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THE NATIONAL COUNCIL FOR PALLIATIVE CARE

POLICY ROUND-UP

AUGUST 2015

All the developments in palliative and end of life care delivered to your inbox



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[New report calls for action to improve end of life care](#)

NCPC has published a [new report](#) calling for commissioners and decision-makers to take action to improve end of life care. In addition, it calls for a review of how end of life issues are dealt with across government departments.

The report, '[Time for Action](#)', is designed to enable decision-makers to understand the key findings of recent reports, including the Health Committee's report on end of life care, the Parliamentary and Health Service Ombudsman's report, and the report from the Review of Choice in End of Life Care, as well as their recommendations about what is needed.

The report contains recommendations based on four key calls for change:

- (1) Leadership that gives end of life care much greater priority throughout the health and social care system;
- (2) More out-of-hospital care and well-co-ordinated community-based care;
- (3) Supporting the workforce to provide compassionate, competent and confident end of life care;
- (4) Eliminating unfairness and inequalities in access to end of life care.

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National survey of bereaved people (VOICES) published

The latest National Survey of Bereaved People, VOICES (Views of Informal Carers - Evaluation of Services) has been [published](#) by the Office of National Statistics.

The [survey](#) finds, amongst several other statistics:

- 75% of bereaved people rate the overall quality of end of life care for their relative as outstanding, excellent or good; 1 out of 10 (10%) rated care as poor.
- 69% of bereaved people (69%) whose relative or friend died in a hospital, rated care as outstanding, excellent or good - compared to 83% for those who died in a hospice; 82% for those who died in a care home; and 79% for those who died at home.
- Ratings of fair or poor quality of care are significantly higher for those living in the most deprived areas (30%) compared to the least deprived areas (21%).

Claire Henry, our Chief Executive, has commented on the survey [here](#).

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NICE 'Care of the Dying Adult' guideline - open for consultation

The National Institute for Health and Care Excellence (NICE) has published its [draft guideline](#) to support the NHS in providing high quality end of life care.

The draft guideline has been published to form the basis of a consultation to which registered stakeholders may respond. NICE anticipates that the guideline will be finalised in December 2015.

Claire Henry, our Chief Executive, has commented on the report on our [website](#), and on the [BBC News](#) website.

The deadline for responses to the consultation is **9th September 2015**.

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Government delays implementation of cap on care costs

The UK government has [announced](#) that the implementation of the cap on care costs will be delayed until April 2020.

The government has said the delay is in response to concerns expressed by the Local Government Association and many other stakeholders about the timetable for implementing the cap on care costs in April 2016.

The Care and Support Alliance has [welcomed](#) the delay.

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NHS Constitution and Handbook updated

NHS England has updated its [Constitution and accompanying handbook](#), to reflect current policy and legislation and to make the Constitution a more practical document.

The recommendations of the report by Sir Robert Francis QC, on the Inquiry into the Mid-Staffordshire NHS Trust, have been fully implemented in the Constitution, which now reflects a series of fundamental standards, below which care must never fall.

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New Accessible Information Standard

NHS England has published its [Accessible Information Standard](#). The standard applies to health and social care organisations and identifies their obligations regarding provision of communication support and information in accessible formats.

The Standard is available in different formats on the NHS England [website](#).

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New NHS Citizen Engagement website

NHS England has launched '[Gather](#)': a new citizen engagement website.

The website is designed to enable people to raise issues and ideas on how the NHS in England can improve.

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Independent Cancer Taskforce publishes national cancer strategy

The Independent Cancer Taskforce has published a new [cancer strategy](#) for England.

The recommendations in 'Achieving world-class cancer outcomes: A Strategy for England 2015-2020' have been developed in consultation with people with experience of cancer treatment and care, cancer charities, and professional groups.

The recommendations include that CCGs should commission appropriate end of life care, in accordance with the NICE quality standard, and taking into account the Review of Choice in End of Life Care, and forthcoming document setting out Ambitions for End of Life Care.

An [executive summary](#) is also available.

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CQC Annual Report published

The Care Quality Commission (CQC) has published its [annual report](#).

The report reflects on how CQC has progressed from designing its new approach to monitoring, inspecting and regulating health and adult social care services across England, to implementing it.

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Sue Ryder launches online community and findings on bereavement

To mark the launch of its new [online community](#), Sue Ryder has published findings from a [new survey](#) which highlight how sharing experiences of bereavement has a positive impact on how long it takes people to feel better.

The research found that it takes an average of two years, one month and four days to feel better following a bereavement. It also reveals that sharing experiences and talking about bereavement enables people to feel better more quickly.

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Alzheimer's Society publishes annual report on dementia and calls to action

Alzheimer's Society has published its fourth [annual report](#) looking at quality of life for people with dementia in England.

The report, [Dementia 2015: Aiming higher to transform lives](#), contains the results of Alzheimer's Society's annual survey of people with dementia and their carers, and an assessment of what is currently in place and needs to be done to improve dementia care and support in England over the next five years.

It includes practical recommendations to the new government on the steps that need to be taken to make quality of life better for people with dementia.

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New report calling for better value in the NHS

The King's Fund has published a [new report](#) calling on NHS staff to engage in a new mission to deliver better outcomes at lower costs.

The report identifies key opportunities for improving efficiency in the NHS, looking back at past trends in NHS productivity and drawing on evidence to illustrate a number of areas where NHS services can be improved in the future.

The report argues that for changes to happen, there will need to be a fundamental shift in approach by government and NHS leaders – away from using external pressures to improve performance towards a sustained commitment to supporting reform from within.

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New findings show major funding and training gaps for end of life care in England

Channel 5 has published [findings](#) from a series of Freedom of Information (Fol) requests regarding funding for end of life care.

Amongst other findings, the responses showed an increase in the number of Clinical Commissioning Groups (CCGs) cutting funding for end of life care, and that 70% of the Acute Hospital trusts that responded do not run mandatory training in care of the dying and palliative care for the doctors and nurses they directly employ.

This follows [research](#) by Hospice UK and Together for Short Lives showing that over two-thirds of the hospices surveyed reported that their statutory funding was frozen or slashed in 2014/15.

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Law Commission opens consultation on Deprivation of Liberty

The Law Commission has opened a [consultation](#) on mental capacity and the Deprivation of Liberty Safeguards (DoLS).

The Commission expects to publish a final report with its recommendations and a draft Bill in 2016.

The deadline for responses is **2nd November 2015**.

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New research shows shortfall in social care for older people at home

Age UK has published [research](#) showing that over 1 million older people are not receiving the social care support they need. This number has increased by 100,000 since last year.

The Association of Directors of Adult Social Services (ADASS) has [responded](#) to the findings.

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Key Events

End of Life Fundamentals - Workshops

[Registration](#) now open

The Royal College of Nursing (RCN) and NCPC are delighted to be working together on a series of [interactive workshops](#) on caring for people at the end of their lives.

Recent surveys have shown that health care staff feel unable to deliver the care they would like for people who are dying for a variety of reasons. These workshops are aimed

at practitioners working with people approaching the end of their lives and will provide opportunities to discuss what good end of life care should look like. They will offer possible ways of initiating conversations about end of life planning that could be useful in all areas of nursing. The workshops will also talk about the importance of nurses looking after themselves.

Sessions will include

- A review of the issues relating to End of Life Policy
- A patient's or carer's story
- Why discussing difficult issues is vital
- Bereavement
- Building resilience
- A review of RCN and NCPC resources
- Ask the audience

These workshops will be of interest to all non-specialist nurses in both the acute setting and the community and general practice, including care homes, particularly those working with people who have a life limiting illness and may want to talk about their worries and concerns.

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NCPC/Dying Matters: Upcoming Events

Training workshops The Mental Capacity Act & Advance Care Planning

3rd September

6th October

10th November

NCPC are holding a series of training workshops on *'The Mental Capacity Act'* and *'Advance Care Planning'* at our offices in London.

The half day workshops will take place on dates from September-November and delegates can join us for a half day choosing either The Mental Capacity Act (morning) or Advance Care Planning (afternoon), or attend both workshops over the course of the full day. There are a limited number of places left for the September date, and the October and November dates are selling fast. Book now on the NCPC website: <http://www.ncpc.org.uk/mca-acp>

15th October *Making Choice Happen: Delivering quality end of life care to make choice a reality for everyone*, The Waldorf Hilton, Aldwych, London, WC2B 4DD

It is widely acknowledged that choice is important to individuals and those close to them when approaching the end of life. However too many people still do not receive good quality care which meets their individual needs and wishes. The recent

independent review 'What's important to me: a review of choice in end of life care' sets out the actions required to enable choice, as more needs to be done to make this a reality for everyone. If you are passionate about end of life care and want to make choice a reality, then this is the conference for you. Registration is now open and the early bird rate of £120 is available to subscribers until 4th September. There is also an opportunity to showcase your work as a poster at the conference - submit your abstract by 8th September. Full details on the NCPC website:

<http://www.ncpc.org.uk/event/making-choice-happen-end-life-care>

****Save the dates****

1st December 10th Annual Conference on Dementia and End of Life, London

Full details for this conference, now in its 10th year, will be announced soon. Please email Marketing Manager, Mary Mc Colgan (m.mccolgan@ncpc.org.uk) to be added to the early bird waiting list.

2016

18th January Dying Matters Awareness Week 2016 Launch Event, London

Dying Matters will host its seventh annual Awareness Week from 9th-15th May 2016. Make sure to save the date for the Awareness Week launch event on 18th January, where we'll be sharing the theme for 2016 and all the top tips and resources to make your activities a success.

10th February Conference on Public health and community resilience in end of life care, North of England

As part of the programme, we will be sharing information from our Dying Well Community Charter Pathfinders. Full details about the Charter are available on our website (<http://www.ncpc.org.uk/communitycharter>), and details about the conference will be announced soon.

****Inaugural two-day conference and awards**, Keele University, Staffordshire**

New dates for your diary - we will be holding our inaugural annual two-day conference and awards on 23rd & 24th March at Keele University. Full details about this new and exciting flagship event, which includes confirmed speakers Sir Keir Pearson, Chairman of Health Education England and Dame Julie Mellor DBE, Chair and Ombudsman, Parliamentary and Health Service Ombudsman, will be announced very soon. The event also includes an awards ceremony recognising excellence and commitment to end of life care, and there are a number of sponsorship opportunities available. For full details, please see the NCPC website (<http://www.ncpc.org.uk/event/inaugural-ncpc-annual-two-day-conference-and-awards>) or email Marketing Manager, Mary Mc Colgan (m.mccolgan@ncpc.org.uk).

For a full list of upcoming conferences and workshops, please visit the events section of the NCPC website (<http://www.ncpc.org.uk/events-training>).

Further Information

About the Policy Round-up

This round-up is an exclusive service for NCPC subscribers. You can find out more and read testimonials at www.ncpc.org.uk/monthly-policy-roundup. It was compiled by Andrew Grey, NCPC's Policy and Public Affairs Officer. Please send comments relating to the content to policy@ncpc.org.uk.

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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.

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

About Dying Matters



Dying Matters is a national coalition led by NCPC which aims to support changing knowledge, attitudes and behaviours towards dying, death and bereavement, and through this to make 'living and dying well' the norm.

The Dying Matters Coalition, which has over 30,000 members, is working to address this by encouraging people to talk about their wishes towards the end of their lives, including how they would like to be cared for, where they want to die and their funeral plans, with friends, family and loved ones.

Membership is automatic for NCPC subscribers and will enable you to access a wide range of resources to help you talk about dying, death and bereavement. To find out more or to join visit: www.dyingmatters.org

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PDF copies of the roundup are stored in the online library: www.ncpc.org.uk/library.

To comment on items please email policy@ncpc.org.uk.

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Our mailing address is:

NCPC, The Fitzpatrick Building, 188-194 York Way, London N7 9AS