

ACTION ON PALLIATIVE CARE

For those who have advanced, progressive illness, our objective must be to provide high-quality healthcare services, tailored to individual needs; this is what providers want to be able to offer and what individuals deserve to receive. Yet palliative care services today still remain heavily focused on care provided in institutional settings, particularly hospitals. This is despite the fact that most people would prefer to be supported to die in their own homes. Choice still remains restricted for individuals. 56 per cent of us would prefer to die at home yet only 20 per cent of us actually achieve this. 24 per cent would choose to die in a hospice, whereas only 4 per cent actually do.

Conservative health policy is based around the principle of patient-centred care. We want to develop health policies which respond to the needs and choices of patients. In line with our policies published in 'The Right to Choose', the next Conservative Government will enable patients to exercise choice, based on information and advice, in a way which enables them to directly influence their care and for their health providers to meet the highest standards.

Evidence-based standards will form the basis of services provided to NHS patients. We will ask the National Institute for Clinical Excellence (NICE) to produce these standards, building on existing work. We will ensure that the resource implications of meeting those standards are assessed and planned for.

In the case of palliative care, NICE have produced standards for palliative care in relation to cancer patients; these will be extended to address the specific needs of those with other conditions at the earliest opportunity. Individuals will be able to choose services, with the help of their GP or health professional, but without the interference of any NHS bureaucracy.

Conservatives believe that by delivering palliative care services through the Right to Choose, we will create an environment where care providers can offer the type of services that best reflect individual needs. Not only will this benefit the service users but, as research conducted by Marie Curie Cancer Care shows, will reduce hospital admissions and enable patients who choose to do so, to die at home. This will increase quality of experience for patients and reduce NHS costs. The research highlights that in the medium to long term every £1 extra invested in the appropriate provision of hospice at home services will release £2 in hospital services.

Support for Hospices

Hospices are chronically underfunded. Adult hospices currently receive approximately 35 per cent State contribution and children's hospices only receive just under 5 per cent. The NHS has relied heavily on the goodwill and charitable funding of the hospice movement. This inequity needs to be addressed and the taxpayer's contribution to hospice services increased.

Young people's palliative care services and hospice provision plays second-fiddle to adult services. While, thankfully, the number of children and young people diagnosed with a life-limiting illness is relatively small, those children and young people with terminal conditions are surviving for much longer than was the case in the past. However, the

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current provision of palliative care services in no way reflects this. Children's hospice provision is particularly under-funded compared to adult provision and children's hospices are not able to treat anyone aged over 18 years, leading to severe problems of continuity.

IMPLEMENTING THE RIGHT TO CHOOSE

Conservatives will give the Right to Choose to those requiring palliative services and hospice care, based on clear clinical standards, as determined by NICE. Patients will then be able to exercise real control over the management of their care and have the freedom to make crucial choices over their care.

The Conservative Secretary of State will ask NICE to develop standards. We support the continued roll-out of the Gold Standards Framework for palliative care. It is this framework that will form the basis for our Right to Choose policy.

The practical framework is based on seven gold standards to encourage and enable professionals to improve care for patients and covers:

- Communication
- Co-ordination
- Control of symptoms
- Continuity out-of-hours
- Continued learning
- Carer support
- Care in the dying phase

To ensure the NHS has adequate and appropriate resources to deliver such standards we will conduct a resource implementation assessment. Resources will therefore be matched to the standards of care set by NICE and be planned in parallel with work on standards. Where services need pump-priming, initial commissioning or capital grants to establish capacity, Primary Care Trusts (PCTs) will be required to undertake the necessary commissioning.

We estimate that the costs of delivering palliative care services likely to be identified by the resource assessment will be for an additional £40 million funding a year for hospices and approximately £60 million for other palliative care services. This we will meet from the additional resources we have already earmarked to the NHS, of an extra £34 billion to 2009/10 over and above the level we inherit from Labour.

The Right to Choose policy will encourage a more cohesive and community based approach to palliative care and engender new initiatives which provide care in a range of new and innovative settings. We will encourage partnerships between local NHS bodies, health and social care providers and the voluntary sector and harness the expertise of professionals to provide care based on quality standards. By allowing money to follow the patient, the patient will have the Right to Choose the place in which they would most like to be cared. They will be able to do this through individual care plans, agreed with their GP (or GP with a Special Interest). We will support services – including voluntary providers – who can help in the preparation of quality information and advice.

CASE STUDY: Marie Curie Cancer Care Lincolnshire Project

In October 2004 Marie Curie Cancer Care launched the first project in their Delivering Choice Programme. The programme aims to develop and help provide the best possible service for palliative care patients, allowing them to be cared for in the place of their choice.

Working in partnership with the NHS, the voluntary sector, other health and social care providers, the Delivering Choice Programme develops patient-focused 24 hour service models that serve local need and ensure:

- The best possible care for palliative care patients
- Equity of access to services
- Appropriate support services for palliative care patients and their carers
- Choice in place of care and death is available and known to all
- Improved co-ordination of care among stakeholders

The first project has started in Lincolnshire and will run for three years. The initiative represents not a theoretical example, but a practical undertaking by Marie Curie to achieve tangible improvements in the provision of end of life care for all terminally ill patients (not just cancer patients), and to double the numbers of people able to make the choice to die at home.

The Lincolnshire pilot provides an important opportunity to plan and develop high quality palliative care in a complex rural setting. Lincolnshire is considered to have many challenges to overcome in relation to its palliative care service. It is England's fourth largest county with a population of over 650,000 and is mainly rural with a poor road infrastructure. A great part of the county (East Lincolnshire) suffers significant deprivation and 50% of the population is over the age of 60.

There is an overall lack of palliative care in-patient beds, no palliative care consultants within the county and a high incidence of patients being admitted to hospitals in the last days of life. The out of hours service is no longer provided by most GPs and the proposed provision is unlikely to have a positive impact on the care of dying patients at home. In addition many parts of the county do not have a 24-hour district nursing service.

Marie Curie Cancer Care is providing project leadership over a 3 year period to establish access and availability of the services currently being provided and working across the county to resolve the inequities which currently exist.

Outcomes of the Lincolnshire Project

Marie Curie are aiming to double the number of cancer patients who are able to be cared for at home and also expect a significant improvement in access for non-cancer patients to palliative care at home. As well as cancer, Marie Curie will particularly target people with heart disease due to the high mortality rate from heart disease in Lincolnshire.

The latest annual study produced for Lincolnshire in 2004 stated that cancer deaths were reported at around 1850 across the county. These statistics showed that in Lincolnshire only around 23% (423 patients) were able to die at home. The same study showed that 1055 cancer patients died in hospital; a total of 57%. The statistic for home deaths shows the extent of the existing inequity and it is the charity's intent to redress this by doubling its service in Lincolnshire to ensure that at least 50% of cancer patients have the choice to be cared for at home. This will drastically reduce the number of unnecessary hospital admissions which in turn will reduce costs to the NHS and free up much needed beds in acute hospital settings.

Education & Training

Working with those facing death requires staff to be skilled in palliative care. New initiatives will also require some staff to have more training and support. We welcome and endorse the call by the National Council for Palliative Care for a national training programme for all health and social care providers who care for patients with advanced progressive illness. We will ask Skills for Health to initiate work and we will take account of this requirement in the resource implementation assessment to accompany NICE guidelines.

Conservatives welcome GPs with a Special Interest in Palliative Care and would encourage GPs to take advantage of this opportunity as part of the GMS contract. Such GPs would be able to work in community based palliative care schemes and help implement the gold standards framework.

Hospices

Hospices have a vital role to play in palliative care and many patients require the specialised and continuous services hospices are able to offer at the end of their life. We will ensure that hospices have the resources they need to respond to the demands upon them. The charitable support provided to hospices by the British people is magnificent and inspiring. However, it is right that the taxpayer, too, should make a substantial contribution, through the NHS.

In recognition of this, therefore, we are proposing new substantial resources to support hospices.

First, if hospices wish to offer services to NHS patients based on NHS standards of care set out in NICE guidelines, including delivery of a full palliative care service outside of acute admissions, then they will be eligible to receive the same level of financial support which would be provided through the NHS tariff for providing palliative care.

Secondly, and recognising that many hospices may not wish to enter into a full agreement to provide NHS services, we will make special provision to meet a minimum of 40 per cent of hospices' income from the Department of Health. This will apply both to adult and children's hospices and will enable those hospices who choose to do so to be able to offer services independently of the NHS (while, of course, subject to the Healthcare Commission's inspection), however being appropriately supported by the taxpayer.

We believe this will enable hospices fully to meet their current and potential role in providing high-quality end of life care.

To be able to provide responsive, quality end of life care, which enables people to bear pain and a progressive illness with dignity is a vital objective. We know that many of the standards of care required have been identified. We know of the useful work being done by voluntary bodies, including hospices, Marie Curie Cancer Care, and Macmillan Cancer nurses. There remain, however, many respects in which the resources and organisation of care fails to provide the framework in which those standards can be met and patient's wishes and needs are respected.