THE NATIONAL COUNCIL FOR PALLIATIVE CARE

Dying Matters

'Let's talk about it'

Dying Matters -

A Community Approach to Raising Public Awareness

Eve Richardson
Chief Executive

THE DYING MATTERS COALITION

Dying Matters

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- Set up by the National Council for Palliative Care, the umbrella Charity for all those involved in palliative care, to support the 2008 End of Life Care Strategy

- It is a broad based, inclusive national Coalition, working in partnership, with over **15,000** members from across the NHS and voluntary and independent health and care sectors, social care and housing, faith, community and retirement organisations, schools, legal, insurance and funeral sectors.

Our Mission:

- ***"Support changing knowledge, attitudes and behaviours towards death, dying and bereavement, and through this to make 'living and dying well' the norm."***

www.dyingmatters.org

THE CHALLENGES

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Talking

- We don't talk about dying and death - impacting on our end of life choices
- Only 29% of people talked about their wishes in 2009 - less than in 2006 (34%)

Planning

- Around 500,000 people die each year in England – 58 % in hospitals, yet 70% of people would like to die at home

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WHY WE DON'T TALK ABOUT DYING

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Death is a long way off

47% of men

43% of women

20% of 75+

3% of 75+

19% of men

16% of women

I am too young to think about it

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RESEARCH AND INSIGHT

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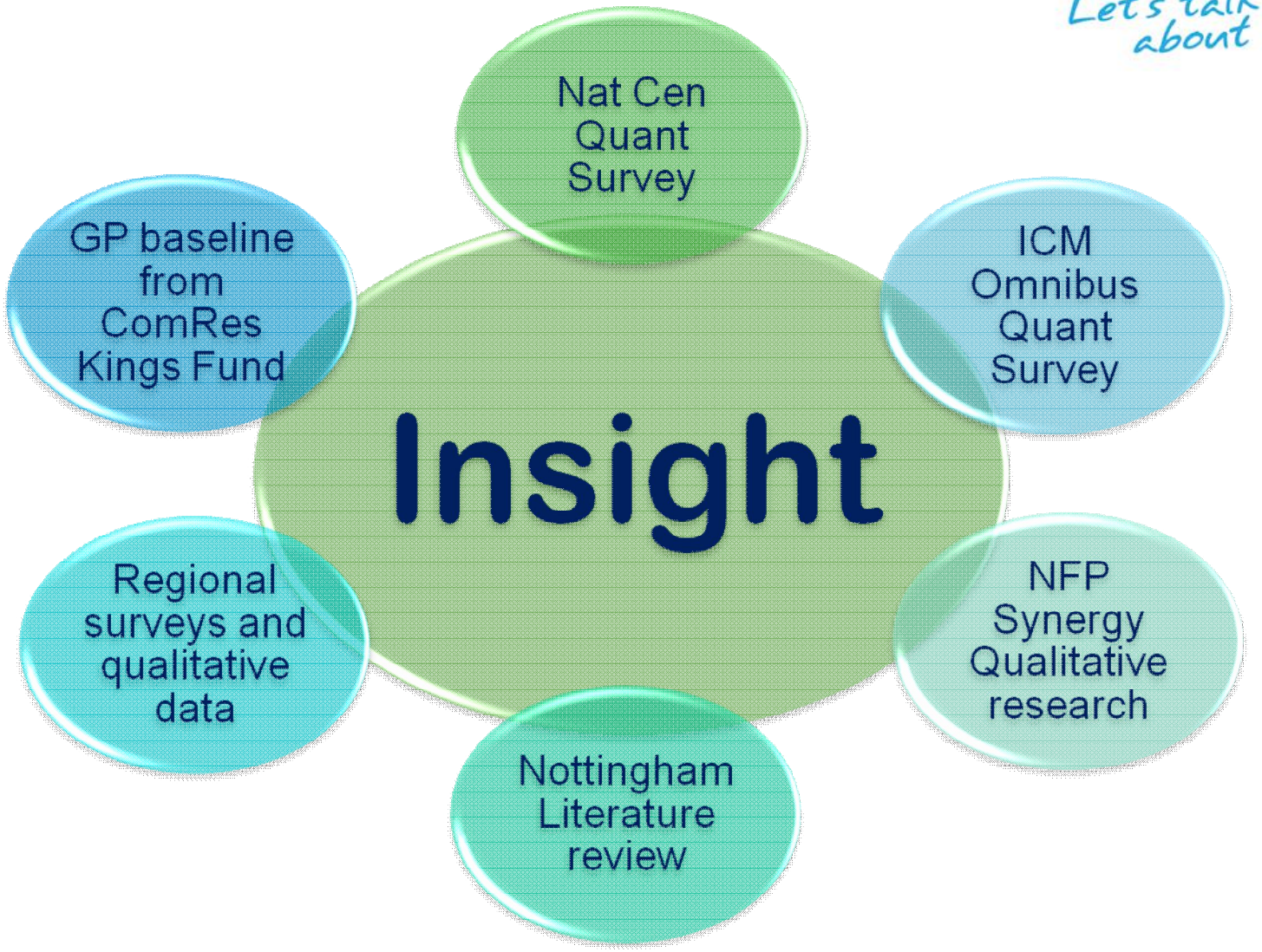

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IMPLICATIONS FOR ACTIONS

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Communication
is the key needed to make it easier for more people to talk about it

The "It's a long way off" perception: People more likely to talk to trusted family members and GPs

Different Approaches/tools Needed for different groups/audiences/ communities

target groups:

- **55 – 65s**
- **65 – 75s**
- **GPs**

Dying Matters GP Pilot Project

31% of public would like information about EoLC from their GP

and…

75% of GPs agree they should encourage patients to plan for EoLC...

Yet, only 5% of GPs have written a living will, 42% have discussed organ donation and 23% have discussed their funeral plans

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CHANGE IN GP CONFIDENCE

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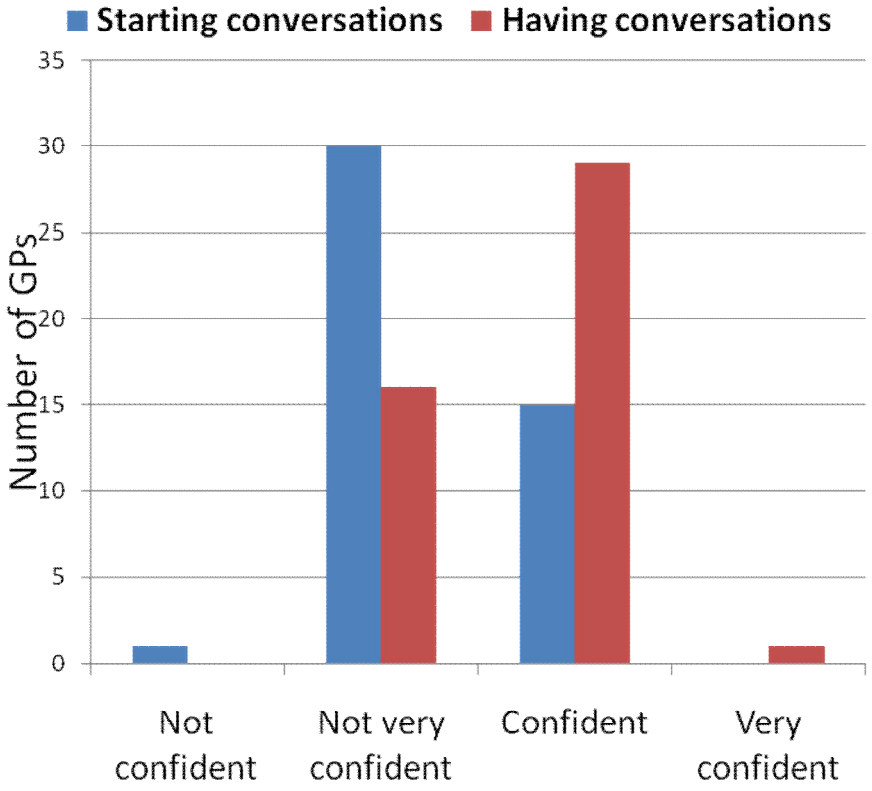
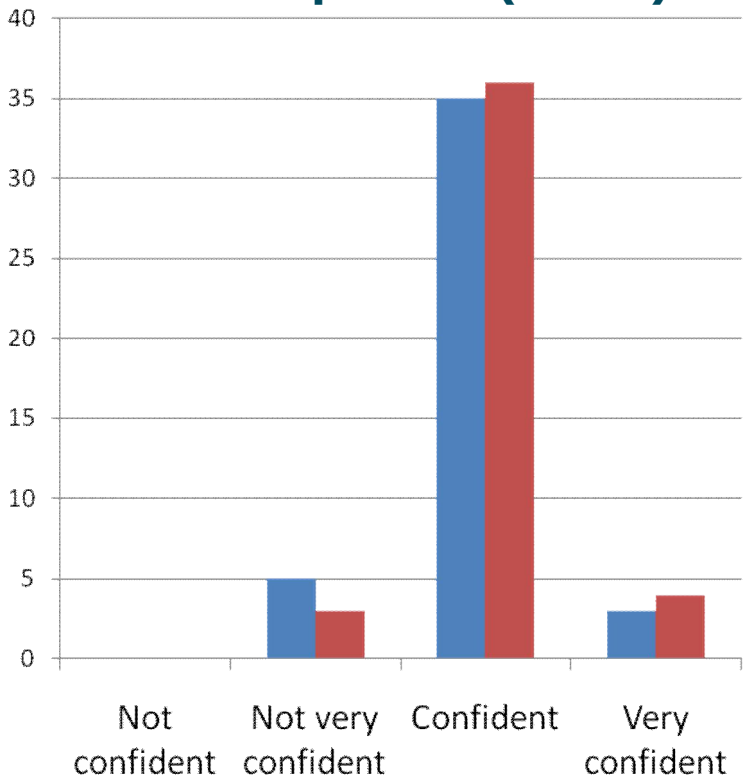
Change in all GP's self-rated confidence in starting and having conversations pre and post pilot

May 2010 (*n* = 46)



Sept 2010 (*n* = 43)



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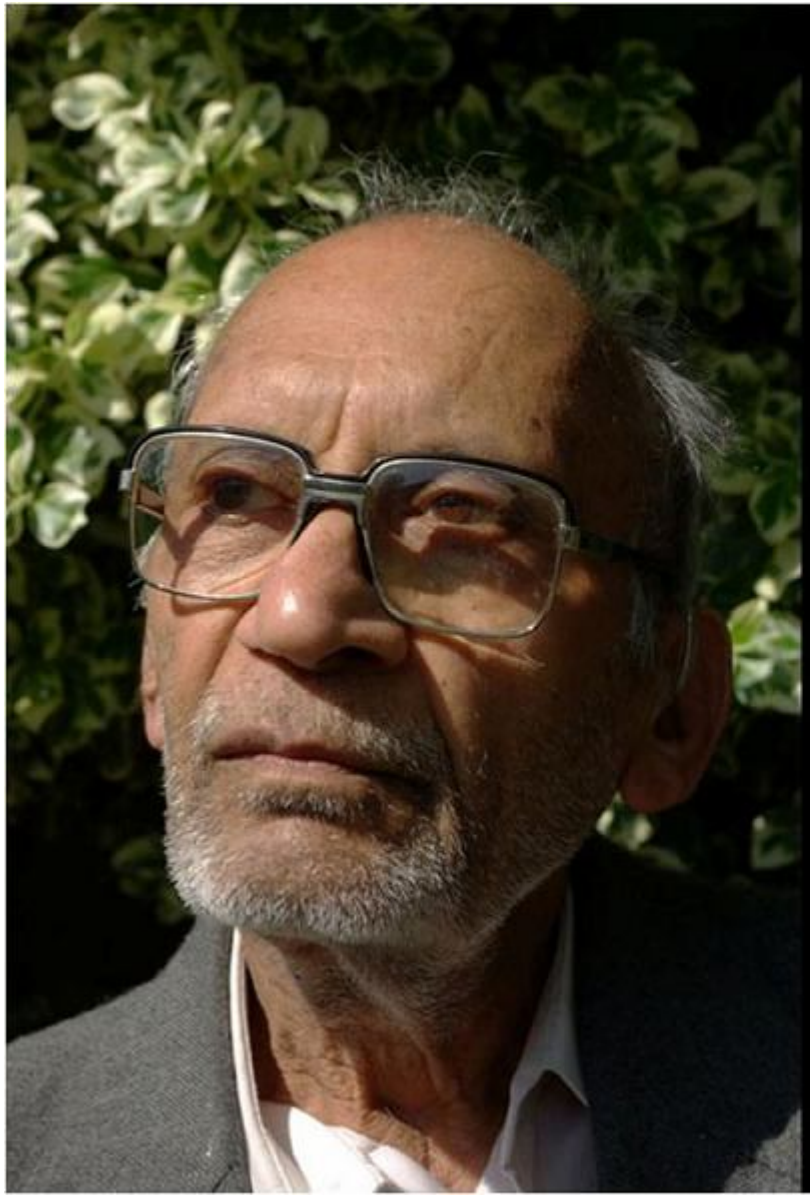

After she died, people crossed the street to avoid me, they weren't unkind, just didn't know what to say.

Community Development Programme

Community Group Members

- Local Hospices
- Funeral Directors & Solicitors, financial advisors
- Local Age Concern , NPC & other pensioner orgs
- Care Homes
- Nursing Homes
- Housing Associations
- Local Authorities
- Schools
- GPs, Carers
- Acute hospitals
- Community Champions
- Faith &belief Groups
- Bereavement groups
- PCTs, SHAs

Outputs

- Local network of engaged organisations
- Supporting materials encourage future planning
- Local events during 2011/12
- Higher local profile for DM

Outcomes

- More conversations leading to more planning, including PPC and ACP
- More DM members
- Greater priority for end of life care

Impact

- More people's wishes are met
- Improved end of life care

Practical resource with information and tips from different sectors on how best to work together to raise awareness in communities

What’s Happening in Lewisham?

DYING MATTERS PROJECTS WITH NCPC

Working with schools & hospices

" I look forward to the kids coming, I don't often get a chance to speak to people from that generation"

"This is the first time our work has ever meant something to someone else"

"I was really nervous about coming here but it's really nice, you kind of forget that people are ill after a while"

"It's really nice for the patients but it's also great for the staff, there's a different feel on a Wednesday when you guys come in"

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DYING MATTERS COMMUNITY

WWW.DYINGMATTERS.ORG/COMMUNITY

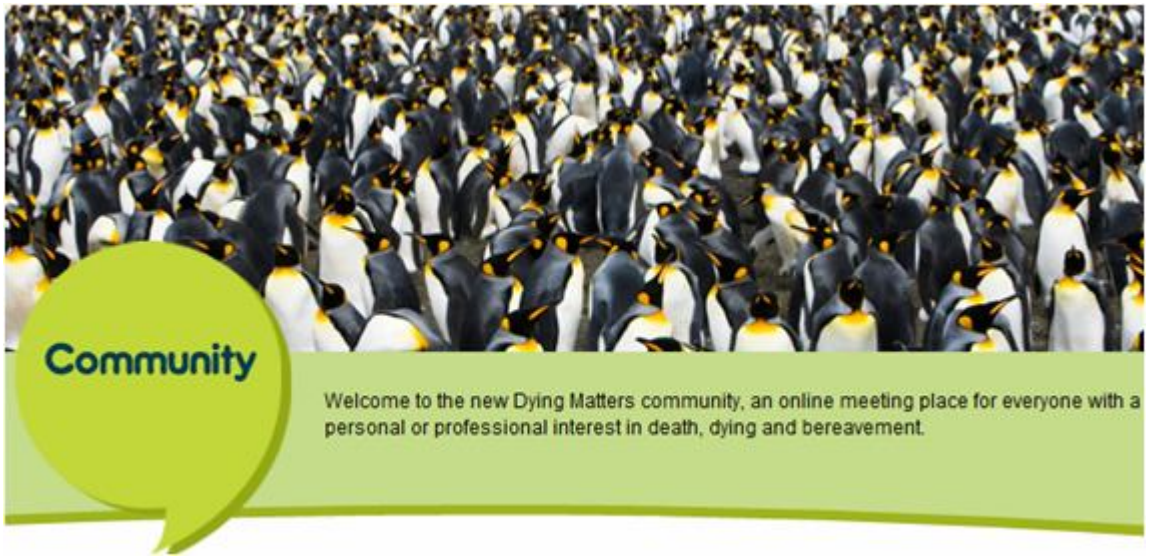
Dying Matters
Let's talk about it

Easy to use

- Simple registration process
- Offers forums, blog, share your event/story
- Users can post comments in forum and blog

You can:

- Register & post comments
- Add links & buttons to your websites
- Provide expert comment/ opinion
- Join DM Twitter & Facebook



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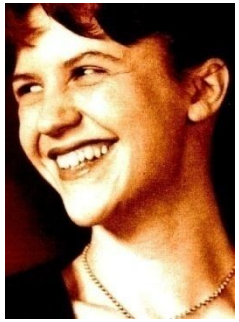
PLANNING FOR A 'GOOD DEATH'

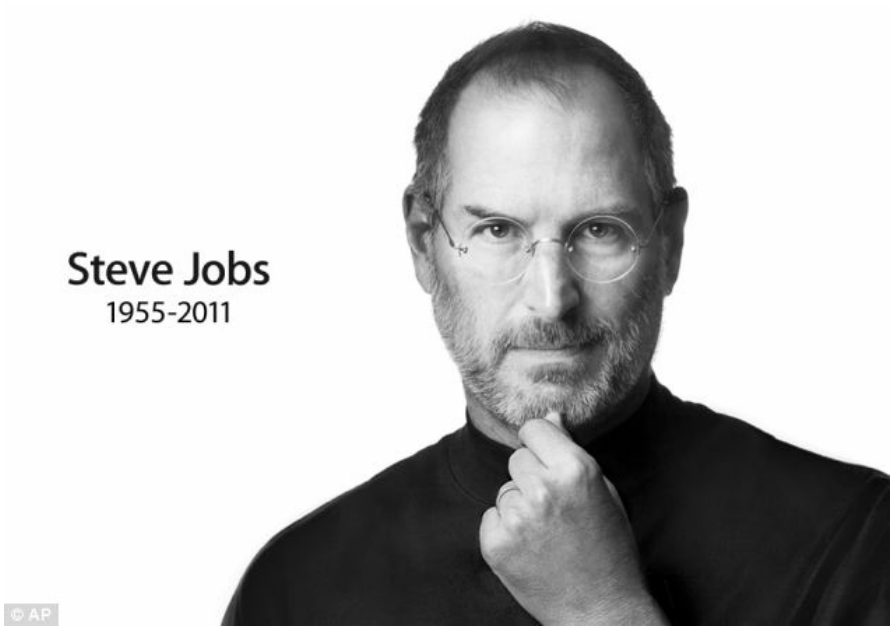
Planning for a 'good death' can include...

- Legal and Financial matters
  - Making a will, insurance, cost of funeral
- Organ Donation – save other lives
- Preferences
  - Type and place of care
  - Worries about being old or ill
  - Resuscitation decisions
- Funeral Arrangements
- Leaving a Memorial / Legacy
- Preparations for bereavement
  - What would you like people to know before you go?

"Dying is an art, like everything else, I do it exceptionally well."

Lady Lazarus by Sylvia Plath





Barack Obama:

“He transformed our lives, redefined entire industries, and achieved one of the rarest feats in human history: he changed the way each of us sees the world.”

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Steve Jobs, 1955 – 2011

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What You Can Do

- **Join Dying Matters** - www.dyingmatters.org
- **Lead by example** - think and talk about your own preferences for the end of life!
- **Get people talking** about their wishes earlier on
- **Get your organisation involved** in the Dying Matters Coalition
- **Join in the Dying Matters Awareness week May 14th – May 20th 2012**

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