

End of Life Care

Sarah Wollaston Chair
House of Commons Health Committee
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Conclusions and recommendations

Beyond the Liverpool Care Pathway

1. Every care provider should have a model in place based on the Five Priorities for Care that will deliver personal, bespoke care to people at the end of life. There should be no reason for any health or care organisation not to have introduced an appropriate alternative to the Liverpool Care Pathway. (Paragraph 34)

2. We recommend that a senior named person in each NHS Trust and care provider is given responsibility for monitoring how end of life care is being delivered within their organisation. (Paragraph 35)

3. We welcome the focus on end of life care by the Care Quality Commission and recommend that they monitor both acute and community health care providers' move to the new approach in their inspections and as part of their thematic review. (Paragraph 36)

4. Generalist staff in acute settings must be competent in identifying people who are likely to be at the end of life, irrespective of their medical condition, so that they can offer specialist care where it will be beneficial. We recommend that NHS Trusts ensure that generalist staff are provided with opportunities to learn from specialist palliative care teams. (Paragraph 51)

Access to Palliative and End of Life Care

5. Round-the-clock access to specialist palliative care will greatly improve the way that people with life-limiting conditions and their families and carers are treated. This would also help to address the variation in the quality of end of life care within hospital and community settings. We also recognise the value of specialist outreach services. We recommend that the Government and NHS England set out how universal, seven-day access to palliative care could become available to all patients, including those with non-cancer diagnoses. (Paragraph 52)

6. People with dementia should have equal access to end of life care as those dying as a result of other conditions. Particular attention should be paid to discussing and documenting their wishes as early as possible following diagnosis. (Paragraph 53)

7. Commissioners should explicitly set out how they will provide specialist palliative care services for people from all backgrounds in their locality, including children and adolescents, people from ethnic minority backgrounds and those living in isolated or deprived communities and how they will ensure that those with a non-cancer diagnosis can also access specialist palliative care. (Paragraph 54)

Competence of the workforce

8. We heard that too often staff lack confidence and training in raising end of life issues with their patients or delivering the right care. Training should be provided for all

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health and social care staff who are likely to provide care to people at the end of life, including training in communication skills. We recommend that NHS England works with care providers to identify and roll out tailored end of life care training. (Paragraph 75)

Advance Care Planning

9. We believe there is a role for the Government and NHS England to provide clarity and leadership with regards to the policy on advance care planning and its implementation. We recommend that the Government considers how it can further raise awareness of the mechanisms available to patients and carers under the Mental Capacity Act 2005 to make their wishes clear about end of life care. This should also include information about Advance Decisions to Refuse Treatment. The

Department should provide an update to our successor Committee on the actions it has taken since publication of its response to the House of Lords Select Committee Report. (Paragraph 88)

10. We recommend that all staff who provide palliative and end of life care to people with life limiting conditions should receive training in advance care planning, including the different models and forms that are available and the legal status of different options. Training should be developed in partnership with the National Council for Palliative Care and other non-government bodies with relevant expertise. (Paragraph 89)

11. We recommend that the Government engage with Age UK to understand the outcome of their awareness raising pilots, learning lessons that can be applied to supporting other groups as well as older people to understand the options, and developing a strategy to promote advance care planning to patients in different settings. (Paragraph 91)

12. We recommend that the Government carry out a review of the cost of making a Lasting Power of Attorney, including the impact on take up by people from different socioeconomic groups, with a view to identifying any financial barriers for those who have been unable to take out LPAs, and what support is available to those who cannot afford to use a legal route. (Paragraph 93)

13. At present, should a person completing the LPA application form make any error, they are obliged to complete a new form and start the application process again, including paying a second time. We recommend that the Government review the LPA application process, with a view to making it simpler and cutting costs for applicants. (Paragraph 94)

14. We recommend that the Government encourage and monitor the take up of electronic care planning and Electronic Palliative Care Coordination Systems (EPaCCS), to facilitate information sharing between providers, and that they review the best mechanisms to facilitate the understanding and take up of these plans. We also recommend that the Government explore options for a universal system for

recording and filing advance care plans, with a standard template for use across England and a website dedicated to explaining the issues. (Paragraph 98)

15. The Department of Health has notified the Committee that NHS England is working with Health Education England to develop a single accredited curriculum for paramedic training that will ensure that paramedics have the skills they need to resolve more calls on the phone (hear and treat) and at the scene (see and treat). We expect end of life care to feature in the new curriculum when the details are issued later in 2015. (Paragraph 99)

Do Not Attempt Cardiopulmonary Resuscitation Orders (DNACPR)

16. We recommend that the Government review the use of DNACPR orders in acute care settings, including whether resuscitation decisions should be considered in the context of overall treatment plans. This Committee believes there is a case for standardising the recording mechanisms for the NHS in England. (Paragraph 108)

Community resourcing

17. We recommend that Health Education England and NHS England set out how they plan to address the shortfalls in the staffing of community care services. The Committee sees this as essential to enabling people to die at home and in other community settings including care homes and nursing homes, where that is their preference rather than in hospital. This should involve their plans for the recruitment and training of district nurses. (Paragraph 113)

Free social care at end of life

18. We recommend that the Government clarify the eligibility criteria for the NHS Continuing Healthcare Fast Track Pathway and phase out the social care means test (financial assessment) for people at the end of life. (Paragraph 134)

19. This Committee strongly recommends that the Government provide free social care at the end of life to ensure that no one dies in hospital for want of a social care package of support. (Paragraph 135)

20. We recommend that the Government set out what it intends to do to ensure sustainable, long term funding for the hospice sector as part of their response to the Palliative Care Funding Review. (Paragraph 136)

21. We recommend that the Government ensure that their proposals for the future funding of palliative care fully recognises the importance of the voluntary sector. (Paragraph 137)

Bereavement support

22. Bereavement support provision is currently fragmented, with services not consistently provided around the country. Family members and carers are too often left inadequately supported. We recommend that the Government and NHS England raise awareness amongst health and social care staff of the impact of

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bereavement and provide for universal access to bereavement services in its funding plans for palliative care. (Paragraph 144)

Measuring quality of care

23. We recommend the development of outcome measures for palliative care. These must be properly evaluated and funded in order to improve the quality of care for people at the end of life. (Paragraph 150)

Research into Palliative and End of Life Care

24. We recommend that the Government pursue the research priorities that matter most to people with terminal illnesses, their families and carers and the staff providing care professionally to them, and set out what funding will be provided to ensure that future policy on palliative and end of life care is informed by a robust evidence base. (Paragraph 155)

Leadership

25. The Five Year Forward View sets out a direction of travel for the NHS in England, covering all the major statutory bodies. The Department of Health and NHS England should ensure that end of life care is prioritised and embedded in future planning at all levels. They should identify named individuals who will be responsible for ensuring that the new approach to end of life care, based on the Five Priorities, is delivered nationally. (Paragraph 159)