

CARE OF THE DYING IN THE NHS

The Buckinghamshire Communique

11th March 2003

The Nuffield Trust

Everyone should be able to expect “a good death” and to exert control, as far as possible, over the process and place of their own dying.

Much progress has been made in England, Wales, Scotland and Northern Ireland in the care of the dying since the Buckinghamshire Declaration, reporting the outcome of a conference of health professionals and others in September 2000, sponsored by the Nuffield Trust:

- **good practice is being encouraged through the NHS Cancer Plan and the National Service Frameworks on Coronary Heart Disease and on Older People**
- **it is increasingly recognised that the principles and practice developed by the hospice movement for the care of cancer patients are applicable more generally to patients dying from other causes**
- **Best practice models of care have been developed successfully in hospital and community settings by statutory and voluntary providers**
- **The National Institute of Clinical Effectiveness is developing evidence-based supportive and palliative care guidelines to improve care for cancer patients from diagnosis to death**
- **An additional £50 million is being invested in England in specialist palliative care services**
- **Listening to patients and their carers is receiving greater priority in the organisation and delivery of services, as a result of better consultation**

- **More money is being invested in palliative care research and practical innovation projects across the UK**
- **Surveys of doctors and nurses have identified more precisely gaps in current provision and areas requiring further improvement**

The challenge now is to enable all health professionals and others, in whatever care setting they are, to access the available expertise and acquire the necessary skills to give appropriate care to patients at the end of their lives.

Two best practice models which can help to improve care for dying patients are described briefly below:

The Liverpool Integrated Pathway for the Care of the Dying Patient

This has demonstrated how the hospice model of care can be successfully translated into a hospital setting and “mainstreamed”. Developed by the Royal Liverpool University Hospitals Trust, and the Marie Curie Centre, Liverpool, this multi-professional care pathway approach provides health care workers with the tools they need to improve their care to the level of the best. More than 100 centres across the UK are involved in work relating to this integrated pathway approach, including implementation in community and nursing home settings.

The Gold Standard Framework in Community Palliative Care

This framework is helping many GPs, district nurses and other community health professionals across the UK to identify dying patients, assess their current and likely needs and to develop plans for meeting them. It is designed to deliver more patient-focused care, improve communication and co-ordination between professionals, deliver better symptom control and promote carer support. Macmillan Cancer Relief in partnership with the Cancer Services Collaborative have already involved more than 400 primary care teams in the Gold Standards project, with further expansion planned.

As a result of pioneering initiatives such as those described above, many more patients are able to exercise genuine choices about the care they receive at the end of their lives, and where they die.

RECOMMENDATIONS

The Second Buckinghamshire Conference proposed a range of measures to improve care of the dying in the NHS. Many of its recommendations are also appropriate for implementation in care homes and independent hospitals.

PRIMARY CARE TRUSTS AND THEIR EQUIVALENTS IN SCOTLAND, WALES AND NORTHERN IRELAND SHOULD:

- 1. Implement a best practice model of care such as the Gold Standard Framework in Community Palliative Care across the countries of the UK.** This will promote better communication, coordination and partnership between carers, professionals and people who are dying
- 2. Implement out of hours protocols to ensure a round the clock service, and to promote continuity of care.**
- 3. Assess the ability of health and social care staff to deliver a 24-hour ‘hands-on’ service which meets the needs of dying people and their families, and make improvements where necessary.**
- 4. Increase the provision of practical resources to support informal carers, and provide or commission training for them in practical skills.**
- 5. Provide information for dying people and their families on the availability of local services, and on how to access these.**
- 6. Ensure that dying children have access to the same high quality services as adults so that all services match the level of the best.** There is a need for more health professionals specialising in paediatric palliative care, and continuing collaboration between GPs and paediatricians caring for dying children, specialists in paediatric palliative care and those delivering equivalent adult services.
- 7. Promote as part of their public health responsibilities more public education and discussion around the issues of death and dying to help people cope better with the prospect of their own death.** Improved experiences concerning death and dying can positively influence public health, and the ability of health professionals to carry out this particularly challenging aspect of their

work.

HOSPITAL TRUSTS SHOULD:

8. **Implement The Liverpool Integrated Care Pathway for Dying Patients** Application of this best practice model of care will help ensure that all dying patients receive good care, regardless of setting.
9. **Ensure that care of the dying is recognised as a core responsibility of consultants and the entire hospital team involved in hospital care**
10. **Ensure that health care professionals develop a better understanding of the issues relating to the diagnosis of dying, and when intrusive – or otherwise inappropriate – interventions should cease**
11. **Investigate barriers to providing consistently good care of the dying within their Trust, and act to overcome these.**
12. **Ensure that they are able to create an environment which is flexible and responsive to the wishes of dying patients and their loved ones, and which respects the spiritual, religious and cultural needs of an ethnically diverse society**

ORGANISATIONS RESPONSIBLE FOR EDUCATION AND TRAINING SHOULD ENSURE THAT:

13. **a set of common standards for the care of the dying is agreed by all the professional regulatory bodies and implemented by all those involved in the education and training of professionals**
14. **all members of the workforce, whether clinical or non-clinical, agency, temporary or permanent, are given training in the care of the dying, funded by education commissioning organisations such as the Workforce Development Confederations with a possible role in England for the NHSU**
15. **a lead person is designated in each health care organisation to oversee education and training in care of the dying, and the adoption of care standards**

16. **team-working is promoted in all education and training about care of the dying, and that health professionals are given the skills they need to work successfully with others.** Effective teamwork not only improves care for patients and families, but also helps ensure health professionals are adequately supported.
17. **appropriate education and training is provided for care home staff**

THE COMMISSION FOR HEALTH IMPROVEMENT (CHI) AND ITS SUCCESSOR COMMISSION FOR HEALTH AUDIT AND INSPECTION (CHAI) AND THEIR EQUIVALENT BODIES IN SCOTLAND AND NORTHERN IRELAND SHOULD:

18. **Consider requiring both Primary care Organisations and Secondary Care Trusts to provide evidence of how they are planning and commissioning or providing services to meet the needs of the dying when they undertake their Reviews/Inspections.** Specifically, they should be asked whether they are using any managed process of care, such as the best practice models described above.

THE DEPARTMENTS OF HEALTH IN THE FOUR UK COUNTRIES SHOULD:

19. **Commission the National Institute of Clinical Effectiveness and its equivalents to develop guidelines on the care of the dying, building where appropriate on guidance for supportive and palliative care**
20. **Ensure that their Performance Management arrangements specify the standards of care that the dying can expect to be given in the NHS and that performance against them is reported nationally.**
21. **Ensure that care of the dying is considered a key indicator of general health care quality and replaces some existing performance targets set by the Departments of Health.**
22. **Consider the implications for care of the dying of the ageing of the health-care workforce, and develop plans to anticipate and respond to this.**

ALL THROUGHOUT THE NHS SHOULD:

23. **Recognise that better care of the dying is not just a matter of delivering better palliative care services for cancer patients, important as these are.**
24. **Recognise the importance of supporting families and others after bereavement:** the emotional and practical needs of people who have experienced a sudden death in their family or close circle, for example, must also be addressed by policy makers and care providers.
25. **Ensure that the planning and delivery of services are informed by consultations with patients and their carers about their experiences, views and requirements.**
26. **Participate in a continuing debate about how best to support dying patients and their families.** Too often there is a reluctance at all levels of the NHS to talk about death and dying – attitudes to this need to change if all dying patients are to receive good care, regardless of cause or setting.

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