



**HELP THE HOSPICES  
COMMISSION**

*into the future of hospice care*

Being ready for the future:  
Key operating principles  
for hospice and palliative  
care services

Heather Richardson

# Overview of presentation

- Introducing the Commission into the future of hospice care
- A glimpse of the future
- Suggested operating principles in anticipation
- What next?

# History of the Commission into the future of hospice care

- 2010 – “Dying for Change” proposed a radical change to the way that end of life care is delivered in the UK
- Important opportunities for hospices
- Major challenges envisaged in the future

“To allow people the deaths they want, end of life care must be radically transformed...”

DYING FOR CHANGE

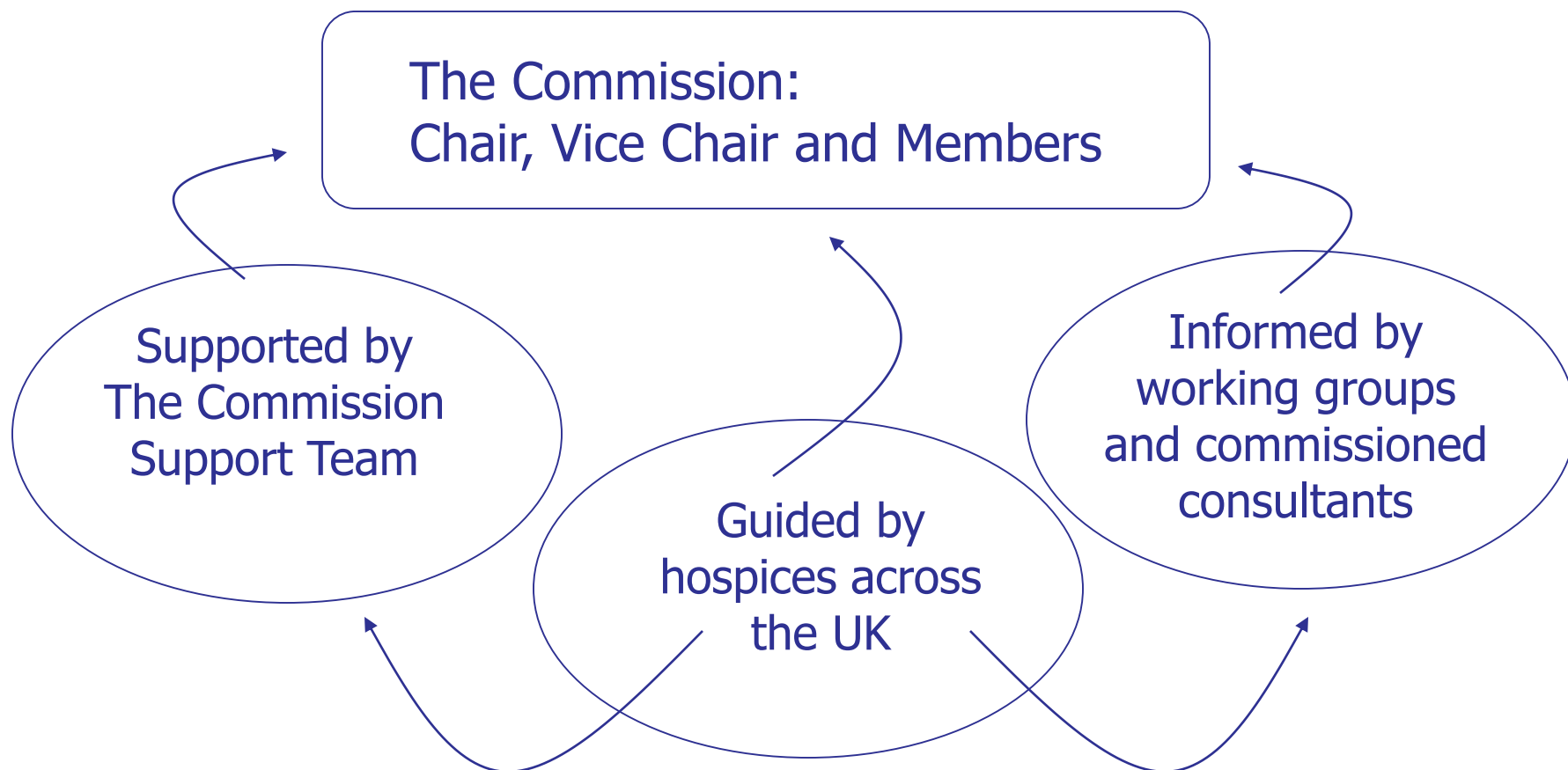
Charles Leadbeater  
Jake Garber

DEMOS

<http://bit.ly/byaDSH>

# Help the Hospices response

- To establish a national Commission that would:
  - Consider the context for hospice care in 10-15 years hence and what hospices need to do in the next 3 years to prepare
  - Take a UK wide perspective
  - Consider children as well as adult hospices
  - Attend to the needs and opportunities for NHS as well as independent hospices
  - Adopt a provocative and challenging approach
  - Report in October 2013



# Key work-streams

- What is the unique offering of hospice care?
- What needs and preferences for hospice care are likely to exist in the future?
- How do existing models of care need to adapt in response?
- What does a hospice workforce fit for the future look like?
- What funding opportunities are likely to exist in the future?
- Who should hospices be working with and how?
- What is the future of hospice education and research?

## Inputs

- Reflections of the Commission members
- Survey of over 700 users of hospice care
- 8 events with member hospices and other stakeholders
- Interviews with influential individuals
- Written submissions from individuals and organisations

## Outputs

- 14 working reports
- 1 toolkit
- Presentations and advice to many hospice boards, senior management teams and professional groups
- A final report with multiple recommendations

# A summary of the learning of the Commission

Future ambitions for  
hospice care: our mission  
and our opportunity

The final report of the Commission  
into the Future of Hospice Care



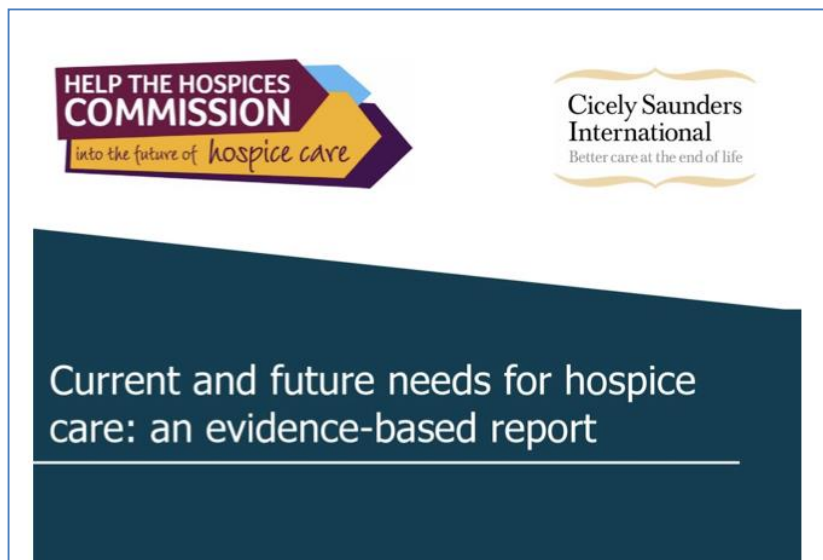
Message 1: Hospice care that is fit for the future needs to look different to what is provided today.

There is a strong case for change....

# A case for change: Different needs....

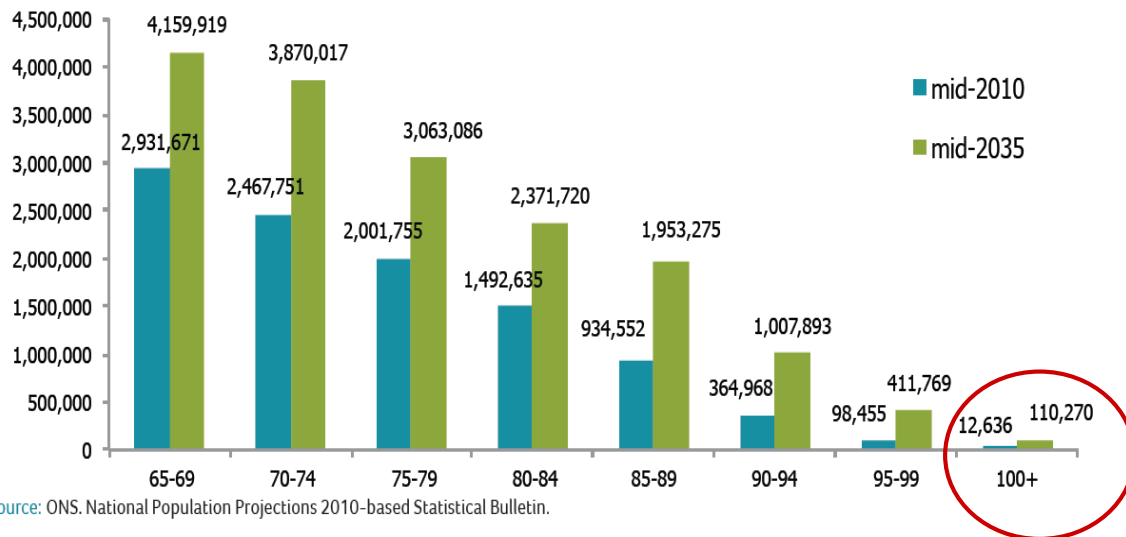
# Significant demographic and epidemiological changes

- Population ↑
- Elderly people ↑
- Chronic illness ↑
- Cormorbidities including dementia ↑
- People living alone ↑
- Access to informal carers ↓



- **UK population expected to increase 17.5% from 2010 to 2035 (from 62.3 mi to 73.2 mi)**
- **Baby-boom generations reaching older age**
  - Aged 65+ to account for almost 1/4 (23%) of the UK population, number of centenarians will increase more than eightfold

Figure 4 – Estimated and projected UK population aged 65+ and age distribution



# Escalating number of deaths replaces decrease in mortality

- **Number of deaths projected to increase very soon (from 2015)**
- **Aged 85+ projected to represent 49.5% of deaths in the UK**

**Table 6 – Actual and projected number and proportion of oldest old deaths in the UK (2010-2035)**

85+ deaths	2010	2015	2020	2025	2030	2035
85-89	104,357 (18.6)	95,974 (17.3)	94,532 (16.8)	97,990 (16.7)	105,344 (16.9)	127,128 (19.2)
90-94	64,509 (11.5)	74,609 (13.4)	77,464 (13.7)	83,923 (14.3)	93,356 (15.0)	105,169 (15.8)
95-99	27,535 (4.9)	28,988 (5.2)	38,494 (6.8)	45,284 (7.7)	55,692 (8.9)	67,587 (10.2)
100+	5,315 (0.9)	6,423 (1.2)	8886 (1.6)	13,579 (2.3)	19,321 (3.1)	28,585 (4.3)

Source: ONS. Mortality statistics: Deaths registered in 2010. ONS. Projected number of deaths obtained upon request.

# Changing picture of ill health

- Cancer on the increase, but as a chronic illness
  - Annual numbers of UK cancer deaths expected to increase 30% for men and 12% for women by 2023 (Olsen et al *Br J Cancer* 2008)
- Dementia will become a major issue
  - Projections show over 1 million people with dementia in the UK in 2021; by 2050 one in three people to die with dementia (Alzheimer's Society 2013)
- Many people living with multiple co morbidities
- Increased levels and incidence of disability associated with older age, frailty and chronic illness
- Impact on family carers will be enormous where these exist

# Changing family structures : multi-generational families and the growing role of grandparents

**The traditional horizontal family**

**The modern vertical family**

Great grandparents



Grandparents



Parents / Aunts & Uncles



Siblings / Cousins



# More people living alone

- In 1961 only 12% of English households were single person households but by 2033, 11.3m people are predicted to be living on their own – arise to 40% of all households.
  - This trend will apply across age groups with the number of people over 85 living on their own set to grow in the England from the current level of half a million to 1.4 million by 2032
  - (ref: Kings Fund – thinking differently).
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# A case for change - Changing preferences and aspirations for care.....

My patients don't  
trust me any more. I  
am constantly  
challenged in my  
decisions on their  
behalf

Hospice consultant 2013

# People want to share risk

## The Telegraph

HOME NEWS WORLD SPORT FINANCE COMMENT BLOGS CULTURE TRAVEL **LIFE** FASHION  
Women Motoring **Health** Property Gardening Food History Relationships Expat Puzzles  
Health News Health Advice Diet and Fitness Wellbeing Expat Health Pets Health

HOME » HEALTH » **HEALTH NEWS**

### Dying man campaigns for right to be human guinea pig

A man dying from motor neurone disease is campaigning for a change in the law so terminally ill people can volunteer to become human guinea pigs by taking unlicensed treatments.



# People want control



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### SPECIAL ARTICLE

## Implementing a Death with Dignity Program at a Comprehensive Cancer Center

Elizabeth Trice Loggers, M.D., Ph.D., Helene Starks, Ph.D., M.P.H., Moreen Shannon-Dudley, M.S.W., L.I.C.S.W., Anthony L. Back, M.D., Frederick R. Appelbaum, M.D., and F. Marc Stewart, M.D.

N Engl J Med 2013; 368:1417-1424 | [April 11, 2013](#) | DOI: 10.1056/NEJMsa1213398

# People want increased access to information

BMJ

BMJ 2013;346:f1990 doi: 10.1136/bmj.f1990 (Published 2 April 2013)

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## ANALYSIS

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### ESSAY

## How the e-patient community helped save my life: an essay by Dave deBronkart

**Dave deBronkart**—otherwise known as e-Patient Dave—describes his four year odyssey from cancer diagnosis to international patient superstar. His journey shows the contribution that patients can make to the complexities of medicine

Dave deBronkart *policy adviser on patient engagement*

## People want to influence the shape of care

*Hospices could do things more radically. They need users and members of the public to be critical and help them with this*

Hospices need to involve patients, families and carers constantly in developing and improving their services. Not as a one-off exercise but in genuine partnership. They need to harness their insights , experiences and use these to improve care services

Commission event for users and the General Public

The general public want greater access to hospice care

*"[End of life care would be improved) with a national definition and brand for hospice care, which confirms clearly what it offers. Who can get it and how they get access to it"*

# Communities want to contribute

Care in the  
community is  
vital with  
community  
involvement

Hospices should be  
key players in  
spreading the  
compassionate  
communities model-  
the country needs a  
shift in perspective  
away from the self

Commission event for users and the  
General Public



# The case for change...

## A very different business and health care context

# HELP THE HOSPICES COMMISSION

into the future of hospice

## DRIVERS

Technological  
advancements

Research  
developments

Availability of  
funding

Policy shifts



## CONSEQUENCES

New roles  
for hospices

New sources  
of funding

New  
alliances

New tasks and  
roles for staff  
and volunteers

### Three scenarios:

- The business of health
- All by myself
- Less is more

*Working towards  
a hospice workforce  
that is fit for the future*

A working paper of the Commission  
into the Future of Hospice Care

# Message 2: Hospices need to adapt in response

# Some key operating principles

1. Developing leadership for a new era
2. Developing the hospice workforce
3. Planning, analysing and acting on good data
4. Constantly reconceptualising hospice care
5. Reaching out – promoting conversation, informing and supporting choice
6. Telling a clear story about hospice care and acting on it

# Leadership fit for the future –

- At local and national levels
- For volunteers and paid staff – drawing in clinical and middle managers
- Strategic in focus
- Concerned with the population as well as the individual
- Some vital new skills required – partnership working, entrepreneurialism, evidence based management, politically adept

# The new hospice workforce

- Paid and volunteers
- Flexible
- New skills, new roles
- A different perspective – outward looking; future focused
- Influencers of others
- Aware of the bigger picture
- Interested to work in partnerships

# Using data more effectively

- Better information; sharper analysis; more entrepreneurial strategic planning
- Systematic measurement of reach and impact of care
- Better use of data to guide decisions
- Consideration of local issues for hospice care in the context of a national movement
- Drawing on the learning of others to guide our own...



# Reconceptualising hospice care

- Moving beyond a complacent belief in our work and impact to a position where we are constantly seeking improvement
- Looking for opportunities for partnering, collaboration and diversification
- More sophisticated balance of integration and independence
- Recognising competitors and new market opportunities, and repositioning accordingly
- Stronger links with users and members of the public to help reconceptualise hospice care to meet contemporary needs

# Reaching out; engaging communities

- Recognising our roots; building on the strengths of community engagement
- Promoting discussions about death, dying and loss
- Supporting community involvement and participation in care
- Using volunteers
- Being clear about what hospices provide; negotiating this with the communities who support us

# Telling a clear story and marketing it

- Articulating clearly what hospice care has to offer – beyond buildings
- Thinking carefully about who the stakeholders of the future are – moving beyond health; thinking of new populations, groups, funders
- Working towards transparency, evidence based promotion, consistent messages related to strategy, care, fundraising and appointment of the workforce

# A description of hospice care fit for the future

- It is concerned with dying, death and bereavement and living in this context
- It is innovative in nature
- It is integrated with the work of other providers
- It is led by people's needs
- It is expert in nature
- It is influential in nature
- It is community engaged
- It is pioneering
- It is provided in partnership with others

Key message 3:  
Hospices can't create a context in  
which they will flourish in the  
future alone

## Some key Steps required:

1. Prepare for significant changes in the future
2. Strengthen the understanding of the contribution of hospice care;
3. Establish hospice care as a solution to future challenges;
4. Strengthen the connection between hospices and local communities as well as the health and social care systems that serve them; and
5. Strengthen the leadership of hospice care.

# Who needs to be involved in the changes?

## Within hospices

- Boards or other governing bodies
- Senior management teams
- Heads of department
- Other staff
- volunteers

## Others

- National organisations supporting hospice care
- Academic centres
- Commissioners of care and education and training
- Planners of palliative and end of life care services
- The general public, users of services or representative organisations

# What next in the UK?

- Encouraging hospices to embrace the learning from the Commission
  - Boards and senior managers are key drivers of change
- Building on the interest at national level to promote hospice care as a solution to long term complex issues
- Establishing new relationships/partnerships
- Being ambitious, bold, creative and pioneering – back to our roots



"You cannot wait for consensus on everything;  
instead you must move fast and seek forgiveness  
later; the time for change is now"

The logo for the Help the Hospices Commission is located in the top left corner. It consists of a dark purple arrow pointing right, with a yellow arrow pointing right inside it. The text "HELP THE HOSPICES COMMISSION" is written in white, uppercase letters on the dark purple background.

HELP THE HOSPICES  
COMMISSION

*into the future of hospice care*

Thank you

[www.helpthehospices.org.uk/commission](http://www.helpthehospices.org.uk/commission)