THE NATIONAL COUNCIL FOR PALLIATIVE CARE

The Fitzpatrick Building
188 – 194 York Way
London N7 9AS
T: 020 7697 1520
F: 020 7697 1530
E: enquiries@ncpc.org.uk
W: www.ncpc.org.uk

Does dying matter to England's new Health and Wellbeing Boards?

Mapping England's Health & Wellbeing Boards' vision for people at the end of life

What we did

The National Council for Palliative Care (NCPC) undertook desk research during September-October 2012 and again in February 2013, to determine the extent to which the 152 new Health & Wellbeing Boards (HWBs) were considering the needs of people approaching the end of life. The HWBs' emerging strategies were reviewed and a traffic light rating system was applied.

What we found[1]

- **Of 152 HWBs, 35 (23%) had not published a draft, consultation or final health and wellbeing strategy.**
- **Of those boards who had published a strategy, only just over half (63/117, 54%) explicitly discussed dying people and end of life care (awarded 'green').**
- 15 /117 (13%) of HWBs were awarded 'amber' as although they did not explicitly consider the needs of dying people, they did discuss related issues in detail.
- 39/117 (33%) of HWBs failed to mention people approaching the end of life either directly or indirectly in their strategies (awarded 'red').
- Of the HWBs that had up-dated their strategies or produced new drafts or versions (some after public consultation) during the research period, **6/67 (9%) added or improved their information on end of life care.**
- Of the HWBs that had up-dated their strategies (some after public consultation) during the research period, **3/67 (4.5%) had taken out information on end of life care**.

What we recommend

HWBs represent an opportunity to do things differently: to innovate, integrate and use resources better. Many HWBs 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 not enough HWBs explicitly consider end of life care. History shows that the omission of end of life care planning leads to a fragmentation in the delivery of better outcomes for dying people.

HWBs take on their statutory powers in April 2013. Action is needed as a matter of urgency, in particular for those HWBs which have not included end of life care in their strategies. In addition, it

[1] Information correct at time of writing, 28th February 2013.

© The National Council for Palliative Care 2012
Registered charity number 1005671 | www.ncpc.org.uk

is of particular concern that 35 HWBs are still to make public their strategies: this must be addressed as soon as possible to achieve transparency for local people. Related to this point, HWBs' websites should also be updated to ensure strategies can be easily accessed, without having to search for them elsewhere on the internet.

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

Full report

Introduction

HWBs are new statutory committees of every upper-tier Local Authority in England, set up by the Health & Social Care Act 2012. The HWBs 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.

HWBs present a key opportunity to achieve a more joined up, systems-approach to supporting people approaching the end of life. HWBs should be concerned about end of life care because:

- It affects large numbers in every geographical area and these numbers are increasing due to our ageing population
- It is often inadequately provided for – at least 90,000 people a year do not receive the palliative care they need [2]
- 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 HWBs and see whether dying people were among their emerging priorities. Most HWBs have been operating in shadow form for several months, in anticipation of their launch in April 2013.

Methodology

A list of the 152 upper-tier Local Authorities was obtained from the Department of Health by the NCPC's policy team. An internet search was carried out for the terms 'health and wellbeing board' and 'health and wellbeing strategy' for all 152 HWBs between 20 September and 10 October 2012 and this was revisited in February 2013. The resulting list was cross-referenced with the Kings Fund HWB directory (www.kingsfund.org.uk/projects/health-and-wellbeing-boards/hwb-map).

Available strategies (the style and length of the document varies depending on the HWB) 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:

[2] *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)

© The National Council for Palliative Care 2012
Registered charity number 1005671 | www.ncpc.org.uk

- **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 in detail (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.

- **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 or dementia but do not provide detail.

Findings

Of the 152 Health and Wellbeing Boards due to be launched in April 2013 across England, NCPC identified 117 published strategies (draft, consultation or final) online during the research period.

The strategies took different approaches to end of life care as would be expected given their remit of focusing on their own local population needs. Many strategies followed the Marmot approach and discussed end of life care within a health inequalities and life-course framework. Other strategies focused on different priorities with end of life care being addressed under a variety of headings such as 'encouraging integrated working', or 'ensuring respect and dignity'. Some strategies identified end of life care as a specific priority for focus.

Of these 117 strategies:

63/117, 54% were rated **green** for explicitly mentioning end of life care in their strategy.	Barking and Dagenham, Bath and North East Somerset, Bedford, Birmingham, Bolton, Brighton and Hove, Bromley, Bury, Cambridgeshire, Cheshire East, Cheshire and West Chester, Cheshire West and Chester, Croydon, Derby, Derbyshire, Doncaster, Dorset, Durham, East Riding of Yorkshire, East Sussex, Essex, Hampshire, Haringey, Harrow, Havering, Hereford, Hillingdon, Hounslow, Kent, Kingston upon Thames, Lancashire, Leicestershire, Manchester, Merton, Milton Keynes, Newham, Northamptonshire, Nottinghamshire, Oldham, Plymouth, Portsmouth, Redbridge, Richmond upon Thames, Sandwell, Sefton, South Gloucestershire, Southampton, Stockport, Stockton on Tees, Suffolk, Surrey, Tameside, Torbay, Tower Hamlets, Trafford, Waltham Forest, Warrington, Warwickshire, West Sussex, Wiltshire, Windsor and Maidenhead, Worcestershire, York
15 /117 (13%) were rated **amber** for indirectly mentioning or implying that end of life care would be considered	Barnet, Blackburn and Darwen, Blackpool, Bradford, Calderdale, Central Bedfordshire, Coventry, Ealing, Hertfordshire, Lincolnshire, Medway, Rotherham, Manchester, Solihull, Southend-on-Sea

© The National Council for Palliative Care 2012
Registered charity number 1005671 | www.ncpc.org.uk

39/117 (33%) were rated **red** for failing to mention end of life care anywhere in their strategy.	Buckinghamshire, Camden, Cornwall, Darlington, Devon, Dudley, Gateshead, Gloucestershire, Greenwich, Hackney, Halton, Isles of Scilly, Isle of Wight, Islington, Kensington and Chelsea, Kirklees, Leicester City, Liverpool, Luton, Middlesbrough, North Yorkshire, Northumberland, Oxfordshire, Peterborough, Reading, Salford, Rotherham, Sheffield, Shropshire, Somerset, St Helens, Staffordshire, Stock-on-Trent, Sutton, Swindon, Telford and Wrekin, Wandsworth, West Berkshire, Wolverhampton

Hillingdon, Stockton-on-Tees, Torbay, Wiltshire, and York were originally graded 'red' in the research carried out in September/October 2013, but were re-classified as 'green' in February 2013 after up-dating their strategies and adding detail on end of life care. Cambridgeshire was originally graded 'amber' but was re-graded 'green' after adding information on end of life care after public consultation.

Leeds and Westminster were originally graded 'green' but were re-graded 'red' after they took out end of life care from their strategies during the research period. Shropshire was originally graded 'amber', but was downgraded to 'red' as there was no mention of end of life care in their latest strategy. Buckinghamshire was originally ungraded as only consultation information was available. But *'better preparation for dying and death; everyone should have a good death'* - was included in the feedback in their consultation document. However it was not then included in their short final strategy which was disappointing.

35 boards had no strategy available online. Reasons for this 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. In addition, some 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.

Good practice

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

Engagement Health ambition	Joint Activity	Outcome measures
At the end of my life I can decide where I want to die	End of life planning and coordination Appropriate support to care homes to improve end of life care.	Numbers dying in setting of choice Numbers with end of life plans

- Wiltshire HWB

© The National Council for Palliative Care 2012
Registered charity number 1005671 | www.ncpc.org.uk

“End of life care - why is it important?

It is estimated that there are people in need of end of life care who are not currently receiving services. Active case finding and good disease management would enable the majority of deaths to be anticipated and the end of life planned for. In 2008/9 195 patients were estimated to be receiving end of life care in comparison to an estimated number of 2102 who may have needed end of life care (NHS Comparators 2010).

General palliative care is provided through a variety of professionals in the community who support patients to manage their symptoms, signpost and refer them to specialist services. District nurses and GPs are the main providers of general end of life care. Additionally, Redbridge has a 24/7 primary care nursing service. [...]

Our vision

To improve availability of good quality, locally accessible, affordable and flexible end of life care for our residents.

What can we do?

Commissioning for end of life care should be based on the published End of Life Care pathway.[...] information for patients and carers, psychological, bereavement and spiritual care services, support for carers, and social care bereavement services also need to be available for the carers and families of patients who do not die in hospice provision but in the community.

Using the necessary levers, commissioners should ensure that providers are compliant with national guidance, including NICE guidance and recommendations on best practice to facilitate improvements in provision of end of life care services, such as the Gold Standard Framework, Preferred Priority for Care and the Liverpool Care Pathway. This should include the provision of 24/7 specialist advice.”

- Redbridge HWB

"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

“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]

Strategic theme	Priorities	Outcomes
Helping people stay well	• End of life and bereavement support services for relatives and carers • Implementation of the suicide prevention strategy	Reduction in suicide rate
Identifying & dealing with problems early	• 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.	
Taking good care of those with health & social care needs	• 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.	Increase the proportion of people who die at home from 19.7% in 2008-10 to 23% by 2015.
Addressing the needs of the vulnerable & complex	Provide specialist support for complex needs	

- Bolton HWB strategy

© The National Council for Palliative Care 2012
Registered charity number 1005671 | www.ncpc.org.uk

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)

EVIDENCE FROM JOINT STRATEGIC NEEDS ASSESSMENT
- For the period 2008-2010 the National End of Life Care profile for county Durham states:
  - 54% (8474) of all deaths were in hospital
  - 22% (3511) occurred at home
  - 19% (2991) occurred in a care home
  - 3% (475) were in a hospice
  - 3% (427) were in other places.
- Most deaths (58%) occur in NHS hospitals, with around 18% occurring at home, 17% in care homes, 4% in hospices and 3% elsewhere *End of Life Care Strategy. Department of Health, July 2008*).
- According to research done by Dying Matters who raise awareness of dying, death and bereavement, around 70% of people nationally would prefer to die at home or their place of residence.

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 24

- Extract from Durham Health and Wellbeing Board draft strategy, which includes end of life as one of six strategic objectives

© The National Council for Palliative Care 2012
Registered charity number 1005671 | www.ncpc.org.uk

Conclusion

It was clear from our mapping that many HWBs had given significant thought to their health and wellbeing strategies, in particular on how they can reduce illness and health inequalities. Many talk about the 'challenge of an ageing population', but few talk about the rising number of people dying each year, or the over 90,000 people with unmet palliative needs.[3] History shows that the omission of end of life care planning leads to a fragmentation in the delivery of care and support locally, resulting in dying people and their carers being seriously let down.

Next Steps

There is still a short amount of time to put this right: Boards take on their statutory powers in April 2013.

The NCPC will be contacting HWBs who have not considered end of life care and who have not produced a strategy offering help in the form of information, support and toolkits to assist them to address their omission before it negatively impacts on local people.

We recommend that:

- **The 35 HWBs who have not yet drafted or made public their strategy should address this as soon as possible to achieve transparency for local people.**
- **HWBs 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
- HWBs 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.
- HWBs 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.
- HWBs' strategies should be easily accessible from their websites to allow local people to see the HWBs' plans for end of life care.
- HWBs' strategies should include end of life planning which is relevant to people across all stages of life and includes specific outcome measurements.
- Local people and politicians are encouraged to check how their local HWB 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.

---

[3] *Where people die (1974–2030): past trends, future projections and implications for care*. Gomes B, Higginson IJ, Palliative Medicine January 2008 vol. 22 no. 1 33-41

© The National Council for Palliative Care 2012
Registered charity number 1005671 | www.ncpc.org.uk

Acknowledgements

This report was written by Alice Fuller, Policy & Parliamentary Affairs Lead, NCPC, with help from Alice Rigby, Policy & Events Officer, NCPC. We are indebted to volunteers Emma Barnes and Caroline Norrie for their assistance.

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 HWBs 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 HWBs 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 HWBs 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*

© The National Council for Palliative Care 2012
Registered charity number 1005671 | www.ncpc.org.uk

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 sits on the HWBs?

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

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

When do the boards come into force?

HWBs 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

© The National Council for Palliative Care 2012
Registered charity number 1005671 | www.ncpc.org.uk