive and/or specialist bereavement support. In an audit of the level of bereavement support required both preceding and following death, St Giles Hospice in Lichfield found that approximately 17% of people were found to require specialist bereavement support. This was in addition to the practical and emotional support routinely offered by nurses. The audit applied to expected deaths only.

3.27 Identifying people's natural coping strategies and their response to loss is now believed to be a more accurate indicator of bereavement, when used alongside traditional risk assessment methods as outlined in *'Guidance for bereavement needs assessment in palliative care'* (Help the Hospices, Second Edition 2010), than traditional methods alone. Self assessment tools,

whereby individuals assess their own bereavement needs, could also be adopted by organisations to assist with the identification of bereavement needs, such as the 'Adult Attitude to Grief' scale (L Machin 2005), which forms part of the 'Ranges of responses to loss' model. Further information about the model can be found at <http://www.helpthehospices.org.uk/our-services/developing-practice/bereavement/assessing-bereavement-needs>.

- 3.28** Specialist assessment resources for people with learning disabilities are currently being developed and further information can be found at www.respond.org.uk.
- 3.29** Where self-assessment tools are used professionals will require training and education on their use and on interpreting and responding to the results. Self-assessment tools should be seen to compliment professional judgement and skills.
- 3.30** In some situations, for example in acute Trusts or hospices where death occurs shortly after admission, there may be little or no opportunity to assess the bereavement needs of family and carers. In these situations, the need for bereavement information and signposting to other services can be particularly important.

Chapter Four:

Bereavement care at the time of death

Care of the family and carers at the time of death

4.1 If family and carers are not present at death, informing them of the death is of primary importance and needs to be conveyed sensitively. Preferably people should be informed either face-to-face or over the telephone, and not via an answering machine.

“I found out she had died that morning when I got home from work. There was a message left on my answerphone. But I couldn’t find out what I should do.”

4.2 When and how to inform children, young people and people with learning disabilities that death has occurred also needs to be considered, and preferably discussed with family members and carers before death occurs. Advice on the bereavement needs of children and people with learning disabilities can be sought from a variety of charities and organisations, some of which are listed in Appendix 1 of this document.

4.3 In any care setting, the family and carers of the deceased individual may wish to spend some time with the deceased immediately after death has occurred. The needs of children and young people at this time also need to be considered and discussed with the children and young people. In care settings other than the deceased’s home, providing a single room for this purpose is necessary, preferably in a quiet location. This may be a mortuary viewing room in an acute Trust.

4.4 If not already in attendance prior to or at the time of death, family and carers may wish to be made aware of the chaplaincy service and request their support, or be put in touch with other relevant faith and spiritual leaders.

4.5 In certain circumstances, and within certain religious faiths, the family and carers may wish to be involved in preparing the deceased for removal either to the mortuary, the funeral directors or to another destination, such as their home. Whenever possible, the wishes of the family and carers should be honoured in this respect. This will not necessarily be possible where a death needs to be reported to the coroner.

4.6 In the event that a death has to be reported to the coroner, and access to spend time with the deceased may be restricted, the reasons for this need to be clearly and sensitively explained to the family and carers. Families and carers will also need to know how to contact the coroner’s officer, so it is advisable for organisations to have information available on their local coroner’s office and the role of the coroner.

4.7 In an acute Trust it is advisable for the bereavement service to be contacted as soon as possible following death so that bereavement service professionals can offer information and support to the family and carers. Where this is not possible, for example out of hours, then Trusts are advised to determine local protocols in respect of contact with the bereavement service and the provision of local bereavement information.

4.8 It is important that professionals and volunteers are well informed, are able to signpost to further information and have information available for people who are bereaved to take away. Poorly informed

professionals and volunteers can cause undue stress and anxiety to people who are bereaved. Some family members and carers may wish to receive a lot of information at the time of death. Others may need some time before being able to ask questions and will wish to wait a day, possibly more, before being given practical information. Some people may not know what to ask, particularly if they have had little or no prior experience of bereavement. Professionals need to use their judgement and be guided by the people who are bereaved.

“When my grandma died, I asked the nurse what would happen next and she didn’t know. I just wanted to know what to do.”

4.9 The type and nature of information that people may require at the time of death can include, but is not limited to:

- Information on how to communicate a death to children, young people and people with learning disabilities
- Information on how, and where, they can view the deceased in the days following death and how and where to collect the personal belongings of the deceased (where applicable)
- Information on the role of the coroner, where applicable
- Information on post mortem examination, organ donation and the disposal of human tissue, where applicable
- Information on the Medical Certificate of Cause of Death (MCCD) and registering the death

- Information on arranging a funeral and local funeral directors
- Information on who to inform of the death
- Information, if required, on how to access financial support for funeral costs from the Social Fund and how to access other benefits, if applicable
- Information on bereavement support services in the hospital and community, including specialist services for children, young people and people with learning disabilities and faith group support networks, including contact details
- Information on normal responses to grief, coping strategies and when to seek help.

Personal care after death (last offices)

4.10 The National Nurse Consultant Group, in conjunction with the National End of Life Care Programme and key stakeholders, has developed ‘*Guidance for staff responsible for care after death (last offices)*’ (2011) which focuses on the physical care of the deceased adult. The guidance is primarily aimed at nursing professionals, but is relevant to health and social care staff that have nursing tasks delegated to them. The guidance relates to a death in hospital, at home, hospices and care homes. Copies of the guidance can be downloaded at <http://www.endoflifecareforadults.nhs.uk/publications/guidance-for-staff-responsible-for-care-after-death>.

4.11 The term ‘care after death’ replaces the traditional ‘last offices’, because the

latter refers only to the physical preparation of the body. The new terminology reflects the different nursing tasks involved, including the ongoing support of the family and carers.

4.12 Organisations may wish to consider using the guidance to develop their own local policies and procedures. The guidance covers:

- Care prior to death
- Care at the time of death, including verification of death and the responsibilities of the verifier with regard to identification
- Good practice and legal issues, including identification and issuing of the Medical Certificate of Cause of Death (MCCD) and notification regarding implantable devices and radioactive substances
- Care after death, including viewing the deceased and care of other patients/residents
- Personal care after death, including physical preparation of the deceased, with or without coronial involvement, and safe keeping of the personal belongings of the deceased
- Transfer of the deceased from the place of death to a mortuary or funeral director
- Recording care after death, including confidentiality.

Verification of death and reporting death to the coroner

4.13 Currently there is no legislation that applies to the verification of death.

Each organisation will need to have in place its own written local policy regarding the verification and reporting of death. Within this policy, it is advisable for statutory organisations to include information on who is responsible for contacting the coroner in the event of a reportable death. Some best practice guidance is available that could be used to inform local policy, for example '*A code of practice for the diagnosis and confirmation of death*' (Academy of Medical Royal Colleges 2008).

4.14 Certain deaths must be reported to the coroner. A death must be reported if it is violent, unnatural, of unknown cause or occurs in prison. The coroner service should be available 24 hours a day throughout the year. Each coroner's office operates slightly differently so each statutory organisation needs to familiarise itself with their local coroner's office's procedures.

4.15 In an acute Trust the body will still be removed to the mortuary in the first instance, prior to the funeral director, coroner's office or the police making arrangements to collect the body as appropriate.

4.16 Once the death has been referred to the coroner, the coroner's office will have responsibility for liaising with the next of kin. Information provided by the coroner will include whether a post-mortem examination will be held, when the body of the deceased can be released for burial or cremation, what, if any, human tissue has been taken from the deceased and whether an inquest into the death will be required. Further information can be found in '*A guide to Coroners and Inquests*' (Ministry of Justice 2010). This is available on the DirectGov website at:

[http://www.direct.gov.uk/
prod_consum_dg/groups/
dg_digitalassets/@dg/@en/documents/
digitalasset/dg_185904.pdf](http://www.direct.gov.uk/prod_consum_dg/groups/dg_digitalassets/@dg/@en/documents/digitalasset/dg_185904.pdf)

- 4.17 Hard copies of the guide can also be obtained from the Ministry of Justice by email at coroners@justice.gsi.gov.uk or telephone 020 3334 3555.

Chapter Five:

Bereavement care in the days following death

Care of the family and carers in the days following death

5.1 Having professionals and volunteers that sensitively acknowledge death can be vital to people who are bereaved. This may include calling the deceased by name, as well as acknowledging the relationship between the deceased, family members and carers. In the days following death, people who are bereaved may require a lot of practical information, advice and support, in addition to emotional support. This applies to any death, in any location. Above all, needs will vary from person to

person so professionals and volunteers are required to be adaptable, able to listen and to ask people what they need.

5.2 Some people who are bereaved may have further questions that they wish to ask about the causes and manner of an individual's death.

"It was all so quick. I still had so many questions, but I was on my own. I didn't have anyone to help."

5.3 Organisations, including care homes and hospices, should consider how to meet

Good Practice

The Bereavement Pathways Project - Solihull Hospital, Heart of England NHS Foundation Trust and Cruse Bereavement Care

A pilot project to bridge the gap between the hospital and community bereavement care services was undertaken between March-August 2009 and October 2009-March 2010.

Early intervention was provided by suitably trained Bereavement Service volunteers and was offered between Monday and Fridays in the form of face to face meetings (first pilot only) and telephone conversations. Feedback from people who were bereaved was positive, as it was from staff within the hospital.

"It was comforting for me to know that the relatives I saw would be followed up. The worry and

responsibility I felt if I had spent time with for example, an elderly person who had lost their life partner after 60 years of marriage, was lifted from my shoulders. We hadn't abandoned them."

"I didn't realise the hospital offered such a fantastic service."

The results also demonstrated that nine formal complaints were prevented, resulting in cost savings to the Trust. For a relatively low cost (£3,250), early intervention with timely information, signposting and support can extend the holistic care offered to people who are bereaved, reduce the number of formal complaints received and reduce referral to formal counselling services.

For more information contact Dawn.Chaplin@uhb.nhs.uk.

with families and carers and offer them the opportunity to ask questions, express their views, concerns and, at times, their appreciation of the treatment and care received. At such meetings, it can be helpful to include attendance by professionals who have been directly involved in the care of the deceased.

- 5.4 One effective way of demonstrating to people who are bereaved that organisations care about, and acknowledge, their bereavement is to send a condolence card within the first week following death.

“After her death, my father and I were moved to receive a beautiful card from the ward sister and staff expressing their sympathy at our loss.”

- 5.5 Early intervention of bereavement care may help prevent or reduce a subsequent need for specialist bereavement care as well as reduce the likelihood of complaints.

Bereavement services within acute Trusts

- 5.6 Bereavement officers/co-ordinators within acute Trusts can offer a range of services to people who are bereaved. This may include accessible information and practical support, signposting to other services, emotional support (including to other professionals), arranging viewings of the deceased, resolution of immediate concerns that may have arisen, and liaising with other

professionals, such as the coroner, mortuary staff, registrar and funeral director. They are also vital in ensuring that other relevant health and social care providers are informed of a death, for example, primary care services, care homes and domiciliary care providers.

“I couldn’t have got through the day without her help - she just seemed to know exactly what to say.”

- 5.7 Local policies and procedures for informing other agencies need to be in place to ensure that people who are

Good Practice

Early notification of death to GPs - Taunton and Somerset NHS Foundation Trust

The Trust have put in place procedures to ensure that GP practices are informed of a death on the same day as the death occurs, or the following working day if the death occurs out of hours.

This will include information written on the Medical Certificate of Cause of Death and whether the coroner has been notified. The notice serves as written evidence that the attending doctor has liaised with the coroner.

For further information contact Elizabeth.Hawden@tst.nhs.uk.

bereaved are not distressed by inappropriate communications or visits relating to the deceased.

- 5.8 The location of bereavement centres within a Trust can have an impact on the overall experience of people who are bereaved and signage should be clear and explicit, using the term bereavement. All staff within an acute Trust should be able to direct people to the bereavement service, with the location of bereavement services included on any map or written information about hospital services.

“The hospital was so big and the route so complicated that I got lost.”

- 5.9 The importance that a Trust gives to the needs of bereaved people can be reflected in the quality of the environment of the bereavement facilities.

“I had to go down into the basement. It was dark and smelly and there was hardly anyone there.”

- 5.10 Organisations should aim to provide a dedicated office with private waiting facilities that are accessible to all, including children, young people and people with learning and/or physical disabilities.
- 5.11 There is some value in locating bereavement centres within mortuary suites. Where this is not possible, travel distances, signage and the quality of the

Good Practice

Amalgamation of bereavement and mortuary services - Salisbury NHS Foundation Trust

The amalgamation of the two services into ‘The Bereavement Suite’ has resulted in a number of benefits for both people who are bereaved and professionals. These include:

- Providing a ‘one stop’ environment for people who are bereaved, and professionals, to seek information and advice, improving the overall quality of the experience. Hospital mortuary and bereavement services can also be available for advice to community professionals.
- Providing a quiet, dignified and respectful environment where a deceased individual can be viewed and information offered and discussed with the family and/or carers
- Reducing the overall amount of time taken in completing and issuing relevant certificates.

For further information contact Samuel.Goss@salisbury.nhs.uk.

environment for both locations should be considered very carefully.

- 5.12 The Department of Health’s best practice guidance ‘*HBN 20 Facilities for mortuary and post-mortem room services*’ is available free of charge to NHS organisations on the Space for Health website at: <http://www.spaceforhealth.nhs.uk/>.

5.13 The King's Fund's Enhancing the Healing Environment Programme includes excellent examples of bereavement and mortuary facilities. See paragraph 1.4.

Death certification and registration

5.14 Primary legislation for the death certification process was included in the Coroners and Justice Act 2009. Revisions to the death certification process will be introduced by regulations to be laid in Parliament, which it is planned will come into force in 2013. Currently, the process for certifying and registering a death, where the death has not been reported to the coroner, is as follows:

1. Verify a death in accordance with local protocols, and a doctor decides if the death is reportable to the coroner.
2. Currently a Medical Certificate of Cause of Death and a cremation form (if required) is completed by the attending doctor. If the attending doctor has not seen the deceased within the previous 14 days, or after death, the death is reported to the coroner. In such circumstances, the coroner may decide that a post-mortem or inquest is not required and will issue a 'Form 100A' to the registrar, permitting the death to be registered. A death certificate will still be required in such cases.
3. The informant, for example next of kin, meets with the registrar to register the death. The registrar completes a 'green form' authorising

burial or cremation. Once registration is complete, the informant is given a copy of the death certificate, as entered in the death register.

4. Once the registrar has issued the green form the deceased may now be buried or cremated. If the deceased is being cremated, additional cremation forms will be completed by doctors and by a medical referee associated with the crematorium.

5.15 The process for certifying and registering a death will change. The key changes under the system are outlined below and further information is available from www.dh.gov.uk/deathcertification.

- **Simpler** - separate arrangements for certification of deaths are replaced with a unified process for all deaths not investigated by a coroner
- **Stronger** - the appointment of skilled medical examiners will enable the independent scrutiny of all deaths not investigated by a coroner. The coroner will still investigate relevant deaths
- **Open** - the medical examiner will have a statutory duty to discuss the cause of all deaths not investigated by a coroner with the next-of-kin or other relevant individual. This will provide an opportunity to raise any concerns regarding the cause or circumstances of the death
- **Higher quality** - advice and scrutiny provided by medical examiners will ensure that deaths are certified more precisely.

5.16 In certain religious faiths burial is required on the same day as death, or as soon as possible following death.

Organisations will need to have protocols in place for deaths that require fast burial. In these circumstances, funerals can sometimes be arranged prior to registration of a death, provided that a doctor has seen the deceased within the last 14 days or after death and the death is not reportable.. A Medical Certificate of Cause of Death will still be needed. Registration of the death will then occur on the next working day. Family and carers may request that the deceased be transported abroad for a funeral. In such circumstances, coroners will provide an additional 'Out of England' certificate. For further in depth information on the death certification process visit www.dh.gov.uk/deathcertification.

Arranging a funeral

- 5.17 People who are bereaved may choose to use the services of a funeral director to arrange a funeral. Funeral arrangements can commence prior to the issue of the death certificate. In any situation where the services of a funeral director are to be employed it may be advisable to contact them as soon as possible following death.
- 5.18 Funeral directors are available 24/7 throughout the year and can offer a liaison and co-ordination service between families and carers and statutory organisations, including bereavement centres and the coroner's office, where applicable. When death occurs in the community and is not reportable to the coroner, the funeral director can be a crucial service for offering practical and emotional advice and support at the time of death and in

the days following death.

- 5.19 Information on the services of funeral directors can be obtained from the National Association of Funeral Directors (www.nafd.org.uk) or The National Society of Allied Independent Funeral Directors (SAIF) (www.saif.org.uk).
- 5.20 Families and carers may wish to take responsibility for caring for the body of the deceased and/or make their own funeral arrangements. Organisations need to be able to signpost people to information that can support them, such as the Natural Death Centre (www.naturaldeath.org.uk). Acute Trusts, hospices and care homes will need to consider what processes they have in place to support the family and carers in transporting the deceased to a temporary place of rest and to the funeral, such as the provision of aids to transfer the deceased to a coffin and vehicle.

Funerals arranged by statutory organisations

- 5.21 In some situations statutory organisations need to take responsibility for arranging a funeral, such as:
- When family and carers cannot be traced
 - When family and carers are unwilling to be involved in funeral arrangements
 - When family and carers cannot afford to finance the funeral and do not qualify for a Funeral Payment from the Social Fund (individuals can

check eligibility through the Department for Work and Pensions Bereavement Service)

- When the only family or carer is a child or individual with a learning disability and has no one to support them with funeral arrangements.

5.22 Professionals within NHS organisations and Local Authorities will need to work together to determine local policies and procedures for arranging and financing funerals, with due regard to the Local Authority responsibilities under Section 46(1) of the Public Health (Control of Disease) Act 1984.

5.23 In any situation where a statutory organisation takes on responsibility for financing a funeral, or assisting with funeral arrangements, it is important to remember that the family and carers of the deceased may still wish to be involved in decision making. Where no known family, carers or friends exist then professionals, and in some cases other patients, could consider themselves friends of the deceased and should be given the opportunity to attend any service held on behalf of the deceased.

5.24 In particular, regard needs to be given to the religious and cultural preferences of the deceased and/or the family and carers in terms of burial or cremation. Where preference is not known cremation is the preferred option. When no known family, carers or friends exist, ashes need to be scattered or interred in a suitable place, where and by whom to be decided locally between the agencies involved. Local agencies may wish to consider whether a permanent memorial to the deceased should be established too.

5.25 The funeral arrangements should be made by the funeral director who will be responsible for the service, the burial or cremation. Due respect should be given to the faith, non-faith and cultural beliefs of the deceased and/or the family and carers in relation to preparing the deceased's body, the timing and nature of the service. Chaplaincy leads and community based faith, humanist and non faith leaders will need to be consulted or directly involved in the service.

Local authority bereavement services

5.26 Local authorities can offer people who are bereaved advice, signposting to other services and practical assistance to help settle the affairs of the deceased, including advice on which organisations should be informed of the death and how to terminate benefits. This is in addition to financial assistance offered under the Social Fund and practical assistance with funeral arrangements offered under Section 46(1) of the Public Health (Control of Disease) Act 1984. Variations between local authorities and the level of service provided do exist, so health, independent and voluntary organisations will wish to liaise with their local authorities about how, when and what services are provided, in order that professionals can signpost people accordingly.

5.27 Many local authorities are part of the national 'Tell Us Once' initiative, detailed below:

Good Practice

The national 'Tell Us Once' programme

The 'Tell Us Once' programme is a national initiative that enables people who are bereaved to inform both central and local government departments just once about the death. This includes:

- The Department for Work and Pensions
- The Pension, Disability and Carers Service
- Jobcentre Plus
- HM Revenue & Customs
- Child benefit
- Tax credits
- Identity and Passport Service
- DVLA
- Housing and council tax benefit
- Council housing
- Blue badges
- Adult services

- Children's services
- Electoral services
- Libraries
- Money owed to the council

Early evaluation of the programme has indicated:

- Quicker collection and redistribution of capital equipment
- Feedback reports that up to 99% of people who used it rated it as 'excellent' or 'good'
- A reduction in the average number of days it takes local authorities to take appropriate action on housing and council tax benefit following a death
- Help to achieve central and local government targets.

For more information please contact tellusonce.communications@dwp.gsi.gov.uk.

Pregnancy loss before 24 weeks gestation, stillbirth and neonatal death

5.28 Women or couples experiencing pregnancy loss, stillbirth or neonatal death need specific information and guidance on all aspects of pregnancy loss. The Royal College of Obstetricians and Gynaecologists' *'Standards for Maternity Care'* (2008) set out clear standards for the levels of care that should be provided to help those whose baby is stillborn or dies shortly after birth. Organisations may also wish

to seek out the guidance *'Pregnancy Loss and the Death of a Baby'* produced by the Stillbirth and Neonatal Death Society.

Pregnancy loss before 24 weeks gestation (referred to in the HTA Codes of Practice as foetal tissue)

5.29 Foetal tissue can relate to ectopic pregnancies, miscarriages, termination and intra-uterine deaths. Women or couples should be told that information

on disposal options is available and they should be given the opportunity to express any personal wishes.

Organisations need to ensure that professionals working with women or couples are aware of the policies related to the disposal of foetal tissue and are able to discuss it in a sensitive and respectful manner.

- 5.30** Foetal tissue can be buried, cremated or incinerated where appropriate depending on the individual circumstances. Professionals need to be able to discuss all of the options available and provide accessible written information as required. Some women and couples may need some time to come to a decision, which will need to be considered as part of the policy on human tissue disposal.

rests with the parents. An organisation may take on this responsibility, on behalf of the parents, provided consent is obtained. In respect of stillbirths, it is considered good practice for hospitals to offer to arrange and pay for burial or cremation, but the parents may still choose to make their own arrangements, so close liaison between hospital staff and the parents is required. Close liaison between chaplaincy services and the parents will also be required in these circumstances as the parents may wish to attend, and invite others to attend, the funeral service.

Stillbirth and neonatal deaths

- 5.31** Babies born dead after 24 weeks gestation are defined under law as stillbirths and must be registered as such. Common law requires that stillbirths must be buried or cremated. Requirements for the burial or cremation of stillbirths also apply in the case of terminations after 24 weeks gestation.
- 5.32** A baby or foetus of any gestational age which is born showing signs of life and dies before the age of 28 days is a live birth and neonatal death, and must be treated as such in terms of registration and burial or cremation. The law requires that where a baby or foetus is born showing signs of life and then dies they must be buried or cremated.
- 5.33** The legal duty for burial or cremation following a stillbirth or neonatal death

Chapter Six:

Workforce training and education

6.1 Different professional and volunteer groups may already receive training and education on bereavement care as part of their foundation training and education programme. Every professional, registered with a professional body, will be required to keep themselves updated on evidence-based care as part of their responsibility towards continuing professional development. Organisations are advised to consider how professionals and volunteers may access available training and education programmes. Similarly, organisations will wish to consider how professionals and volunteers are offered supervision and support to undertake their role. For example, training needs analysis and supervision groups could be organised through the local bereavement forum.

6.2 It is advisable for all professionals to have a basic level of understanding of grief and bereavement. Professionals who work continuously or frequently with people who are bereaved need to have a deeper understanding of grief and bereavement in order to meet a person's practical, emotional and social needs. It is important to include components that reference the specific needs of children, young people and people with learning disabilities, including signposting to specialist information.

6.3 Health and social care organisations are encouraged to use and apply the *'Common core competences and principles for health and social care workers working with adults at the end of life'* (Skills for Care and Skills for Health 2009) when assessing and monitoring the training and education needs of the workforce. The core

competences are supported by *'A framework of National Occupational Standards to support common core competences and principles for health and social care workers working with adults at the end of life'* (Skills for Care and Skills for Health 2010). An updated version of this work, reflecting bereavement and spiritual care, should be available in autumn 2011. Visit www.skillsforhealth.org.uk or www.skillsforcare.org.uk for further information.

6.4 From May 2011, an additional six e-learning sessions focusing on bereavement have been available for organisations registered with End of Life Care for All. To register, visit www.e-lfh.org.uk/projects/e-elca/register.html.

In total 150 sessions covering end of life care are now available including new sessions on spirituality, social care and care after death. The six bereavement sessions include:

- Carers assessment - suitable for any professionals who work with carers
- Practical support after bereavement – suitable for bereavement officers, chaplaincy staff, community staff, volunteers, funeral directors, local authorities, hospice staff, nurses, medical staff and care home staff
- Children and bereavement - suitable for any professional who works with children who are bereaved
- Talking about death and dying - suitable for any professional who works with people who are dying, their families and carers, in particular those whose role requires them to open conversations about death and dying

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- Emotional support after bereavement
- suitable for any professional who supports people after a bereavement
 - Sudden death – suitable for any professional who frequently deals with sudden death and who works in areas where sudden death may have occurred, particularly A&E staff, coroner's officers, ambulance staff and the police.

6.5 The National End of Life Care Programme has led a workforce development project to explore communication skills training in the health and social care workforce.

6.6 The final project report, *'Talking about end of life care: right conversations, right people, right time'* has been published. The report highlights the achievements of the 12 pilot sites and identifies the good practice and collective learning from the project. The report is particularly relevant for all those that are engaged in commissioning education and training or services for end of life care and for those that deliver education and training or care. It will also be of interest to other groups involved in end of life care or workforce development.

6.7 The final project report can be downloaded at <http://www.endoflifecareforadults.nhs.uk/publications/talking-about-eolc>

Chapter Seven:

Commissioning and quality outcomes in bereavement care

7.1 A whole systems, integrated approach to commissioning and providing evidence-based services is required whenever possible. The documents *'The NHS Outcomes Framework 2011/2012'* (DH 2010) and *'Transparency in outcomes: a framework for adult social care'* (DH 2010) highlight the need for approaches that support integrated working at a local level.

'If the outcomes that matter most to people are to be delivered, the NHS, public health and adult social care services need to be fully aligned and in some cases held to account for providing joined up or integrated services.'

The NHS Outcomes Framework 2011/2012 (DH 2010)

"By sharing the same or complementary measures between sectors, there could be a strong incentive for local services to work together and measure their progress on the same basis. The approaches of the three services to outcomes should not be separate entities but part of a single whole."

A consultation on proposals - Transparency in outcomes: a framework for adult social care (DH 2010)

7.2 NHS and Local Authority commissioning that concentrates on quality outcomes

for individuals, their families and carers is desirable, regardless of the setting in which care is provided. Bereavement services that can meet the needs of individuals, their families and carers need to be available in both acute and community settings. Commissioners may wish to commission bereavement services as an integral part of the end of life care pathway.

- Commissioners are advised to work with providers, including the voluntary sector, to develop pathways of provision that flow across the whole end of life care pathway, as identified in the *'End of Life Care Strategy'* (2008) and across the Bereavement Care Pathway.
- Commissioners will wish to consider how they work with providers to ensure that the workforce is suitably trained and educated to work with people who are bereaved. Integrated commissioning of workforce training and education programmes can have particular benefits in terms of standardising quality and providing value for money.
- Implementation and timely monitoring of established quality markers is desirable if care quality is to be maintained and improved upon year on year. This approach is supported by the separate NHS and Social Care Outcomes Frameworks. For example, Cruse in Craven is using the Clinical Outcomes in Routine Evaluation (CORE) to assess the impact of its services on people who are bereaved. A NICE Quality Standard for end of life care, which will inform the commissioning of services, is being developed for publication in November 2011.

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- Commissioners will wish to consider how to utilise Quality, Innovation, Productivity and Prevention (QIPP) to deliver efficiency savings that can be reinvested in services that deliver year on year quality improvements. The QIPP workstreams which are particularly relevant to bereavement care are end of life care and primary care commissioning. Further information on QIPP can be found on the DH website www.dh.gov.uk or on the NHS Improvement website www.improvement.nhs.uk.
 - There needs to be recognition that a quality outcome cannot always be formally defined and a quality outcome may be what an individual says it is, in particular if it meets the needs of the individual, or their families and carers, have themselves identified.

Good Practice

Supporting an individual's desired outcome

A hospice cared for a man who was reaching the end of his life. Important for him, in his sense of life and personal identity, was to be able to take a lot of pain. He was, therefore, very resistant to any type of medication to ease the physical distress which he found himself in, because for him he was still alive and living whilst feeling pain.

This is a direct contrast to how a family, carers and professionals may perceive quality care to be, as a 'good death' is often considered to be the control of symptoms. This was the case for the man's family, they found it hard to understand and staff found it hard to respect his wishes.

The man's wishes were given priority, and he died as he wished to, but professionals worked closely with the family, as well as each other, to support everyone involved in his care.

Appendix 1

The following organisations and websites can offer useful information about bereavement:

ACT & Children's Hospice UK www.actchildhospice.org.uk

Association of Anatomical Pathology Technology www.aaptuk.org

Bereavement Advice Centre www.bereavementadvice.org

Bereavement Services Association www.bsauk.org

Care Quality Commission www.cqc.org.uk

Child Bereavement Charity www.childbereavement.org.uk

Childhood Bereavement Network www.childhoodbereavementnetwork.org.uk

Cruse Bereavement Care www.crusebereavementcare.org.uk

Department of Health www.dh.gov.uk

Department of Work and Pensions www.dwp.gov.uk

DirectGov www.direct.gov.uk

Dying Matters www.dyingmatters.org

End of Life Care for All (ELCA) www.e-lfh.org.uk

Gold Standards Framework www.goldstandardsframework.org.uk

Grief Encounter www.griefencounter.org.uk

Help the Hospices www.helpthehospices.org.uk

Human Tissue Authority www.hta.gov.uk

If I should die www.ifishoulddie.co.uk

Information prescription www.nhs.uk/Planners/Yourhealth/Pages/Information.aspx

Liverpool Care Pathway www.mcpcil.org.uk

Macmillan Cancer Support www.macmillan.org.uk

Marie Curie Cancer Care www.mariecurie.org.uk

Ministry of Justice www.justice.gov.uk

Miscarriage Association www.miscarriageassociation.org.uk

Much Loved www.muchlovedpartners.com

National Association of Funeral Directors www.nafd.org.uk

NHS Choices www.nhs.uk

National Council for Palliative Care www.ncpc.org.uk

National End of Life Care Programme www.endoflifecareforadults.nhs.uk

National Society of Allied Independent Funeral Directors (SAIF) www.saif.org.uk

Natural Death Centre www.naturaldeath.org.uk

Respond www.respond.org.uk

Skills for Care www.skillsforcare.org.uk

Skills for Health www.skillsforhealth.org.uk

Stillbirth and Neonatal Death Society www.uk-sands.org

Survivors of Bereavement by Suicide www.uk-sobs.org.uk

Winston's Wish www.winstonswish.org.uk

www.endoflifecareforadults.nhs.uk

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