

## The Response of the National Council for Palliative Care to the 'Your Health, Your Care, Your Say' Consultation

Through the autumn, the Department of Health ran a major consultation to influence the forthcoming White Paper on Health and Social Care ('care outside hospital'). There were three main approaches to this work: through appointed task forces of statutory and voluntary sector experts looking at particular themes; through a series of public engagement events; and through submissions from individuals or from organisations on behalf of their constituencies.

NCPC was asked to 'gather the views of people at the end of their lives' known in the consultation as a 'seldom heard group' and as a result we have consulted with service users, subscribers and all key stakeholders. NCPC asked service users via our website for their views on key issues and solutions and held a key meeting of our User Liaison Group to seek their views. In addition, NCPC's policy groups sought the views of the range of service users and stakeholders who require access to good palliative and end of life care. This publication reproduces the response sent by NCPC as its formal contribution to the consultation.

NCPC found the recurrent themes that arose to be:

- *the need to be listened to*
- *for a navigator around services*
- *for co-ordinated care, for anticipatory care*
- *to be treated with dignity and respect at the end of life*
- *and not to forget the range of needs for the support of carers.*

NCPC welcome the wide ranging consultation and particularly the inclusion of end of life care as a priority area. However, it is important to acknowledge at the start that palliative care is wider than end of life care. It may be needed from diagnosis until death and people may live with a life threatening condition for years. Therefore, both services are required in an integrated way to meet the wide range of needs of service users, their families and their carers.

In addition, we consider that the NICE Guidance on Supportive and Palliative Care offers many solutions for the future and should be fully implemented with funding and a commitment for action now. NCPC needs assessment model (1) developed for people with cancer is being modified to identify the needs of people with other life threatening conditions. Working through our policy groups, NCPC are identifying future models of good practice which we hope will be included in the White Paper. NCPC's work to date has been instrumental in identifying unmet need and shows that often the most vulnerable groups are the most disadvantaged.

NCPC's Minimum Data Sets analysis shows that 95% of access to hospice and specialist palliative care is by people with cancer (2). 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 diagnosis (3). 19% of deaths are attributable to coronary heart disease but this accounts for only 1.6% of referrals for specialist palliative care (4).

The 'PALCOPE' project and Help the Aged's recent publication also highlight the inequity of access to palliative care by older people from diverse ethnic and cultural backgrounds (5, 6).

We are delighted that it is the Government's intention to double the investment in palliative care and that in determining how this investment will be made the Government is using this listening exercise to consider

the views of service users and key stakeholders. Palliative care services are still predominantly provided and funded by the voluntary sector and this important sector should be a key partner in future services: its added value should be acknowledged and learning from their models of personalised care should be included in the new White Paper.

A summary of the responses and possible solutions to the consultation is set in this briefing along with some examples of good practice. NCPC's response focused on the following questions:

1. When you and your family need help and support, how, when, where and from whom do you want to get it?
2. How might existing services be improved and extended?

NCPC's responses:

People want their wishes about their care, including palliative and end of life care to be listened to and understood before any professional assessment is made - this requires sensitivity and understanding and training of all professionals involved.

People want a streamlined assessment system to assess their needs across health and social care (and housing where relevant), with co-ordinated services and information available. This requires integrated commissioning so

that joint funding can be available for packages of care and support. Currently barriers exist to prevent this for many people. For 'commissioning a patient-led NHS' to be effective it must address this, and ideally merge health and social care commissioning.

*Signposting of available services through effective navigation:*

*Use of information with user-friendly information, about what is on offer locally from the NHS, local Authority and social care services, hospices, care homes and other local voluntary sector services. This is required nationally and locally for both professionals and users e.g. nationally extend NHS Direct, develop Cancer Bacup model for all other conditions and publicise it well. Locally people want up to date information in hospital and primary and community care settings.*

*An identified navigator/patient companion/advocate role is required to help navigate the complex care pathway of palliative care into end of life care. This could potentially be part of the existing professional role, although trained volunteers could be used, and recruited from diverse communities to support local people.*

It is important for people who need palliative care provision that services are joined up across sectors, including the whole range of care and support such as help with cook-

ing and cleaning, benefits, daily living aids and housing, through to specialist clinical support, access to urgent care, out of hours services and bereavement services. Networks are a good vehicle to coordinate and monitor this. Cancer Networks have established good practice in this area.

People want personalised care and support for themselves and their families to make life as easy and as fulfilling as possible when living with a life threatening condition, especially at the end of their lives. People want surveillance services that enable anticipatory care and respond to their changing needs. Personalised, high quality, responsive services in the right setting were considered more important than choosing between say similar hospital services.

*Some examples of good practice identified by patients:*

- *One palliative care service has addressed out of hours issues by identifying who to call in an emergency rather than 999 and provides a comprehensive handover to the out of hours service including the patient's wishes regarding place of care, resuscitation etc.*
- *A clinic where patients have the option of joint review by a Consultant Neurologist and Palliative Medicine consultant in hospital or in neurology outpatients. Most choose the hospice review and, once they have 'crossed over the*

*threshold' and experienced the hospice first hand, their fears about hospice services often evaporate.*

- *98% of heart failure patients recommend the service of a specialist heart failure nurse because the nurse helped them understand their condition and reduce anxiety. (7).*
- *A hospice day centre offering a heart failure support group, fortnightly for two hours with volunteer drivers. The group offers one to one support and sessions on different self management subjects around living with heart failure.*
- *Older people have a range of long term conditions. NCP's 2020 title (8) on the future of palliative care highlights the rising number of older people living on their own and not always in the setting of their choice, or in receipt of the care and support needed. Older people want to see:*
  - *More creative housing, transport and care solutions as they get older and more people live alone, with sensitive surveillance and anticipatory care planning.*
  - *Independent living combined with access to services friends and neighbours to avoid hospital and emergency admissions.*
  - *Combining housing expertise*

*with health and social care and welfare support to maximise new solutions and resources and offering a range of extra care and housing models rather than one size fits all.*

- *Effective use of telecare and telemedicine in a more systematic way to maintain independence and support outside of hospitals.*

- *Enabling people to choose the right type of service to meet their palliative care needs and at the end of life, and for some this will be to promote independence for as long as possible. Discussing and documenting the preferred place of care and death in a systematic way is crucial as well as rolling out the Liverpool Care Pathway and Gold Standards Framework for use in all settings and for all conditions to enable proper advanced care planning and a good death (9).*
- *Supporting carers' needs - in the consultation process carers stressed the importance of meeting their needs in sustained and creative ways. Carers are diverse, they may be ageing, or in full time work and with children. Support should include planned leave for carers and carer training, particularly in terms of end of life care and support. Help the Hospices have launched a major project, Time to Care, and are working with the University of Sheffield and their findings on this area*

- *End of life care requires co-ordinated and rapid response services - This should be an integral part of rapid response and emergency services, with effective use of specialist palliative care teams supporting and training other primary care and specialist teams to ensure planned out of hours services. Rolling out the recommended end of life care tools will help.*
- *Enabling people to die where they want to be with dignity, appropriate care and support requires a well trained workforce sensitive to all key issues at the end of life that good palliative care provides through its focus on physical, social, psychological and spiritual dimensions. Palliative care should be a core component of all health and social care undergraduate and postgraduate training and a requirement in all support workers training. It should also be a key component in the new role of community matrons.*

*Normalising of death in society. Given that we all die, much more understanding and public awareness campaigns are needed about death and dying especially if more people are going to be supported at home. This could then encourage community awareness, engagement and participation in services. It should be part of the school curriculum and a core component of all training of health and social care professionals. This would also*

*help with understanding and dialogue on the challenging societal issue of whether assisted dying should be legalised and what the implications would be.*

*Inclusion in high level performance management - Mainstreaming palliative and end of life care across all settings requires a commitment at Board and top team level and inclusion in the performance management process for health and social care commissioners and providers using the NICE guidance as the means to achieve this. The Healthcare Commission and the Commission for Social Care Inspection should include integrated quality measures in all sectors building on the end of life care tools. This must be a priority in the new General Practitioner contract.*

In summary, service users and a range of key stakeholders have contributed to and support this submission. NCPC's Policy Unit is working in partnership to develop the models of good practice in palliative care and end of life care. NCPC considers that the views set out merit application beyond the context and time frame of this consultation. NCPC would welcome its use in development of good practice for people nearing the end of life.

NCPC looks forward to being actively involved in the development and implementation of the new White Paper.



**Organisations who have collaborated with and supported the response from the National Council for Palliative Care are:**

*Age Concern*

*Anchor Housing Trust*

*Association of Hospice and Specialist Palliative Care Social Workers*

*Association for Palliative Medicine*

*The Alheimers Society*

*British Geriatric Society*

*British Heart Foundation*

*British Lung Foundation*

*British Society for Heart Failure*

*Centre for Policy on Ageing*

*Help the Aged*

*Help the Hospices*

*Macmillan Cancer Relief*

*Marie Curie Cancer Care*

*Motor Neurone Disease Association*

*Parkinson's Disease Society*

*Policy Research Institute into Ageing and Ethnicity*

*The Royal College of Nursing*

*Sue Ryder Care*

**References**

1 Tebbit, P. 2004. *Population Based Needs Assessment for Palliative Care. National Council for Hospice and Specialist Palliative Care Services (NCHSPCS).*

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3 NCHSPCS. 2003. *Palliative Care for Adults with Non-Malignant Disease.*

4 British Heart Foundation (BHF). 2005

5 Policy Research Institute in Ageing and Ethnicity. 2005. *Palliative Care Older People & Ethnicity: PALCOPE 'Stories that Matter' Project.*

6 Help the Aged. 2005. *Dying in Older Age: reflections and experiences from the older person's perspective.*

7 BHF. 2005. *Patient Satisfaction Survey.*

8 NCPC. 2005. *20:20 vision: The Shape of the Future for Palliative Care.*

9 National Institute for Clinical Excellence. 2004. *Supportive and Palliative Care Guidance.*

10 Help the Hospices. 2005. *Time to Care Project.*

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