

## **BGS BRIEFING 25<sup>TH</sup> JUNE 2014**

LEADERSHIP ALLIANCE FOR THE CARE OF DYING PEOPLE (LACDP)

### ANNOUNCEMENT OF PRIORITIES FOR CARE OF THE DYING PERSON

#### **BGS Response to LACDP System Wide Response ([www.gov.uk](http://www.gov.uk))**

1. BGS welcomes the system wide response from LACDP and strongly supports the approach of personalised care planning for all people who are anticipated to be nearing the end of their life, in order that their own priorities for care can be recognised and incorporated into the care they receive. These approaches illustrate and are driven by the core values which underpin high quality care for people in later life.
2. We support the use of an outcome based approach to end of life care for older people which focuses on the needs and personal preferences of the person in receipt of that care.
3. We believe that Geriatricians and those specialising in the care of older people are well placed to support the professional approaches required to deliver high quality end of life care.
4. BGS recognises that the majority of people who die in the UK are older people, many with multiple long term conditions who will have made increasing contact with health and care services as they approach the end of their life.
5. While the LACDP response specifically refers to good care in the last few days and hours of life, BGS welcome the recognition the principles of palliative and end of life care apply from a much earlier point in a person's life than is common practice currently.
6. BGS welcome and strongly support the emphasis which has been placed upon advance care planning, symptom control, rehabilitation to maximise social participation, and emotional and spiritual support in helping an individual live well until they die.
7. BGS recognise that personalised care planning for end of life is emotionally demanding for older people and their families, complex, time consuming and requires considerable professional skill. Importantly it requires effective communication and well coordinated continuous care to be delivered across a multiplicity of organisations and care settings.
8. We recognise that end of life care planning and the delivery of care in the last few days and hours of life will require considerable professional support to be offered to older people by the care professionals with whom they are already in contact. This has important implications both for workforce development and training of professionals and carers supporting older people at the end of their life.

**ENDS**

## Background briefing

In July 2013 the independent review of the Liverpool Care Pathway (LCP) chaired by Baroness Julia Neuberger by published its report 'More Care, Less Pathway' . This recognised that where the LCP was used properly, many people died peaceful and dignified deaths but that in some cases, the LCP had come to be regarded as a generic protocol, which was the wrong approach. The review panel recommended that the use of the LCP be phased out within 6-12 months.

In response to the report's 44 recommendations, the Leadership Alliance for the Care of Dying People (LACDP) was set up to lead and provide a focus for improving the care for these people and their families.

Further details are at: <http://www.england.nhs.uk/ourwork/qual-clin-lead/lac>

The Alliance is chaired by Dr Bee Wee, National Clinical Director for End of Life Care at NHS England. Membership of the LACDP includes those statutory organisations to which the review panel addressed recommendations, as well as other organisations, including those from the voluntary sector. These include:

- CQC
- NICE
- College of Health Care Chaplains
- NHS England
- DH
- NHS Trust Development Agency
- GMC
- NHS Improving Quality
- General Pharmaceutical Council
- NMC
- Health and Care Professions Council
- Public Health England
- Health Education England
- RCGP
- RCN
- RCP
- Macmillan Cancer Support (also representing the Richmond Group of charities)
- Sue Ryder Care (also representing the National Care Forum (NCF) and the Voluntary Organisations Disability Group)
- Marie Curie Cancer Care (also representing Help the Hospices and the National Council for Palliative Care)
- National Institute for Health Research

The immediate objectives of the Alliance are to:

- support all those involved in the care of people who are dying to respond to the findings of the review; and

- be the focal point for the system's response to the findings and recommendations of the LCP review.

Amongst other things, the Alliance has been:

- developing advice for professionals on individual care plans and other arrangements in place of the LCP;
- considering how health and social care can best address the recommendations in the review about the accountability and responsibility of individual clinicians, out-of-hours decisions, nutrition and hydration and communication with the patient and their relatives or carers; and
- engaging with patients, carers, the public and clinicians as part of developing a set of desired outcomes and guiding principles that will describe what high quality care for people should look like in the last days and hours of life no matter where they are being looked after.

## **BGS Involvement**

In October 2013 Dr Martin Vernon, BGS Lead for End of Life Care, was appointed on the advice of NHS England to the Clinical Advisory Group (CAG) which has supported the LACDP in formulating its system wide response. This group met on multiple occasions to assist in the development of two linked documents setting out the Priorities of Care of the Dying Person:

1. Implementation Guidance for Service Providers and Commissioners
2. Duties and Responsibilities of Health and Care Staff.

### **1. Implementation Guidance for Service Providers and Commissioners**

The NICE Quality Standard for End of Life Care (2011) describes what a high quality service for the last year of life should look like, and sets the context for this work, which focuses on care in the last few days to hours of life. The principles of palliative and end of life care apply from a much earlier point in a person's life than is common practice currently. Advance care planning, symptom control, rehabilitation to maximise social participation, and emotional and spiritual support are all important in helping the individual to live well until they die. These processes are individually time consuming and complex, requiring time and skill to deliver. Identifying people with multiple conditions and/or frailty which may together limit life expectancy is a key step in beginning this process.

All health and care staff who care for dying people must ensure that they are aware of, and follow, guidance and local best practice. They should recognise that the evidence on which this is based will continue to evolve, so a commitment to lifelong learning and continuous improvement is fundamental.

The **Priorities** are all equally important to achieving good care in the last few days and hours of life. Each supports the primary principle that individual care must be provided according to the needs and wishes of the person. To this end, they have been set out below in sequential order.

### When it is thought that a person may die within the next few days or hours...

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

To achieve the Priorities, service providers and employers must:

- Provide strong managerial leadership and a strong governance framework with prioritises care of dying people with Board level accountability
- Provide strong clinical and cultural leadership which prioritises care of the dying person and makes it the responsibility of all health and care staff
- Implement a local policy recognising the responsibilities of all staff to continually improve quality of care for dying people through audit, learning and research
- Ensure staff acquire the necessary competencies including communication skills
- Provide access to locally agreed evidence based guidelines for palliative and end of life care
- Work with commissioners to ensure an adequately resourced palliative care workforce
- Promote an organisational culture which prioritises care, compassion, respect and dignity as fundamental
- Ensure consistency, compassion and effectiveness through clear local guidelines
- Ensure the dying person is supported to eat and drink if they wish to
- Ensure access to assessment for and provision of clinically assisted hydration where this is in the persons' best interests and wanted by them
- Ensure adequate (9am to 5pm 7 days a week and 24 hour telephone advice) access to specialist palliative nursing and medical cover routinely including access to a second opinion where needed
- Ensure staff know how and when to seek specialist support including interpreters and advocacy
- Ensure families are welcomed, encouraged, facilitated and empowered to participate
- Promote the well being of family members after death and awareness of the environmental impacts of care for a dying person in institutional settings
- Put in place governance arrangements including clear identification of a senior doctor with overall responsibility for care and the nurse leading care delivery at any given time
- Ensure explicit policies to document decisions and discussions about drug treatments, prognosis, treatment goals and concerns raised at each point in time, together with the names of those responsible for care

- Ensure policies are in place for food and drink
- Ensure access to necessary equipment and medications with advice and support at all times
- Put in place arrangements for families and carers to seek urgent help when needed
- Ensure clear and adequate arrangements for handover and transfers of care

## **2. Duties and Responsibilities of Health and Care Staff**

Health and care staff who are involved in the care of dying people have duties and responsibilities as set out in this document. These are aligned with professional regulatory guidance and relevant legal requirements, including the obligations on staff set out in the Mental Capacity Act 2005 (the MCA) and its supporting Code of Practice<sup>1</sup>. Health and care staff will need the appropriate education and training to enable them to recognise and deliver these responsibilities in practice. Their employers and the system in which such staff work must support them in doing this.

The document deals specifically with the priorities for care when a person is imminently dying, i.e. death is expected within a few hours or very few days. However, it should be noted that, for people living with life-limiting illness, the general principles of good palliative and end of life care (reflected in the Duties and Responsibilities) apply from a much earlier point. Advance care planning, symptom control, rehabilitation to maximise social participation, and emotional and spiritual support are all important in helping any individual to live well until they die.

The Duties and Responsibilities relate to care and treatment decisions made when a person has capacity to decide and when someone lacks capacity to make a particular decision. Anyone who works with or cares for an adult who lacks capacity to make a decision must comply with the Mental Capacity Act 2005 when making decisions or acting for that person. The Act makes clear who can take decisions in which situations, how they should go about this, who they must consult and involve, and the legal principles that they must apply to ensure that decisions are within the law. The Duties and Responsibilities statements take account of the requirements in the Mental Capacity Act and its Code of Practice, in particular the obligation on staff and others to make decisions in the “best interests” of the person who lacks capacity to decide.<sup>2</sup>

As with other areas of practice, all health and care staff who care for dying people must ensure that they are aware of, and follow, up-to-date guidance and local best practice. They must recognise that the evidence on which good care is based will continue to evolve, so a commitment to lifelong learning is fundamental.

Martin Vernon (BGS End of Life Care Lead)

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<sup>1</sup> The Mental Capacity Act Code of Practice can be found on the Ministry of Justice website at: [www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act](http://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act).

<sup>2</sup> See also the ‘Reminder about the law on capacity’ in the ‘Generic good practice reminders’ section of this document, below.