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## Consultation on the NHS Constitution: Response from the National Council for Palliative Care

### Key message:

The right to good End of Life Care needs to be explicitly stated within the preamble to the NHS Constitution. Clear links should also be made to the patient pledges within the End of Life Care Strategy to ensure clear joined up policy messages are given to the public, patients, carers and staff.

### Key points

- We welcome the intention behind the NHS Constitution however as it currently stands it will fail to meet the needs of the considerable number of people who end their lives within the NHS, over 500,000 in England alone.
- We support the idea behind the preamble to the Constitution, setting out the purpose of the NHS and principles which define how the NHS achieves its purpose. However, the issues of end of life care and a good death, which were raised at the deliberative event in February 2008, do not appear to be appropriately captured. This needs to be rectified in order to recognise the fact that the NHS is closely involved in end of life care (the majority of deaths are in hospital) and to reflect its cradle-to-grave ambitions. It will also help to address the problem, identified in the End of Life Care Strategy (July 2008), of continuing difficulties amongst both NHS staff and patients of discussing and making plans for death. We agree with Age Concern England that this change could helpfully be achieved by amending the preamble to the NHS Constitution to: ‘...and when we cannot fully recover, to stay as well as we can *to the end of our lives.*’
- We welcome the patient and carer pledges within the recently published End of Life Care Strategy, as do the patients and carers who are members of our service user advisory group. These pledges also reflect what patients and carers have been telling us: that they wish to discuss end of life care and be able to plan for their future. This is something that infrequently happens in the NHS at present hence the high level of complaints about end of life and bereavement care. These pledges must be linked directly to the NHS Constitution to ensure both that they are seen as important priorities and that patients, carers and staff receive consistent and clear policy messages. Linking these together explicitly will ensure the aims of the End of Life Care Strategy and NHS Constitution are achieved.

## **Summary of consultation**

The NHS Constitution establishes the principles and values of the NHS in England. It sets out commitments to patients, public and staff in the form of rights to which they are entitled and pledges which the NHS will strive to deliver, together with responsibilities which the public, patients and staff owe to each other to ensure that the NHS operates fairly and effectively. All NHS bodies and private and third sector providers supplying NHS services will be required by law to take account of the constitution in its decisions and actions. A consultation exercise has been carried out to ensure that the draft constitution reflects the needs of all stakeholders.

This document constitutes NCPC's response. It reflects the views of those with both professional and personal experience of palliative and end of life care in the following areas: heart failure and renal conditions, chronic respiratory conditions, neurological conditions, cancer and older people including those with dementia.

## **Background**

### **End of Life Care**

Unless it explicitly refers to end of life care, the NHS Constitution will fail to meet the needs of the 500,000 people who die in England every year.

The Constitution rightly asserts that the NHS belongs to the people. Currently, many of the people who will be affected by the NHS constitution are extremely unhappy with the standard of end of life care they receive. At present, 54% of complaints in acute hospitals relate to care of the dying and bereavement care (Healthcare Commission, 2007). Most people would prefer to die at home (approximately 50-60%), although current statistics indicate that only 18% manage to achieve this. Long term projections indicate that this is likely to decrease to 10% by 2030 if current trends continue which means that without an overall shift in culture people will not be able to meet their choice to die at home. This highlights the need for a specific reference within the NHS Constitution as one of the given commitments of any health service should be to deliver the right to good end of life care.

The fastest growing age group in the population are those aged 80 years or over. (National Statistics, 2008). This will bring an increase in the number of people who die from cancer (Higginson, 2005) and an increase in the number of people who suffer from more than one condition. For example, 29% of people over the age of 85 will also have dementia. The need to provide dignified and appropriate end of life care will only increase. In an ageing and increasingly diverse population the importance of equality of access for all becomes even more vital.

The End of Life Care strategy outlines a series of pledges for patients and carers indicating their right to be involved in all decisions about their care and receive excellent end of life services. These are included in Appendix 1. They should be clearly referenced in the constitution, leaving no doubt in peoples' minds about their rights and entitlements as well as ensuring consistent and joined up policy messages.

In addition, the word "strive" should be removed from the statement concerning involving patients and carers.

*"It says: 'you should strive to involve patients, their families and carers in the services you provide.' There shouldn't be any 'striving' about it - this should happen as a matter of course."*

Reasons for varying levels of end of life care include difficulties discussing and making plans for death. Failing to include specific mention of end of life care will risk perpetuating this problem, resulting in the tragedy of unmet needs at end of life.

Staff not only need to be clinically competent but also need to express compassion and empathy to ensure that patients and carers are treated with dignity. They need training that will enhance all of these qualities.

Explicitly stating the importance of good end of life care will ensure that the NHS Constitution reflects the needs patients and carers from the beginning to the end of their lives.

*“Creation of a constitution for the NHS is a perfect opportunity to be vociferous in the public arena about the need for western society to wake up to the great gift that good end of life care is for those we care about.” (A service user)*

### **Monitoring, implementation and legal enforcement**

Methods for effective monitoring and implementation should be clearly explained, including how the constitution could be legally enforced.

Ability to measure the effectiveness or hold organisations to account remains doubtful due to use of ill defined terms such “strive”. This brings the constitution’s benefit into question. Means of measuring adherence to the constitution should be included. Similarly, systems for complaint and redress should be outlined more clearly. Both of these would enable people to make a judgement concerning review intervals.

*“One could argue that any legal cases taken out under the NHS Constitution would probably not even make it to court and if they did, would be thrown out due to a lack of proper and enforceable rules”*

To ensure that the NHS constitution influences standards of care and empowers patients and carers the principles should permeate all Department of Health guidance. The Constitution itself must be accessible to all patient, carers and staff in all places of care including hospitals, hospices and care homes.

## **NCPC recommends that:**

1. The right to good end of life care must be reflected in the preamble to the Constitution.
2. There should be clear reference to the End of Life Care Strategy pledges for patients and carers.
3. Methods for effective monitoring and implementation should be clearly explained, including how the constitution could be legally enforced.
4. The right not to be discriminated in the provision of NHS services must include discrimination on the basis of age and race.
5. Principles of the NHS Constitution should be evident in all future Department of Health guidance
6. The NHS Constitution should be accessible and understandable to patients, carers, and health care staff across places of care.
7. The word “strive” should be removed from all references to the involvement of service users.
8. Staff should be trained to a level that ensures clinical competence, compassion and dignity.

The key points reflected in our response are also supported by the responses and recommendations from Age Concern, Patient Opinion and Help the Hospices.

### **About the National Council for Palliative Care**

The National Council for Palliative Care (NCPC) is the umbrella charity working to support all those involved in providing, commissioning and using palliative and end of life care services in England, Wales and Northern Ireland. The goal of palliative care is achievement of the best quality of life for patients and their families towards the end of life. Palliative care is also applicable earlier in the course of the illness, offering a person centred approach of symptom control, pain relief and social, psychological and spiritual support.

**Our mission** is to ensure that ALL those who need it have access to palliative and end of life care

- We benefit patients by offering evidence based advice and information to commissioners, policy makers and service providers.
- We collect and analyse data to ensure our work is evidence based
- We run national regional conferences and workshops to share good practice, disseminate information and listen to what is happening at grass roots level.
- We work in dedicated groups to develop and improve access to services for people with cancer, neurological conditions, heart failure, chronic respiratory disease and older people
- We campaign to influence the development of health and social policy in the interest of all those with a life threatening or life limiting condition.
- We encourage awareness and discussion around death, dying and bereavement

### **References**

Department of Health (2008a) *End of Life Care Strategy: Promoting High Quality Care for all Adults at the End of Life*. DH, London

## **Appendix 1 – End of Life Care Pledges**

You will have access to:

**1. The opportunity to discuss your personal needs and preferences with professionals who can support you. You will have the opportunity for these to be recorded in a care plan so that every service which will be involved in supporting you will be aware of your priorities. Your preferences and choices will be taken into account and accommodated wherever possible:**

- All health and social care staff will be trained in communication regarding end of life care;
- Health and social care professionals will be trained in assessing the needs of patients and carers and, where necessary, reconciling differing requirements; and
- A care plan will be offered to every patient and carer, to help ensure services are provided to meet their needs and preferences.

**2. Coordinated care and support, ensuring that your needs are met, irrespective of who is delivering the service to you:**

- Every organisation involved in providing end of life care will be expected to adopt a coordination process, such as the Gold Standards Framework ([www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk));
- Local end of life care coordination centres will be established to coordinate care across organisational boundaries; and
- End of life care registers will be piloted and established to ensure that every organisation which will be involved in care is aware of a patient's wishes.

**3. Rapid specialist advice and clinical assessment wherever you are:**

- Patients and carers will have access to dedicated 24/7 telephone helplines and rapid access homecare services; and
- Specialist palliative care outreach services will be established in every area.

**4. High quality care and support during the last days of your life:**

- A care pathway approach for management of the last days of life, such as the Liverpool Care Pathway ([www.mcpcil.org.uk/liverpool\\_care\\_pathway](http://www.mcpcil.org.uk/liverpool_care_pathway)), will be rolled out across England; and
- Facilities will be provided to support relatives and carers who wish to stay with a patient in hospital.

**5. Services which treat you with dignity and respect both before and after death:**

- A major programme to provide training in end of life care for health and social care staff will be established.

**6. Appropriate advice and support for your carers at every stage.**

To support this, your services will be:

**7. Well planned and coordinated, ensuring you have access to the care you need, when you need it, irrespective of your condition or the setting in which you are being cared for, and that your choices are respected and will be taken into account:**

- PCTs will develop comprehensive local strategic plans for end of life care, based on an assessment of the needs of the population they serve.

**8. Quality assured and delivered to a high standard:**

- Quality standards covering all providers of end of life care services will be developed (see Executive Summary paragraphs 17 and 24).

**9. Monitored and assessed to ensure quality. Best practice will be identified and spread so that others may benefit:**

- A national intelligence network will be established to collect, analyse and publish data on service quality performance; and
- A dedicated multiprofessional national support team will work with commissioners and providers to identify and spread good practice.

**10. Informed by the experience of others who have been in a similar situation to you. Equally your experience will help inform the care of future patients, leading to year on year improvements in quality:**

- Surveys of bereaved relatives and carers will be introduced, based on the successful Views of Informal Carers – Evaluation of Services (VOICES) programme;
- A comprehensive analysis of complaints relating to end of life care will be undertaken; and
- A national End of Life Care Research Initiative will be launched to further our understanding of how best to care for people reaching the end of their life and support those caring for them.