National Council for Palliative Care (NCPC) & Help the Hospices
response to
Right care, right place, right time: How can we improve health & care for vulnerable older people?
September 2013

Summary

We believe that it is a striking and disappointing omission that there is no explicit mention of end of life care in the initial priority areas in the Vulnerable Older People’s Plan. We strongly endorse the recommendation of the independent review into the Liverpool Care Pathway:

“Given the very strong links between the vulnerability of older people and the quality of care for the dying, the forthcoming Vulnerable Older People’s Plan should include a strand on care for the dying, and NHS England’s contribution to it should also be specified as a priority in the NHS Mandate”.

1. Better early diagnosis and support to stay healthy

- We welcome the ambition to strengthen the GP’s role in managing the health of their populations, including identifying those people most at risk. However we recommend that the role of the GP also be strengthened to ensure better identification and care management for people who might be approaching the end of life

2. Named accountable clinician

- We welcome the proposal to appoint a named clinician to be responsible for overseeing the care provided in the community for vulnerable older people. We recommend that this person be trained to co-ordinate care and support services for people approaching the end of life and their carers who may often themselves also be vulnerable older people
3. Improved access

- Overall we agree with the Government’s ambition to try to improve access to primary care for vulnerable older people and support the proposed use of new and innovative methods of communication.

4. Consistent and safe out-of-hours services

- We strongly recommend that the Government use the phrase “24/7 care” or “at any time of day or night” instead of “out-of-hours” services. The needs of vulnerable older people, those approaching the end of life and those close to them arise around the clock and are not confined to other people’s normal working hours.

5. Enhanced choice and control

- We warmly welcome the proposal to offer more choice and control to people, carers and families over the services that they can access. However we recommend that an equal emphasis on shared decision-making be included in the plan alongside greater choice, to enable people to be partners in decisions about their care.

6. Better information sharing

- We welcome the ambition to better share information about the services, care and treatment that an individual is accessing in a coordinated and a timely way. For people approaching the end of life time is precious and therefore it is important to ensure that they are not being made to repeat themselves unnecessarily.

**Full response**

We welcome the opportunity to comment on the Department of Health’s consultation on *Right care, right place, right time: How can we improve health & care for vulnerable older people*. We hope that you find our response useful.

NCPC is the umbrella charity for all those involved in commissioning, providing and using hospice, palliative and end of life care in England, Wales and Northern Ireland.

Our comments are based on feedback from people with experience (patients, carers and former carers) and expertise within our organisation.
Background: Making the case for end of life care

End of life care is an exemplar for what the reformed health & care system as a whole and more specifically the Vulnerable Older People’s Plan is trying to achieve. End of life care crosses conditions, settings and sectors. It is complex, with people living with more than one condition, and requiring co-ordination between many different services. Dignity, compassion, communication, coordination and person-centred care are central to good palliative & end of life care. There are many examples of good practice, but there is also much more to do to ensure everybody gets the care they need at the end of life. If we get it right in end of life care much else will follow.

The fundamental importance of end of life care to the mission of the NHS is set out in two key documents in particular:

- **The End of Life Care Strategy** (2008), which is strongly supported and implemented by the coalition government, stated: “How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services.”

- **The NHS Constitution** states in its opening paragraph that the NHS “is there to improve our health and well-being, supporting us to keep mentally and physically well, to get better when we are ill and, when we cannot fully recover, to stay as well as we can to the end of our lives.” It also goes on to state that “You have the right to be involved in discussions and decisions about your health & care, including your end of life care, and to be given information to enable you to do this.”

End of life care was included as the first priority area for improvement, along with care of older people, in the original NHS Mandate published in 2012. However, it has not been identified as a priority area in the proposed plan for vulnerable older people, despite the many recent reports that showcase the results of poor care and compassion at the end of life. People at the end of life are very vulnerable. There is only one chance to get it right at the end of life and therefore we strongly recommend that the Vulnerable Older People’s Plan is updated to ensure that good end of life care is included as an additional priority area. It is important that the priorities in high-level strategies and documents are aligned in a consistent way.

End of life care is a vital part of the strategic and demographic context within which the Department of Health & NHS England must operate. The Mandate to NHS England rightly refers to increased life expectancy over the last 30 years (para1.1). And now, as predicted, the numbers of people dying each year are increasing.
adding enormous strain to the already pressurised health & care system. Despite the increasing numbers of deaths, the majority are still dying in hospital, even though the preferred place of care and dying for most people is their home or care home. More needs to be done to ensure that people can receive good quality care in the community, alleviating the pressure on secondary care services and allowing more people to get their end of life wishes met and receive a good death.

We strongly recommend that the needs of those approaching the end of life, their carers and those close to them are included as a key strand in the Vulnerable Older People’s Plan as recommended by the review into the Liverpool Care Pathway. As our population continues to age, we need to think carefully about how we support them throughout their later life and right up until the end of life.

Priority Areas

1. Better early diagnosis & support to stay healthy

1.1 We welcome the ambition to strengthen the GP’s role in managing the health of their populations, including identifying those people most at risk in the communities they serve and ensuring fast access to specialist care when require. However we recommend that the role of the GP also be strengthened to ensure better identification and care management of those known or suspected to be approaching the end of their life.

1.2 Identifying those people on a GP’s register who might be approaching the end of life (those for whom it would not be a surprise if they died in the next 12 months) is vital to ensure that they get the care and support that they need and that they can express their end of life wishes, therefore increasing their chances of receiving a good death. It is estimated that at least 1% of people on a GP’s register will be in the last 12 months of life and NCPC & the Dying Matters coalition are working with NHS Improving Quality to encourage GPs to identify people who might be in the last year of life, place them on local palliative care coordination registers, and offer discussion and planning about their wishes.

1.3 Diagnosing people as being at the end of life gives them an opportunity to come to terms with their prognosis and to set out and plan what care they will require. Filling in advance care plans and DNAR forms can help both the person and the GP plan for future treatment and ensure that everything has been to done to help prepare and give the person the best death possible. For those who lack capacity, it is important that those close to them are aware (partner, family members), so that they can be involved in this process. We
recommend that the Vulnerable Older People’s Plan outlines how important it is to make this end of life diagnosis and to support people through the last months of their life.

2. Named accountable clinician

2.1 We warmly welcome the proposal to appoint a named clinician to be responsible for overseeing the care provided in the community for vulnerable older people. As people approach the end of life, it is common for there to be multiple community teams involved in the person’s care, especially if the person wishes to die at home. Coordinating these services often puts unnecessary stress and worry on the individual and those close to them. By appointing someone to help coordinate these services, it would alleviate much of this stress and allow people to enjoy the short amount of time that they have left.

2.2 The majority of people want to die at home, but, despite considerable progress, most are still dying in hospital. As well as a named clinician to help coordinate care in the community, better services in the community to ensure more people to have their wishes met, and to avoid costly and unnecessary emergency hospital admissions are also needed. This should be highlighted in the Vulnerable Older People’s Plan.

2.3 We know that far too many people at the end of life are admitted to hospital unnecessarily because the right care and support is not available in the community. Indeed 86% of all admissions in the last year of life are emergency ones and of the 89,000 admissions recorded for people in the last year of life, 79,000 were emergencies. If there is not high quality care and support in the community then people will be rushed into hospital when their pain and symptoms become too great to bear. Sadly this means that 89% of those who die in hospital do so after an emergency admission. The national VOICES survey of bereaved relatives has shown that fewer than one in five (19%) reported that for people who died at home, pain was relieved all of the time. Contrast 63% reported that pain was relieved all of the time for the person who died in a hospice. High quality pain management and other care and support services must be provided in the community so that vulnerable older people may have their end of life care wishes met.

2.4. We recommend that the named clinician be adequately trained to co-ordinate care and support services for people who are approaching the end of life. We also recommend that they be able to provide information and advice
about advance care planning and expressing and recording other specific end of life wishes.

3. **Improved access**

3.1 Overall we **agree** with the Government’s ambition to try to improve access to primary care for vulnerable older people and for future generations, and praise the proposed use of new and innovative methods of communication. However we **recommend** that the plan recognise that face-to-face consultations must still be made available for all those that want them, and that for many people, access to technology may be limited by knowledge, money or disability. We strongly believe that different access methods to primary care must be made a choice, and information must be offered to people about how they can go about using these different access methods.

3.2 We **welcome** the proposal to build on and extend the hours of existing services. Carers and those still working often find it difficult to get appointments. Working around people’s needs is key to offering a person centred service

4. **Consistent & safe out-of-hours services**

4.1 We **strongly recommend** that the Government use the phrase “24/7 care” or as recommended by the NICE End of Life Care Quality Standard “at any time of day or night”, instead of “out-of-hours” services. The needs of vulnerable older people, those approaching the end of life and those close to them arise around the clock and are not confined to other people’s normal working hours, therefore the phrase “out-of-hours” is inappropriate and not reflective of people’s needs. “Out of hours” is a completely provider-centric phrase and we recommend that its use be discontinued.

4.2 We welcome the proposal to have more 24/7 services in the community, especially for those at the end of life. As previously stated, if people are to be cared for outside hospital there are some services that they and their carers will need to be able to access at any time of day and night. Failure to ensure these are available may mean that people have inappropriate and unplanned emergency admissions at the end of life.

5. **Enhanced choice & control**
5.1 We warmly welcome the proposal to offer more choice and control to people, carers and families over the services that they can access.

5.2 However, as well as greater choice of services, we recommend that the importance of shared decision-making also be included in this priority area. People want accurate information and to be treated as partners in decisions about their care. This involves creating a culture of communication between professionals, the person approaching the end of life, their carer(s) and those close to them, allowing an open dialogue about different treatment options. We believe that it is vital for older people and those approaching the end of life to be involved in discussions about their care and to fully understand the range of choices available to them and the consequences of the decisions that they are making. Offering choice alone does not achieve this. However offering greater choice alongside shared decision-making and allowing people to be partners in decisions about their care will.

6. Better information sharing

6.1 We welcome the ambition to better share information about the services, care and treatment that an individual is accessing. At the end of life people and their carer(s) are often faced with communicating and coordinating lots of different people involved in their care. But for people at the end of life, time is precious and therefore it is even more important to ensure that they are not being made to repeat themselves. Information should be shared across health and social care teams to ensure that care is provided in a timely and coordinated way.

6.2 EPaCCs (Electronic Palliative Care Co-ordination Systems) are a good example of how information sharing can be done well to ensure that people at the end of life have their care needs communicated with all of those involved in their care. We strongly recommend that these be rolled out across England. Co-ordinate My Care, which is the system used in London, has achieved particularly good results. For more information please visit: http://www.endoflifecare.nhs.uk/care-pathway/step-3-co-ordination-of-care/epaccs.aspx

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About NCPC

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all.

NCPC is a registered charity number 1005671 and a company limited by guarantee number 2644430. Visit www.ncpc.org.uk for more information.

We lead the national Dying Matters coalition, which currently has over 30,000 members, to change knowledge, attitudes and behaviours towards dying, death and bereavement, and through this to make ‘living and dying well’ the norm. Visit www.dyingmatters.org for more information.

References

i Independent Review of the Liverpool Care Pathway (July 2013). More care, less pathway: A review of the Liverpool Care Pathway


iii Office for National Statistics (July 2013). Deaths Registered in England & Wales, 2012

iv National End of Life Care Intelligence Network (March 2012). Hospital admissions in the last year of life and death in hospital

v Hospital Episode Statistics (2012). Analysis of hospital admissions for people with dementia in the last year of life

vi National End of Life Care Intelligence Network (March 2012). Hospital admissions in the last year of life and death in hospital

vii Office for National Statistics (July 2013). National Bereavement Survey (VOICES)