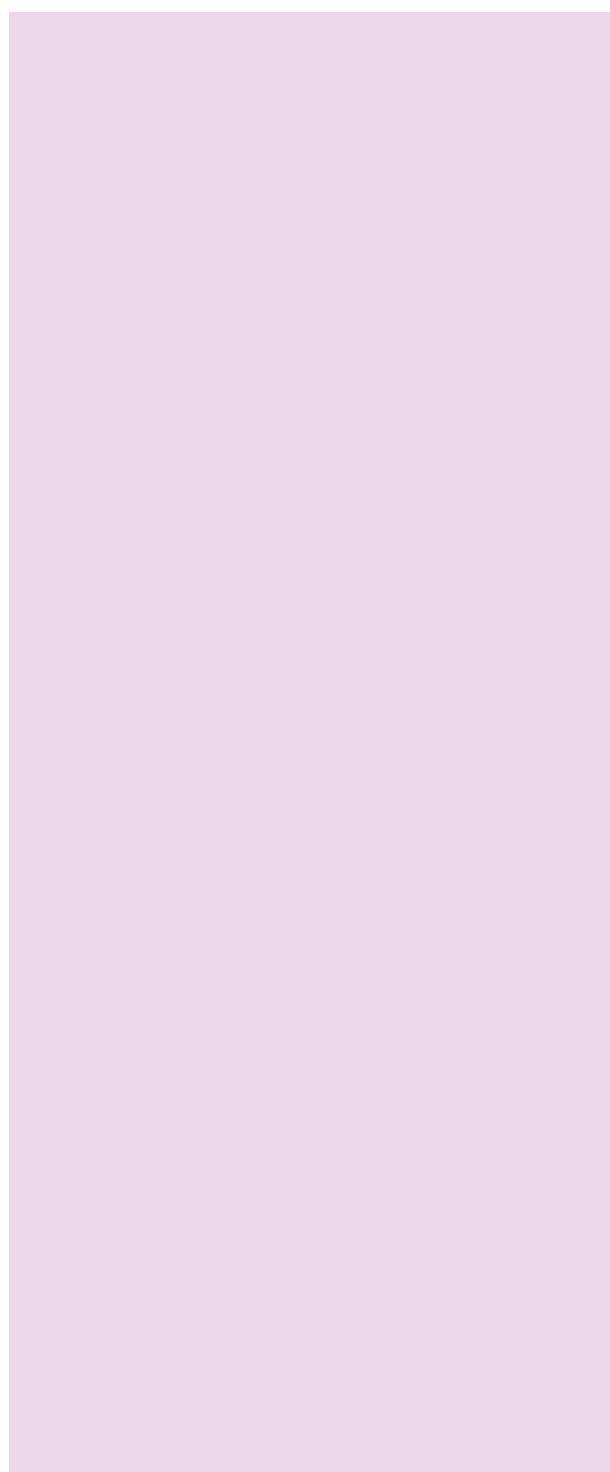


A 2030 Vision:

Building communities and environments to support people to live and die well



“We need to build compassionate communities which support people to grow older and die in the community. This requires clever use of housing and neighbourhood design, a long-term vision and partnership working across all sectors”



Contents

Executive Summary	2
About the workshop	3
Background	4
Roundtable discussion	5
Recent developments	5
Themes	6
Next Steps	11
Acknowledgements	12
References	13
About the authors	14

**THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE**



Executive Summary

This briefing describes the themes, challenges and solutions identified by participants at a strategy workshop held by the National Council for Palliative Care (NCPC) and National Care Forum (NCF) in August 2011. It forms part NCPC's wider, long-term 2030 Vision project, which cuts across health, social care and housing, and across voluntary, statutory and independent sectors.

Building compassionate communities in which people approaching the end of life and their families and carers feel supported, valued and cared for, not hidden away or isolated, will enable more people to die well in the community, which is the public's preferred, but largely unmet, place of care.

Clever use of housing and neighbourhood design is required to enable people to remain in the community through to the end of life, and improve their quality of life.

Greater public awareness of the need to plan for later life is required, accompanied by a funding system which helps people to prepare for the cost of long-term care.

A long-term vision which outlives government's inevitably short-term focus is required – a robust 2030 vision for palliative and end of life care encompassing housing, health, social care and beyond.

About the workshop

NCPC and NCF have worked closely on palliative care, housing and older people's issues for a number of years. The organisations came together to look at the theme 'Housing, design and the built environment' as the next step in NCPC's 2030 vision for palliative and end of life care, joined by leaders working across health, social care and housing, in August 2011.

The workshop was facilitated by Eve Richardson, Chief Executive of NCPC and the Dying Matters coalition, and Des Kelly, Executive Director of NCF.

The speakers were:

- David Hughes, Senior Partner at Pozzoni Architects
- Jeff Jerome, Strategic Advisor, Think Local Act Personal Partnership
- Simon Chapman, Director of Policy & Parliamentary Affairs, NCPC

Presentations from the main speakers set the scene and provided food for thought. Workshop participants, consisting of a range of professionals (see Acknowledgements), then participated in roundtable discussions. This briefing distils the discussions from the workshop as the means of setting out an agreed agenda for action.

Background

Workshop delegates identified a number of demographic, epidemiological and political factors which are central to the debate:

- **More people are dying each year.** The number of deaths each year in England and Wales is predicted to rise by 17% between now and 2030, from half a million to nearly 590,000 deaths each year.¹

- **Longer periods of ill-health.** Men can currently expect to spend 14.7 years of their life in poor general health, 16.9 years for women.²

- **Increasing prevalence of dementia and multiple conditions.** As people survive acute life-threatening diseases, they are living longer with chronic life-limiting conditions, and often with more than one condition. The impact of dementia in particular is increasingly being recognised, in light of the fact that one in three older people will die with the condition.³

- **More older people.** There were 14.1 million people aged 60 and over in the UK in 2010. This is projected to increase to 19.9 million by 2030, representing 28% of the total population.⁴

- **More people living alone.** Around two million people aged 75 and over live alone. The number of middle aged people (45-64 year olds) living alone increased sharply by a third between 2001 and 2011, with the 1960s baby boom generation having started to reach this age group.⁵ One million older people say they are always or often feel lonely.⁶

- **There is a lack of public awareness of both:**

- **The cost of long-term care.** Andrew Dilnot's Commission on Funding of Care and Support reported that the public are still largely ignorant of the potential cost of their long-term care bill, or how much of this will be picked up by the state. There is also a lack of private insurance plans available to cover risk.⁷

- **Dying, death and bereavement.** 68% of the public say they are comfortable talking about death, but less than a third have actually discussed their wishes around dying. A quarter of older people haven't written a will.⁸

- **People are working for longer and retiring later.** People need to work for longer in order to support themselves financially in retirement. Only 51% of UK workers are saving adequately for old age, with a fifth of people saving nothing at all.⁹ People are now free to work for longer, with the default retirement age scrapped in 2011, and the state pension age is set to rise to 66 for men and women by April 2020.

- **A context of deficit-reduction.** Funding will be very tight, at least for the next two parliaments. The overall degree of funding "chill" will depend on the extent to which government is prepared to cut funding in other public services or raise tax. Real terms NHS spending will have to rise by 1% per annum between now and 2017, just to keep track of population changes.¹⁰

Roundtable discussion



Recent developments

Delegates discussed the role of physical environments, infrastructure and communities in supporting the increasing number of older people living and dying in society. A number of existing national policy documents were identified as being important catalysts in this process:

- *End of Life Care Strategy* (2008, Department of Health) – the first comprehensive national strategy for palliative and care of life care for England. The strategy aims to alter the current trend towards less than one in ten people dying at home by 2030. Similar strategies are now in place in Wales, Northern Ireland and Scotland.

- *Lifetime Homes, Lifetime Neighbourhoods: A National Strategy for Housing in an Ageing Society* (February 2008, Departments for Communities and Local Government, Health and Work and Pensions) – a cross-cutting strategy aiming to ensure there is enough housing to meet forecasted pressures on homes, health and social care services, and new homes are built that can be easily adapted.

- *The Housing our Ageing Population Panel for Innovation (HAPPI)* - established in June 2009 following a commitment in Lifetime Homes (above) to advance good practice in specialist housing for older people with high or extra care needs. A final report was

published by Homes and Communities Agency, Department of Communities and Local Government and Department of Health in December 2009.

- *Think Local, Act Personal* is a sector-wide partnership which published a statement in January 2011 linking the government's Vision for Adult Social Care (Nov 2010) and the Putting People First programme (which ended in March 2011). The Think Local, Act Personal partnership was formally established in April 2011, comprising of over 30 national and umbrella organisations (including the NCF) to provide strategic leadership across the whole sector.

Themes

With these developments in mind, delegates identified a number of themes, opportunities and models of good practice:

1. Integrating housing, health and social care strategies and services

Strategies looking at housing must consider the specific needs of people approaching the end of life, and end of life strategies must consider the housing situation of people in this group. The environment in which a person lives and the support network they have access to has a profound impact on their needs, preferences and chances of receiving a good death.¹¹

NCPCC regularly hears of carers having to spend the last months, weeks or days of life telephoning various agencies across health, social care and housing trying to secure and coordinate services. It's not acceptable that people should undergo unnecessary stress and worry because services are not talking to each other. Structural integration, however, seems to be notoriously difficult to achieve, despite promises from a series of governments.

Health and Wellbeing Boards, subject to the Health and Social Care Bill, will be involved in the decisions of

local clinical commissioning groups and have the right to refer back plans that are not in line with the health and wellbeing strategy. Assuming that they are given strong enough powers, thoroughly employ the Joint Strategic Needs Assessment process and effectively engage with key providers locally, Health and Wellbeing Boards present a significant opportunity to join up health, social care and housing to the benefit of people approaching the end of life.

Involving all stakeholders - private, non-profit, voluntary, and statutory - in strategic decisions is essential. Jeff Jerome highlighted that over 90% of social care is provided by the independent sector (by private and voluntary sector service providers) and for every £100m spent by councils on social care services, around £40m is spent from the pockets of individuals.¹²

The **Think Local, Act Personal Partnership** established in April 2011 to provide strategic leadership on the delivery of the government's vision for adult social care comprises over thirty organisations, including English Community Care Association and NCF. This is a good example of an approach which includes the housing sector in the search for pragmatic solutions.

The same applies to providers of palliative and end of life care. In lieu of the state providing fully comprehensive care, voluntary and private sector providers will continue to fill the gap. **The Palliative Care Funding Review** proposed a tariff whereby money follows the individual through the system and awards funding to providers be they statutory, voluntary or private. It will be important that this tariff is fully integrated with the Commission on Funding of Care and Support's proposed funding system.



2. Addressing the double taboo – the fear of growing old and fear of dying

There is an urgent need for an informed public debate about the fact that people are growing older and dying without the support they need. Despite the abundance of negative stories in the press about mistreatment of older people and people at the end of life, the issue is still not treated as a national priority.¹³ Dying, death and bereavement still feel too remote for many people, particularly the baby boomers who often think they will live forever.

Practical resources to generate more conversations about dying, such as those produced by the [Dying Matters coalition](#) and its partners, have been shown to equip the public and professionals to have more open conversations about dying, death and bereavement. Find out more at www.dyingmatters.org

[Inter-generational volunteering opportunities](#), discussed further below, can also help to break down barriers that exist between younger and older people in society and misconceptions about what it is to grow older.

3. Helping people to plan for the cost of later life

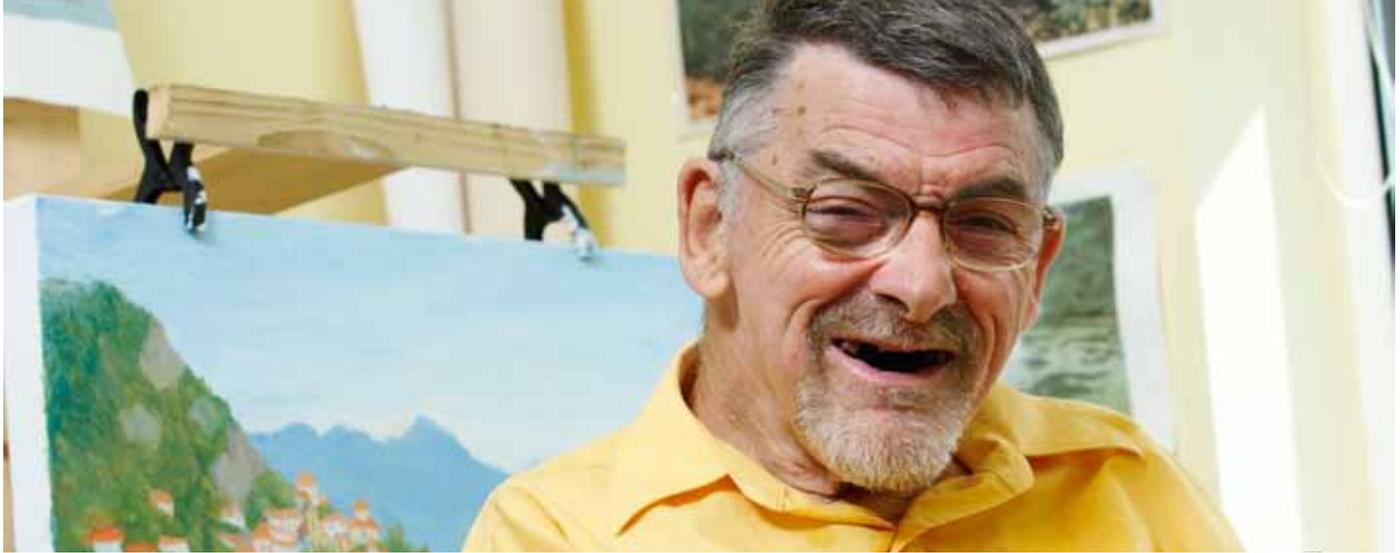
Participants at the workshop wondered if individuals needed to take more responsibility for planning for later life. Some felt that people had become too reliant on the safety net offered by the State in other areas, and wrongly assume that long-term care services would be in place and available free at point of use when they come to need them.

Simon Chapman from NCPA suggested that [Andrew Dilnot's proposals to cap the cost of long-term adult social care, if introduced, have the potential to enable people to better plan for later life](#). If a person has an idea of how much they are likely to have to pay for institutional care they will be more likely to plan for it and opt for cost-effective ways of delaying it, for example, by making practical adjustments to their home.

A more transparent system with clear caps is also likely to stimulate the financial sector to develop [new insurance policies which people can buy to protect against costs of care in later life](#). Dilnot's recommendation that the Government set up a working group for the financial services

industry and voluntary sector organisations to take this forward, would be a productive next step. Alongside this an [awareness raising campaign](#) is needed to educate the public about the cost of care in later life and confront the societal taboos which prevent people from planning ahead. [Dying Matters](#) is already working on changing people's behaviours in this regard.

Planning must be built into existing structures. People need to be 'nudged' into action, with prompts built into everyday services. For example, when you are writing your will, you should be prompted to think about long-term care costs and preferences for the end of life. This is the reason Dying Matters has been engaging with the banking and legal sectors. A good practice example can be found in the [Money Advice Service Health Check](#), an initiative from the Financial Services Authority which has pages on planning for retirement and bereavement.¹⁴



4. Making adaptations to people's homes

If more people's wish to die at home or other community setting is to be granted, we need to build homes and community settings that are capable of being adapted.

The **Lifetime Homes standard** introduced by the previous government went some way to ensuring future homes are more functional. Amongst the sixteen design criteria which form the standard several are particularly relevant to people approaching the end of life, including sloping entrances to homes, wide hallways, social spaces that are accessible to frail older people and places for residents to sleep if no longer able to use stairs.

The previous government committed to ensuring that all public sector housing would be built to the Lifetime Homes standard by 2011, with all new housing built to these standards by 2013. The Lifetime Homes Foundation

set up by Age UK, TCPA and Habinteg continues to promote the Standard, although progress is patchy.

5. Crafting different models of housing for different needs

Older people are not a homogenous group. They have different needs, preference, hopes and fears in relation to growing older and end of life.

David Hughes, senior partner in an architecture firm, commented that 'old age' is understood in the USA as anywhere between the age of 50 and 110. The group 'older people' will become broader as people live for longer. The needs and preferences of a person approaching the end of life in their 90s, who is very frail and has multiple long-term conditions including dementia, are likely to be very different to the needs and preferences of someone at 70 who is relatively fit and well.

One tangible example of this relates to preferred place of death. Home is generally preferred by everyone, although admission to hospice is preferred by many of the very old. This group currently has the lowest chance of dying in a hospice.¹⁵

We need to be clear about these differences and resist the urge to apply a 'one size fits all' approach. The **HAPPI panel** identified numerous examples of good practice of housing for older people, covering a spectrum of needs. The panel's final report contains a range of good practice examples from village to city setting, affordable to luxury, and levels of care.¹⁶

The **World Health Organisation's Age-Friendly Environments Programme** has also produced useful checklists for neighbourhood planning covering outdoor spaces and buildings, transport, housing, social participation and inclusion, employment and more.¹⁷

In addition to introducing more housing options, delegates said that people needed **access to genuinely accessible information**, to make choices about the sort of home they want to be in. Materials should be written in partnership with people with experience of using services. It was also pointed out that there will be an important role for brokerage, particular if initiatives such as personal budgets are to be effective as people approach the end of life. People can't choose if they don't know what their options are.

6. Combating social isolation

The majority of older people want to die at home, with hospice coming a very close second for people over 75.¹⁸ It could be speculated that the reason people move away from wanting a home death as they get older is that as death approaches the practical difficulties of dying at home become more apparent. It might also be that one's chance of being alone increases, particularly for women, making the prospect of dying home alone less appealing. Particular attention needs to be paid to supporting the growing number of older people who do not have access to support from family or friends.

The Dying Matters coalition

have sort to reduce isolation and break down taboos experienced by people facing death, dying and bereavement through the use of **regional champions and local development projects**. For example it partnered with the Lewisham Pensioners Forum's to deliver a **Home Alone at Christmas campaign** to raise awareness of the number of frail older people living alone, both in the national press and at the local level amongst communities.

7. Building compassionate communities

An essential part of reducing social isolation and loneliness is building communities wherein different generations support one and other. The sentiment behind the current government's vision of a **Big Society** wherein the states "equips people and organisations with the power and resources they need to make a real difference in their communities" has been welcomed by palliative and end of life care organisations.¹⁹

Examples of building compassionate communities were provided:

- Designing inter-generational communities where older people and those approaching the end of life aren't hidden away from younger generations. One example is

the **Gojikara Village in Japan** in which assisted living and care facilities for older people are built alongside a nursery for young children.

- Volunteering as a means of breaking down negative connotations of ageing. Delegates thought that schemes that encourage younger people to visit care homes, hospices and similar settings raise consciousness as to the reality of end of life and encourage people to think about one's own wishes.

- Ways of encouraging volunteering should be considered, such as the Japanese **care credit system** that allows people who volunteer with older people to claim back the credits for their own care in later life. The initiative had been endorsed by the current care services Minister. Delegates thought this might be one way of encouraging people who wouldn't normally volunteer to do so.

- There are ways of developing communities which foster relationships and go with the grain of people's lives and wishes. Mutually beneficial initiatives such as the **NAAPS' Homeshare scheme** wherein older people invite younger people to live in their homes in exchange for help and support, can work well.²⁰



8. Making better use of new technology

David Hughes gave examples of ways new technologies can be used to support older people and enrich quality of life. One example is the Japanese invention **RIBA** (short for ‘Robot for Interactive Body Assistance’) designed to assist nurses lifting people in and out of their beds and wheelchairs, and **Paro**, an interactive pet seal used as a therapeutic learning tool, particular for people with dementia.

Delegates also suggested that there would be a significant role for **social networking sites** in tackling social isolation in later life. It was noted that people over 50 were the fastest growing age group to

use social networking website Facebook.²⁰ There is no reason to think that such sites wouldn’t continue to be used by this group as they grow older and want to stay in touch with one and other into retirement.

9. Being realistic and accepting imperfection

In speaking about examples of good practice in housing design around the world, David Hughes noted that in many cases the designers and people living in the communities recognised that the environment worked despite being imperfect. This resonated with many of the workshop delegates who reflected how this had been true of many health, social care and housing

environments they’d been involved in.

It is important to be realistic about what we can achieve, use the resources and existing buildings we have to best effect and focus on what people approaching the end of life and their carers say they want from environments and services, rather than imposing a fixed model of care and support.

People would much rather have an imperfect experience which was personalised to their needs and offered them what they actually wanted, rather than a perfect but rigid or inappropriate service. Part of this is avoiding being so averse to risk that no chances are taken, and thus no benefits gained.

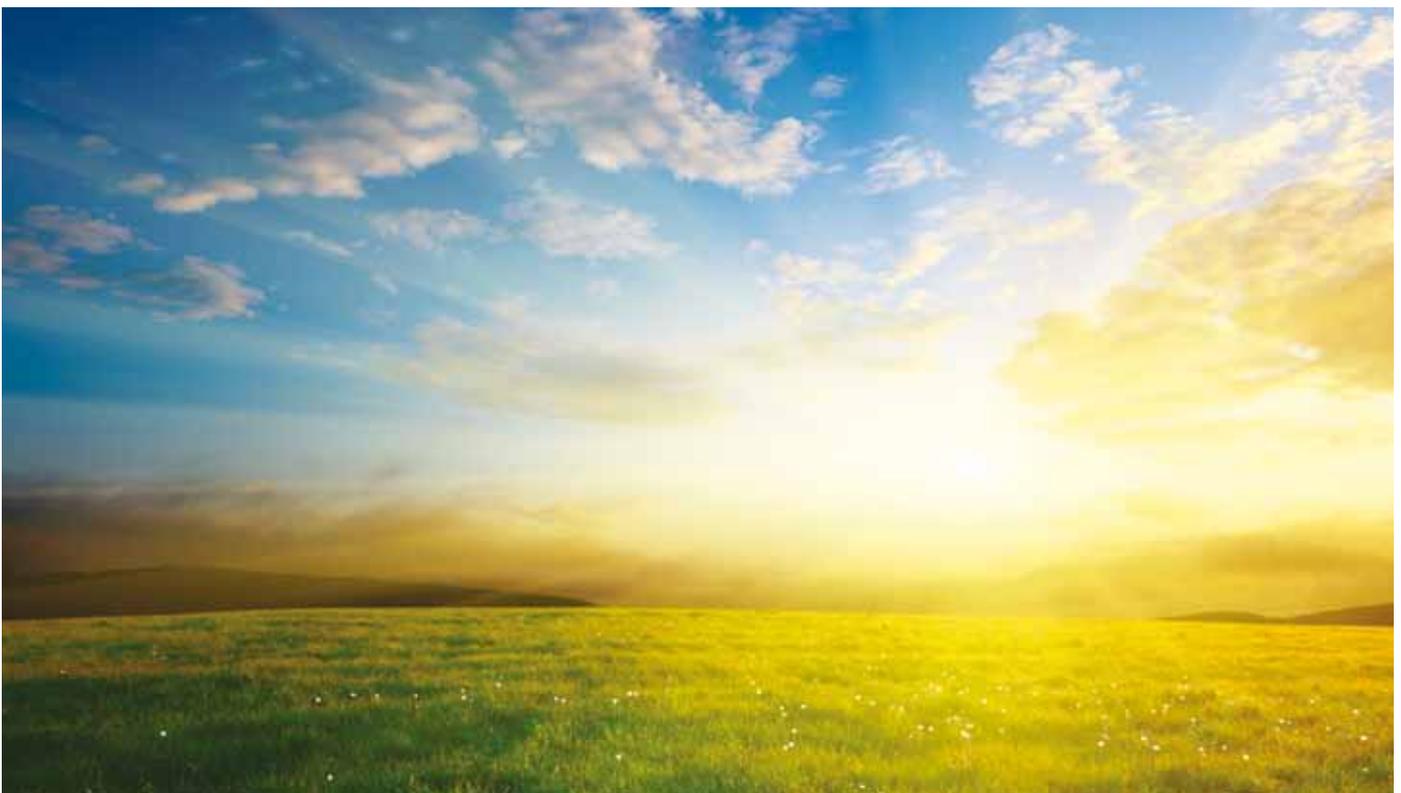
Next Steps

The workshop identified some of the challenges and potential solutions to bringing about change. Action is now required on the part of decision makers, commissioners and providers to make sure the inter-relationship between housing, health and social care are embedded in decisions made locally about how we support people approaching the end of life.

This requires disinvestment from acute services and

reinvestment in community services. We must also build compassionate communities in which death, dying and bereavement are no longer taboo subjects, and people approaching the end of life are supported to die in the way they wish and deserve.

NCPC and NCF will work with partners across health, social care, housing and beyond to craft and implement a vision for 2030 to which we can look forward.



Acknowledgements

The workshop facilitators were:

Eve Richardson, Chief Executive, NCPC and Dying Matters coalition

Des Kelly OBE, Executive Director, National Care Forum

We would like to thank the speakers who stimulated conversation on the day:

Jeff Jerome, Strategic Advisor, Think Local Act Personal Partnership

David Hughes, Partner, Pozzoni architects

Simon Chapman, Director of Policy & Parliamentary Affairs, NCPC

We are also grateful to the participants for offering their insights and expertise:

Caroline Bernard, Policy Manager, National Skills Academy for Social Care

Sharon Blackburn, Policy & Communications Director, National Care Forum

Leon Ferreira, Professional Social Care Consultancy, Leon Ferreira Associates

Helen Findlay, Former carer and member of NCPC's People in Partnership Group

Alice Fuller, Policy & Parliamentary Affairs Lead, NCPC

Kate Heaps, Chief Executive, Greenwich & Bexley Community Hospice and NCPC trustee

Pamela Holmes, Practice Development Manager, Social Care Institute for Excellence

Gerald Lee, Director, St Monica Trust

Joe Levenson, Director of Communications, NCPC

Marie Lovell, Project Manager, Skills for Care

Richard Macintyre, Operations Manager, Practice Development, Avante Partnership

Kwesi Marles, Cancer Environments Design Lead, Macmillan Cancer Support

Vicki Morrey, NCPC Vice-chair and trustee

Lewis Pickett, Public Affairs Officer, Care Quality Commission

Janet Rigby, Research Associate, The International Observatory on End of Life Care, Lancaster University

David Roberts, Assistant Director, Care Services, Adult and Community Services Dept on behalf of the Older Persons Network of ADASS

Sam Turner, Director Public Engagement, NCPC

Sarah Vallely, Intelligence Manager, Housing 21

This briefing was written by:

Alice Fuller, Policy & Parliamentary Affairs Lead, NCPC.

References

- ⁰¹ *Where people die (1974–2030): past trends, future projections and implications for care* Barbara Gomes and Irene J Higginson, *Palliat Med* 2008; 22; 33
- ⁰² *Deduced from Health Expectancies at birth and at age 65 in the United Kingdom, 2007–2009*. Office for National Statistics (ONS) Statistical Bulletin (August 2011)
- ⁰³ *Dementia before death in ageing societies – the promise of prevention and the reality*. Brayne et al, *PLoS Med* 2006; 3; 10
- ⁰⁴ *2010-based national population projections - principal projection and key variants*. ONS Statistical Bulletin (October 2011)
- ⁰⁵ *Families and households, 2001 to 2011*. ONS Statistical Bulletin (January 2012)
- ⁰⁶ *One Voice: Shaping our ageing society* (2009) Age Concern and Help the Aged
- ⁰⁷ *Fairer Care Funding: The Report of the Commission on Funding of Care and Support* (2011) Dilnot et al
- ⁰⁸ *Dying Matters NatGen Survey*, 2009
- ⁰⁹ *Scottish Widows UK Pensions Report* (2011)
- ¹⁰ *How cold will it be? Prospects for NHS funding: 2011–17* (2009) The King's Fund and Institute for Fiscal Studies
- ¹¹ *Factors influencing death at home in terminally ill patients with cancer: systematic review* Gomes and Higginson, *BMJ* 2006; 332
- ¹² *The State of the Adult Social Care Workforce in England, 2010* (Skills for Care 2010) showed that 73% of care only homes are privately owned and 17% are operated by voluntary sector organisations, taking the independent sector's share of care only homes to over 90%. That £40m is spent by individuals for every £100m spent by councils was calculated for the National Market Development Forum by the Institute for Public Care.
- ¹³ *See No Dress Rehearsals: Four key priorities to ensure we get end of life care right first time* (2011) NCPC
- ¹⁴ See <https://healthcheck.moneyadvice.service.org.uk>
- ¹⁵ *Local preferences and place of death in regions within England 2010* Barbara Gomes, Natalia Calanzani, Irene J Higginson (2011) Cicely Saunders International
- ¹⁶ See www.homesandcommunities.co.uk
- ¹⁷ See www.who.int/ageing/age_friendly_cities
- ¹⁸ Gomes (2011)
- ¹⁹ The Office for Civil Society, 2011 www.cabinetoffice.gov.uk/big-society
- ²⁰ See www.naaps.co.uk/en/homeshare
- ²¹ *Older Adults and Social Media* (2010) Pew Research Center

About the authors

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.

For more information visit www.ncpc.org.uk
email enquiries@ncpc.org.uk
or telephone 020 7697 1520



NCPC leads the Dying Matters coalition which aims to change public attitudes and behaviours around dying, death and bereavement.

For more information visit www.dyingmatters.org

ABOUT NCF

The National Care Forum (NCF) members are not-for-profit care providers. They are united by a common social purpose in which a commercial business approach to the provision of services enables reinvestment in services and development. By bringing together the entrepreneurial drive of a business approach with the ethos of public service, not-for-profit

organisations offer an innovative model of service delivery to the care sector. In this way NCF members are already making a significant contribution to communities and local economies through the full range of social care services.

The NCF embraces the diversity of the care sector and includes within membership a wide range of services. This includes: home care, housing with care, day care, intermediate care, outreach, residential and nursing care, and specialist provision for all adults and older people receiving care and support services through the not-for-profit sector.

For more information visit www.nationalcareforum.org.uk
or telephone 024 7624 3619

For more information visit www.ncpc.org.uk or www.nationalcareforum.org.uk

THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



**THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE**



£5 (free to NCPC subscribers and NCF members)

The National Council for Palliative Care

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

Tel: 020 7697 1520
Fax: 020 7697 1530

enquiries@ncpc.org.uk
www.ncpc.org.uk

Registered Charity no.1005671

A company limited by guarantee no.2644430

© Copyright the National Council for Palliative Care 2012

Published by National Council for Palliative Care
February 2012

The National Care Forum

3 The Quadrant
Coventry
CV1 2DY

Tel: 024 7624 3619

Web: www.nationalcareforum.org.uk