

Palliative Care Manifesto

The National Council for Palliative Care seeks the endorsement of the major political parties at the forthcoming General Election to this manifesto for palliative care. This manifesto is based on **three principles**:

That everyone has a right of access to palliative care services appropriate to their need.

That everyone should be able to exercise choice about their place of care at the end of life.

That everyone is entitled to a good death.

In July 2004 the House of Commons Health Committee published a report of its Inquiry into Palliative Care in England. It found that:

There is gross inequity of access to hospice and other specialist palliative care services by diagnosis (particularly those suffering from diseases other than cancer), by age group (particularly the very elderly), by geographical area and by ethnicity

The 2004 NICE (National Institute for Clinical Excellence) Guidance on Supportive and Palliative care for Adults with Cancer should be fully implemented and that its underlying principles should be applied to develop palliative care for patients with conditions other than cancer

Only a small proportion of those who wish to die at home or in a hospice are currently able to do so. Reform is required of the mechanisms for NHS funding of services provided by both the voluntary sector hospices and the NHS.

The National Council for Palliative Care agrees with these findings which are also true of the United Kingdom as a whole. It believes that the next Government will need to take specific action if patients and carers are to be assured of quality care at the end of life, whatever their age, diagnosis, ethnicity or place of residence. It urges all the political parties to incorporate the following **pledges** into their manifestos as an initial step towards this end.

1. To invest an additional £100 million annually in palliative care:

£50 million to encourage the development of services to meet the palliative care needs of those with diagnoses other than cancer

£50 million to support implementation of the NICE Guidance on supportive and palliative care

2. To introduce full cost recovery by 2006/7 (at an annual cost of at least £100 million) for both voluntary and NHS providers who deliver palliative care services for NHS patients in accordance with service level agreements with NHS commissioners

3. To introduce monitoring of care of the dying as a key element of performance management for NHS organisations at board level

4. To establish on a continuing basis a national training programme in palliative care for all health and social care professionals who care for patients with advanced progressive illness.

Explanatory Notes

The National Council for Palliative Care is the umbrella organisation for all those who are involved in providing, commissioning and using hospice and palliative care services in England, Wales & Northern Ireland. It promotes the extension and improvement of Palliative Care Services, in all health and social care settings and across all sectors, to government and national and local policy makers.

Palliative care has been defined by NICE as the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

The NICE Guidance stated that:

“patients want to be treated as individuals, with dignity and respect, and to have their voices heard in decisions about treatment and care. Should they need it, they expect to be offered optimal symptom control and psychological, social and spiritual support. They want to be assured that their families and carers will receive support during their illness.”

(Guidance on Improving Supportive and Palliative Care for Adults with Cancer, National Institute for Clinical Excellence, March 2004)

Key Statistics

Funding

Of the order of £450 million is spent annually on hospice and specialist palliative care services for adults in England.

Adult hospices in England receive only about 35% of their income from the NHS.

Access to palliative care

95% of access to hospice and specialist palliative care is by people with cancer.

Each year about 300,000 people with life threatening conditions other than cancer would benefit from palliative care but are excluded from it by reason of their diagnosis.

(Palliative Care for Adults with Non-Malignant Diseases, The National Council for Palliative Care, April 2003)

65% of cancer patients said they were in pain during the hospital visit for their first treatment.

Choice about place of care and death

56% of us would prefer to die at home; 20% of us actually die at home.

24% would choose to die in a hospice; 4% actually do die in a hospice

In contrast, whilst only 11% would choose to die in hospital, 56% actually die in hospital.

(Priorities and preferences for end of life care, The National Council for Palliative Care and Others, July 2003)

¹ National Survey of NHS Patients with Cancer, National Overview 1999/2000