What about end of life care?
Mapping England’s Health & Wellbeing Boards’ vision for dying people

What we did

The National Council for Palliative Care (NCPC) undertook desk research during September-October 2012 to determine the extent to which the 152 new health & wellbeing boards (hereafter ‘boards’) being established across England were considering the needs of local people approaching the end of life. The boards’ emerging strategies were reviewed and a traffic light rating system applied.

What we found

- Of 152 boards, 118 had either published or consulted on their health and wellbeing strategy. Of these, 83 had a final or draft strategy available online for analysis during the research period. Nearly half of local boards (69/152) have no strategy publicly available.
- Fewer than half (46%, 38/83) of boards have explicitly considered dying people. Only 38 boards’ strategies talk about the need to improve or integrate support at the end of life (‘green’). 15 boards consider related issues or groups (e.g. older people), but do not directly mention the end of life (‘amber’).
- 30 strategies fail to mention people approaching the end of life either directly or indirectly in their strategies (‘red’).

What we recommend

Health & Wellbeing Boards represent an opportunity to do things differently: to innovate, integrate and use resources better. Many Boards have given significant thought to their strategies, in particular on how they can reduce illness and health inequalities. Many also talk about the ‘challenge of an ageing population’, but few explicitly consider the end of life. History shows that the omission of end of life care from strategies leads to a fragmentation in the delivery of better outcomes for dying people.

There is still time to put this right: Boards take on their statutory powers in April 2013. But action is needed as a matter of urgency, in particular for those boards who omit end of life care entirely. Also concerning are the 69 boards who have not yet drafted or made public their strategy: this must be addressed by local authorities as soon as possible to achieve transparency for local people.

NCPC have produced a What about end of life care? Action Sheet to help boards consider end of life care and support - visit www.ncpc.org.uk/influencing-toolkit for more information.
Full report

Introduction

Health & wellbeing boards (hereafter ‘boards’) are new statutory committees of every upper-tier Local Authority in England, set up by the Health & Social Care Act 2012. The boards bring together a range of key decision makers and are designed to improve integration between health, social care and public health. See About Health & Wellbeing Boards below for more detail on the purpose and design of the bodies.

Health & wellbeing boards present a key opportunity to achieve a more joined up, systems-approach to supporting people approaching the end of life. Boards should have a concern for end of life care because:

- It affects large numbers in any population and these numbers are increasing (consider current and bereaved carers too)
- It is often inadequately provided for – at least 90,000 people a year do not receive the palliative care they need
- It often lacks proper oversight (various services might be commissioned, but no one person looks at coordination, integration and outcomes)
- There are solutions, and getting it right can save money

In light of this The National Council for Palliative Care (NCPC) took the decision to track the progress of the boards and see whether dying people were among their emerging priorities. Most Boards have been operating in shadow form for several months, in anticipation of their launch in April 2013, and enough boards had started work that mapping could be started. At the same time, there remains enough time for boards who hadn’t considered end of life care to address their omission before it negatively impacted on local people.

Methodology

A list of the 152 upper-tier Local Authorities was obtained from the Department of Health by NCPC’s policy team. An internet search was carried out for the terms ‘health and wellbeing board’ ‘health and wellbeing board consultation’ and ‘health and wellbeing strategy’ for all 152 between 20 September and 10 October 2012. The resulting list was cross-referenced with the Kings Fund health and wellbeing board directory (www.kingsfund.org.uk/projects/health-and-wellbeing-boards/hwb-map).

Available strategies/ priorities (the style and length of the document varies depending on the board) were searched for references to ‘end of life’ care or people approaching the end of life. A traffic light system was used to categorise the extent of the mention:

- **Green** where the strategy explicitly mentions people approaching the end of life or end of life care services. This includes brief mentions (e.g. “improve end of life care services”) as well as those detailing why end of life care is important and how they will deliver it.
- **Amber** where the strategy considers related issues or groups (e.g. supporting older people), but not end of life care directly. A direct mention of ‘end of life’ is not necessary for this category, thus making amber quite generous in scope.

- **Red** where end of life care is not mentioned either directly or indirectly. This includes strategies which make reference to “the ageing population” or older people but do not provide detail.

**Findings**

Of the 152 Health and Wellbeing Boards due to be launched in April 2013 across England, NCPC identified 118 who had either published or consulted on their health and wellbeing strategy. Of these, 83 had some form of strategy (either in draft or final form) available online for analysis during the research period. Of these 83 strategies:


- **15 (18%)** were rated **amber** for indirectly mentioning or implying that end of life care would be considered. Including: Barnet, Blackburn and Darwen, Blackpool, Buckinghamshire, Calderdale, Cambridgeshire, Central Bedfordshire, Coventry, Ealing, Harrow, Lincolnshire, Manchester, Shropshire, Solihull, Southend-on-Sea

- **30 (36%)** were rated **red** for failing to mention end of life care anywhere in their strategy. Including: Brent, Camden, Devon, Dudley, Gateshead, Hackney, Hertfordshire, Islington, Kirklees, Leicester City, Luton, Medway, Middlesbrough, North Yorkshire, Northumberland, Oxfordshire, Peterborough, Reading, Rotherham, Sheffield, Somerset, St Helens, Stockton-on-Tees, Sutton, Swindon, Telford and Wrekin, Torbay, Wandsworth, Wiltshire, York

69 boards had no strategy available online. Reasons might include a lack of activity within the Local Authority to set the board up and/or draft a strategy; no information had been published for public consultation; a consultation has closed and the strategy is no longer available for the public to view online.
Good practice

Some examples of how ‘green’ boards have included end of life care in their strategies:

“Croydon performs significantly worse than the national average for end of life care [...] Not enough people are spending the end of their lives in locations of their choice. [...] People will tend to be taken to A&E when they become ill and, if their poor prognosis is not recognised or if support in the community cannot be arranged quickly, it is likely that they will die in hospital. [...] Better coordination of care across different locations and by different professionals is needed. [...] Improving the quality of end of life care in hospitals and across all other settings will make a positive difference to people at the end of life and their carers.”

- Croydon Health and Wellbeing Board, which proposes end of life care be one of two top priorities over the next five years

“Improve pathways for end of life care across health and social care to support and enable individuals with terminal conditions to actively plan death with dignity and choice. Through improving the systematic identification of patients who are at the end of life, and then providing the appropriate support, in particular, improving the co-ordination of care, quality of communication, and the provision of bereavement care.”

- Barking & Dagenham Health and Wellbeing Board

“We are also committed to delivering high quality end of life care that is co-ordinated around the needs of the individual, develop and implement a strategic approach to the management of long term conditions including end of life care. Develop integrated working and agreed pathways for older and frail elderly people (including end of life care) which take the whole person into account.”

- Derby City Health and Wellbeing Board

“Whilst we would all aspire to live a healthy long life, death is inevitable and our experience of death is important not only to minimise the individuals personal suffering but also for those who are bereaved.

What does the JSNA tell us? [Analysis of characteristics of Bolton residents dying every year]

<table>
<thead>
<tr>
<th>Strategic theme</th>
<th>Priorities</th>
<th>Outcomes</th>
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</thead>
<tbody>
<tr>
<td>Helping people stay well</td>
<td>• End of life and bereavement support services for relatives and carers</td>
<td>Reduction in suicide rate</td>
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<td></td>
<td>• Implementation of the suicide prevention strategy</td>
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<tr>
<td>Identifying &amp; dealing with problems early</td>
<td>• Identify all people with end of life needs in primary and secondary care through embedding the use of the NHS NW End of Life model, Prognostic indicator guide and the Gold Standard Framework.</td>
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<td>Taking good care of those with health &amp; social care needs</td>
<td>• Ensure people have a dignified and respectful death which supports the individual’s choices and preferences as far as possible and considers the needs of their families/carers using the PPC record and Liverpool Care Pathway.</td>
<td>Increase the proportion of people who die at home from 19.7% in 2008-10 to 23% by 2015.</td>
</tr>
<tr>
<td>Addressing the needs of the vulnerable &amp; complex</td>
<td>Provide specialist support for complex needs</td>
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- Bolton Health and Wellbeing Board
Strategic Objective 6: Allow people to die in the place of their choice with the care and support that they need

Why is this a strategic objective?
To ensure that people approaching end of life will be able to have a good experience in their preferred place of death, be that hospital, hospice or home. (County Durham the End of Life Care vision).

What is going well?
• County Durham has slightly higher numbers of people at the end of their life dying in their usual place of residence compared to the national figures.
• Approximately 1000 staff from across the agencies in County Durham have undertaken End of Life training.

Areas of development
• A lack of prompt access to services in the community may lead to people approaching the end of their life being unnecessarily admitted to hospital. The absence of 24 hour response services and timely access to advice and medication leads to unplanned admissions.

What you told us
• Encouraging a more open debate on the issues would be useful.
• End of life pathways need to be more joined up e.g. GPs, social care, agencies and families.
(Big Tent Event, June 2012)

Strategic Actions – How we will work together
• Adopt and implement the North East charter relating to a ‘good death’.
• Reduce the number of emergency admissions to hospital for people who have been identified as approaching their end of life by providing services in the community.

What are the outcomes / measures of success?

National End of Life Care Profiles
• Percentage of all deaths that occur in: hospital; own home; hospice; care home
• Percentage of hospital admissions ending in death (terminal admissions) that are emergencies

Draft for consultation
Conclusion

It was clear from our mapping that many Boards had given significant thought to their health and wellbeing strategies, in particular on how they can reduce illness and health inequalities. Many also talk about the ‘challenge of an ageing population’, but few about the rising number of people dying each year, or the over 90,000 people with unmet palliative needs. History shows that the omission of end of life care from strategies leads to a fragmentation in the planning and delivery of care and support locally, resulting in dying people and their carers being seriously let down.

It was also discovered during the course of the mapping that many Local Authorities already had health and wellbeing strategies pre-dating the Health & Social Care Act. It is unclear whether these were going to be used as the official strategy upon April 2013 or whether a new strategy would be developed.

Recommendations

There is still time to put this right: Boards take on their statutory powers in April 2013. We recommend that:

- **Boards rated red consider dying people as a matter of urgency.** There is a lot of help available, see for example NCPC’s *What about end of life care?* Action Sheet which gives tips and signposts to other resources – available at [www.ncpc.org.uk/influencing-toolkit](http://www.ncpc.org.uk/influencing-toolkit)

- **Boards rated amber could consider the particular needs of people at the end of life in more detail.** If there is a ‘green’ board nearby, why not ask them what they are doing.

- **Boards rated green are encouraged to tell NCPC more about what they are doing so we can share your tips and examples of good practice with red and amber boards.**

- The 69 boards who have not yet drafted or made public their strategy should address this as soon as possible to achieve transparency for local people. Where applicable they should also clarify whether health and wellbeing strategies pre-dating the Act would be refreshed or continued.

- **Local people and politicians are encouraged to check how their local board is faring on end of life care and push for commitments to making this a priority.**

Contact

We welcome your comments – please email policy@ncpc.org.uk or write to us at NCPC, The Fitzpatrick Building, 188-194 York Way, London, N7 9AS.

Acknowledgements

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About us
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.

NCPC leads Dying Matters, a national coalition of nearly 30,000 members changing knowledge, attitudes and behaviours towards dying, death and bereavement, and through this to make ‘living and dying well’ the norm. To find out more or to join visit: www.dyingmatters.org

Appendix - About Health & Wellbeing Boards

What are Health & Wellbeing Boards?

The Health and Social Care Act 2012 established local Health & Wellbeing Boards (hereafter ‘boards’) as a new statutory committee of every upper-tier Local Authority in England. They are designed to bring together key leaders from the health and care system work together to improve the health and wellbeing of their local population, promote integration of services and reduce health inequalities.

What will the boards do?

According to the Department of Health, the boards will:

- have strategic influence over commissioning decisions across health, public health and social care.

- strengthen democratic legitimacy by involving democratically elected representatives and patient representatives in commissioning decisions alongside commissioners across health and social care. The boards will also provide a forum for challenge, discussion, and the involvement of local people.

- bring together clinical commissioning groups and councils to develop a shared understanding of the health and wellbeing needs of the community. They will undertake the Joint Strategic Needs Assessment (JSNA) and develop a joint strategy for how these needs can be best addressed. This will include recommendations for joint commissioning and integrating services across health and care.

- Through undertaking the JSNA, drive local commissioning of health care, social care and public health and create a more effective and responsive local health and care system. Other services that impact on health and wellbeing such as housing and education provision will also be addressed.

Source: A short guide to health and wellbeing boards DH, 28 February, 2012

Who is on the boards?

Mandated members include:
the local authority director for adult social services
the local authority director for children’s services
the local authority director of public health
at least one local elected representative (e.g. the elected mayor or leader of the local authority and/or a councillor or councillors nominated by them)
a representative of local Healthwatch
a representative of each local clinical commissioning group

Boards are free to appoint additional persons as members, for example local voluntary groups or service providers.

When do the boards come into force?

Boards take on their statutory functions from April 2013. Many are currently operating in shadow form.

What are health & wellbeing strategies?

The Health & Social Care Act 2012 imposes a duty on Local Authorities and CCGs to produce “a joint health and wellbeing strategy” for meeting the needs identified in the joint strategic needs assessment.

The legislation does not specify the form the joint health and wellbeing strategy should take, but requires the Local Authority and CCGs to have regard to the Secretary of State’s mandate and any guidance issued by the Secretary of State when preparing the strategy. The strategy can be high level and strategic, focusing on the interface between the NHS, social care and public health commissioning, rather than being a detailed study of all the commissioning across health and social care in the local authority area.

The Act imposes a duty on partner CCGs, the local authority and the NHS Commissioning Board (in relation to its local commissioning responsibilities) to have regard to the joint strategic needs assessment and joint health and wellbeing strategy when carrying out their functions.

The Act requires the local authority and partner CCGs to consider how the needs in the joint strategic needs assessment could more effectively be met through the use of flexibilities available under section 75 of the NHS Act, such as pooled budgets, when preparing the joint health and wellbeing strategy.

Source: Health and Social Care Act 2012 explanatory notes

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1 Funding the Right Care and Support for Everyone Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review (DH, 2011)