PROGRESS WITH THE DYING MATTERS COALITION

Eve Richardson, Chief Executive
NCPC & Dying Matters

Hilary Fisher, Director
Dying Matters

"Many consider death to be the last great taboo in our society and ….most of us find it hard to engage in advance with the way in which we would like to be cared for at the end of life."

End of Life Care Strategy, Department of Health, 2008

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THE CHALLENGES

Dying Matters
'Let's talk about it

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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THE DYING MATTERS COALITION

Dying Matters
'Let's talk about it

- 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 **14,000** 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."*

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WORDS USED TO SAY DEATH OR DYING

Dying Matters
'Let's talk about it

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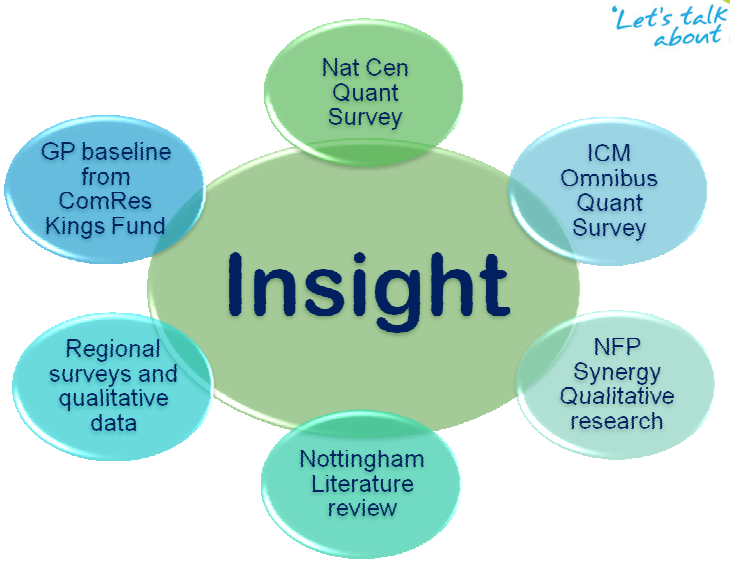
RESEARCH AND INSIGHT

Dying Matters
'Let's talk about it



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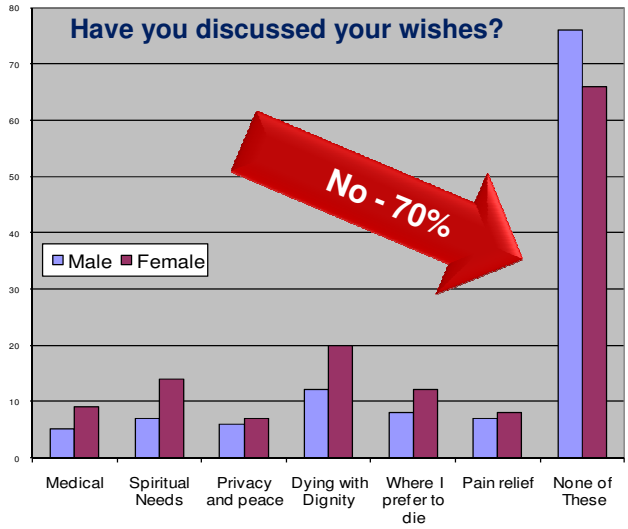
DYING MATTERS NATCEN SURVEY RESULTS (2009)

Dying Matters
Let's talk about it



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WHY WE DON'T TALK ABOUT DYING

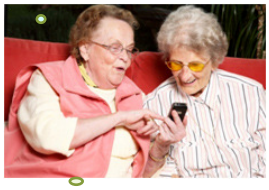
Dying Matters
Let's talk about it

Death is a long way off

47% of men

43% of women

20% of 75+



3% of 75+

19% of men

I am too young to think about it

16% of women

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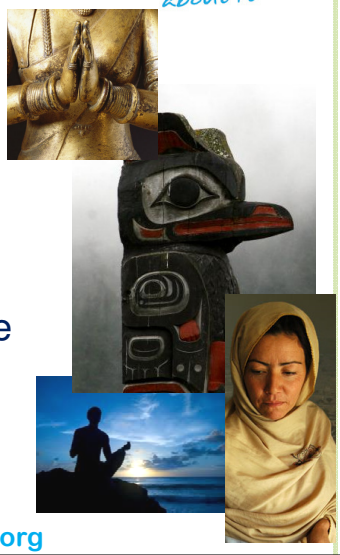
RESEARCH CONCLUSIONS

Dying Matters
'Let's talk about it

- Consensus among the public, across cultures, on factors for good EoLC
- We don't talk about dying
- Women more likely to talk than men
- Culture, history, faiths and meaning and belief systems are critical
- The trigger to is: "*To make life easier for family and friends*"



IMPLICATIONS FOR ACTIONS

Dying Matters
'Let's talk about it

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

TARGET AUDIENCES

Dying Matters

'Let's talk about it'

Identified key target groups:
- 55 – 65 years
- 65 – 75 years
- GPs

"We have classes if you're going to have a baby, getting married, divorced, but there's nothing for dying!"

Good Social Networks

Less well off

Well off

Poor Social Networks

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SANDRA: FEMALE 55 – 60 WEAK SOCIAL NETWORKS - LESS WELL OFF

Dying Matters

Part time shift manual worker. Lives in rented accommodation shift worker with husband. Could be a hospital or social care employee. Has no savings, close to parents. Fairly unhealthily lifestyle. Not many friends so no-one to talk to, husband not willing to talk.

Propensity to 'Talk'	2/5
Has close family members	Only husband
Is a carer	keeps an 'eye' on mum
Parents alive	Yes mother
Has a will	No
No. Visits to a GP per year	2-5

Partner organisations used to target	NHS employees Social Clubs Bingo network
Proposed Targeting Activities	Popular Media Soaps Local Radio
Objectives	To find someone to talk to Has a will
Activities 2011/12	Workplace outreach
Desired Change by 2012	Has been offered chance to talk. Has a Will

Media influences

Local Radio
Local free sheet
Employee Newsletter

Social Networks / groups and clubs

Work Social
Clubs
Bingo

Dying well is more likely to be achieved by talking about it early on.

DYING MATTERS PROJECTS WITH NCPC

Dying Matters
Let's talk about it

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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Community Development Programme

Dying Matters
Let's talk about it

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

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DYING MATTERS GP PILOT PROJECT

Dying Matters
'Let's talk about it'

- **Aim:** Support GPs in conversations with patients & relatives about dying & death
- **31%** of public want information about EoLC from their GP
- **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
  - 23% have discussed their funeral plans

Evaluation results

- It is possible to increase GPs confidence in having end of life conversations
- Conversations between GP and patients, family members and carers result in actions which contribute to a good death
- The Dying Matters communication materials were useful to GPs and helpful to patients

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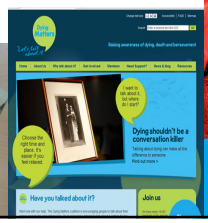
DYING MATTERS SUCCESS 2010/11

Dying Matters
'Let's talk about it'

- Party for Kath won HC in IVCA Clarion Video Awards 2010
- **Awareness Week** saw 127+ members run self-funded events
- Website successful it will now be the public facing website for the NHS QIPP campaign
- **Materials** popular sent out over 50,000
- **GP project** improved confidence & patient's experience
- **Working in partnership** range of communities testing materials & messages
- **Working with schools** on a range of projects (led to a *Jack Petchy* award) and developed a schools lesson



PLANNING FOR A 'GOOD DEATH'

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

Lady Lazarus by Sylvia Plath

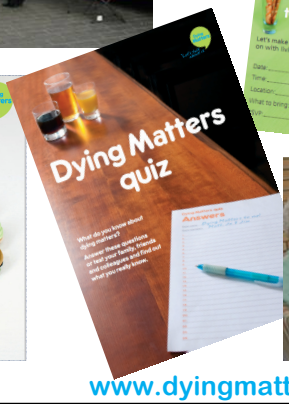
Planning for a 'good death' can include...

- 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 MATTERS AWARENESS WEEK 16 – 22 MAY 2011?

Dying Matters

'Let's talk about it



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WHAT YOU CAN DO

Dying Matters

'Let's talk about it'

Join Dying Matters Today...
Sign up for FREE at
www.dyingmatters.org

- Become a local champion raise awareness in your community
- Get your organisation involved & plan an event in your community

'How people die remains in the memory of those who live on' *Dame Cicely Saunders*