



**Dying  
Matters**

*'Let's talk  
about it'*



**RAISING PUBLIC AWARENESS  
OF DYING DEATH, LOSS AND  
BEREAVEMENT**

**Hilary Fisher,  
Director, Dying Matters Coalition**

# 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%)

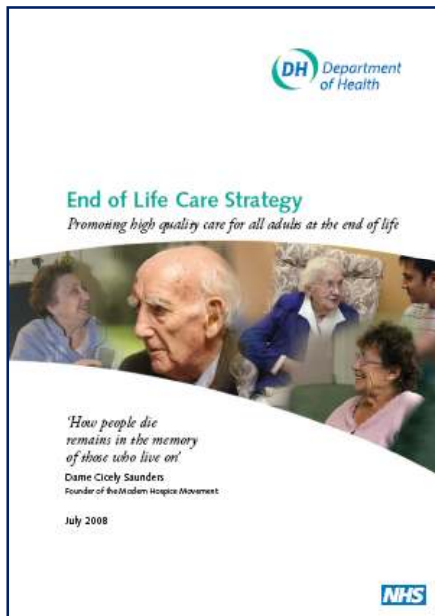
## Planning

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

# NEED TO PROMOTE PUBLIC AWARENESS

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*“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, July 2008*

[www.dyingmatters.org](http://www.dyingmatters.org)



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# WHY TALK ABOUT IT



# WORDS USED TO AVOID SAYING DEATH OR DYING

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A word cloud of various euphemisms for death and dying. The words are arranged in a roughly circular shape, with some words being significantly larger than others. The words include: last, bread, better, Run, daisies, Met, place, Kick one, Bit, clogs, Taken, Croaked, Fallen, Checking, coil, joined, Sleeping, Jesus, curtain, Expired, Pegged, toes, south, ghost, dust, maker, quickly, Shuffled, Turned, Gone, breath, chips, Six, Popped, underneath, Passed, away, Pushing, Paying, Fading, Brown, Deceased, mortal, Demise, Cashed, bucket, Checked, perch, Invisible, mortal, Bitten, grass, bucket, sleep, nature, Given, nature, big, Choir.

# METHOD - COALITION

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- **Dying Matters Coalition** - set up by NCPC
- No quick fixes – medium to long time frame
- Rationale – social marketing - shifting social norms requires a broad range of organisations using their combined influence
- Enables reach and support of wide range of groups - 12,000 members across a range of sectors

## Our Mission:

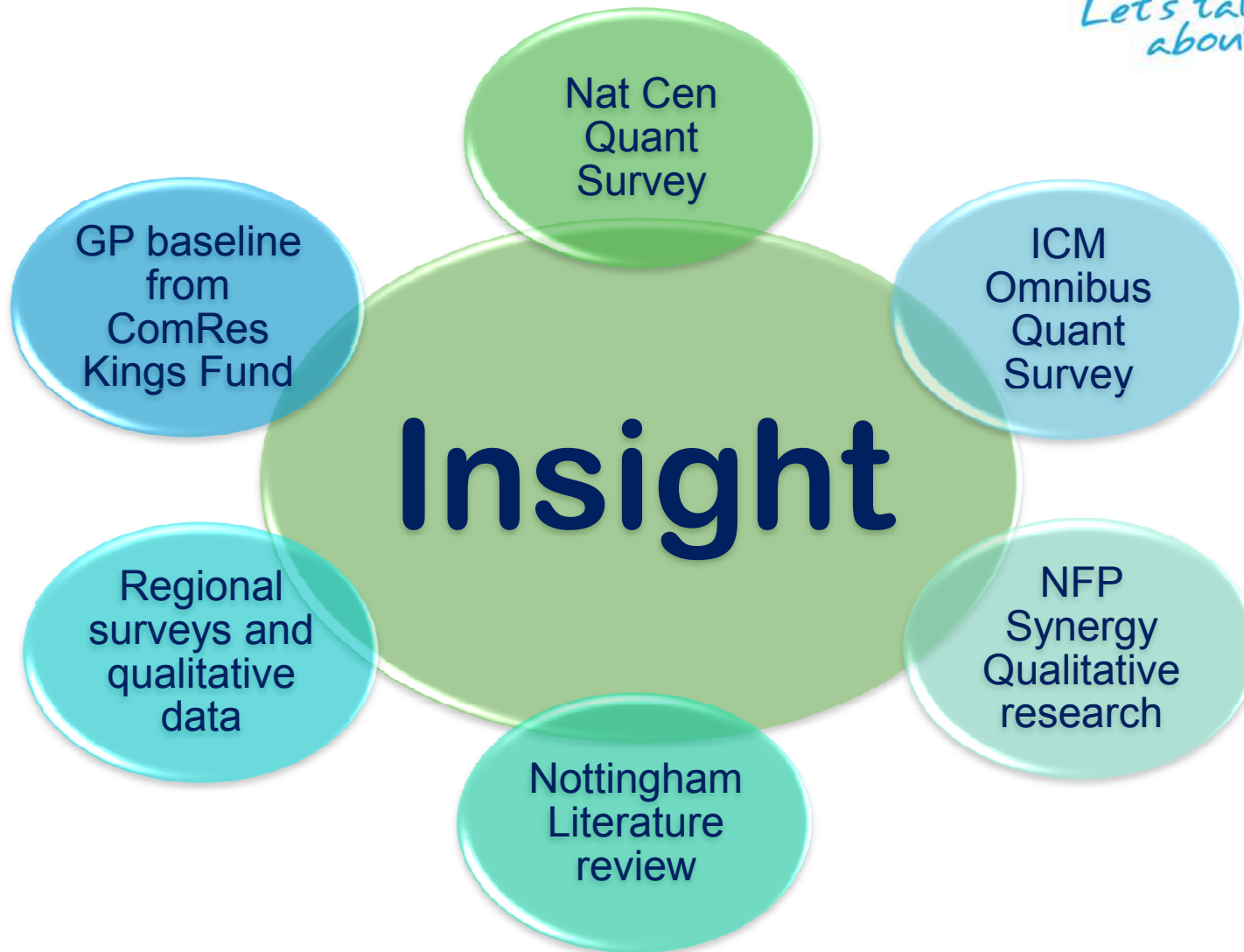
- *“Support changing knowledge, attitudes and behaviours towards death, dying and bereavement, and through this to make ‘living and dying well’ the norm.”*

[www.dyingmatters.org](http://www.dyingmatters.org)

# RESEARCH AND INSIGHT

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# LITERATURE REVIEW FINDINGS

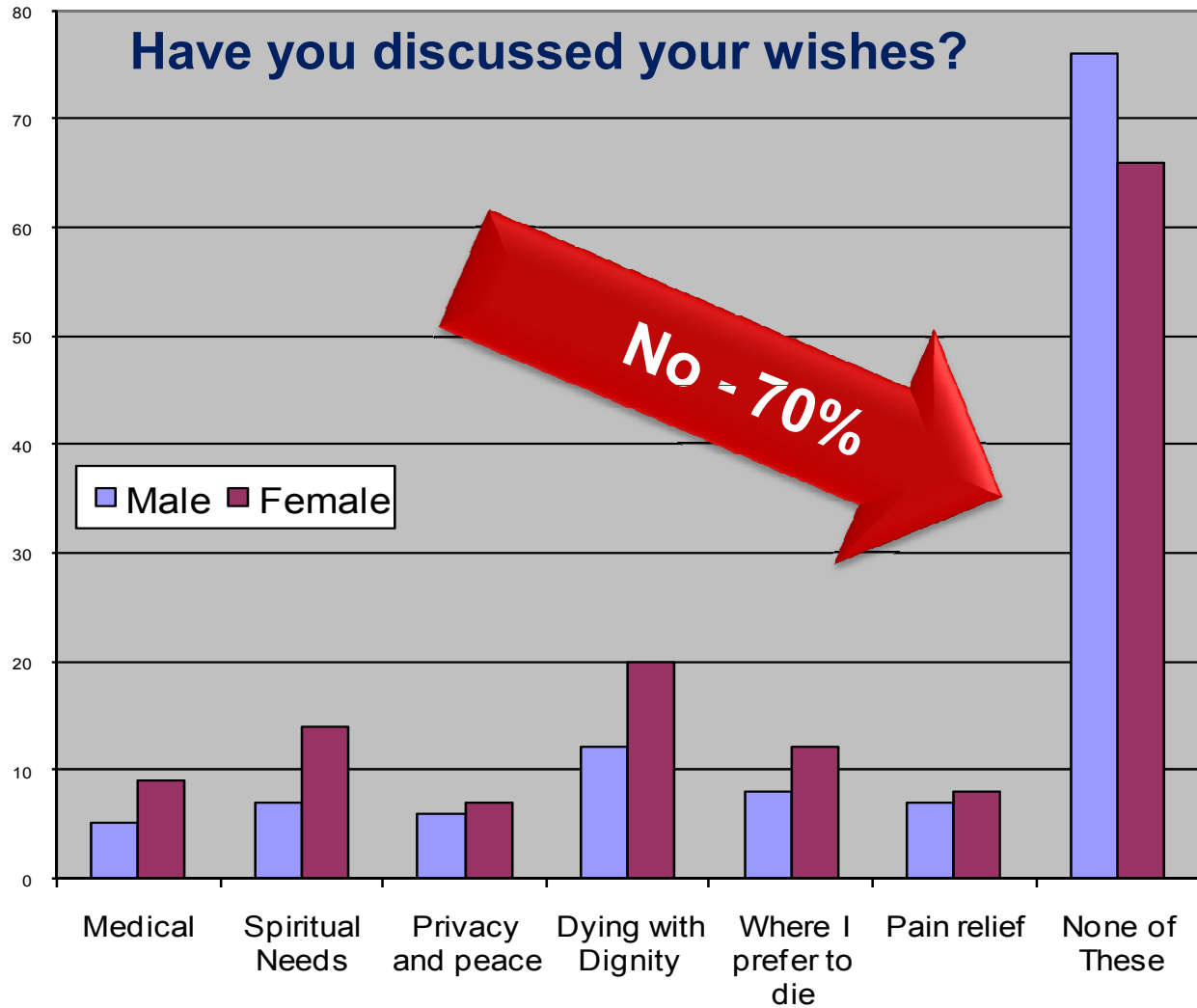
## Attitudes

- Public confusion/contradiction about definitions of death and organ donation
- Shifting preferences for hospice, home and hospital care related to culture and history
- Persistent differences across socio demographic groups
- Women prioritise quality over length of life
- Theme of 'burden' appears to be older age and gender related

## Preferences

- People welcome clinicians who initiate discussion on an advance care plan
- There is wide agreement about characteristics of quality care at end of life
- Hidden concerns: spiritual issues, practical concerns about care of the dying
- Ethnic minorities less keen on withdrawal/withholding treatment

# DYING MATTERS NATCEN SURVEY RESULTS (2009)



[www.dyingmatters.org](http://www.dyingmatters.org)

# WHY WE DON'T TALK ABOUT DYING

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47% of men

Death is a long way off

43% of women

20% of 75+



19% of men

I am too young to think about it

16% of women

[www.dyingmatters.org](http://www.dyingmatters.org)

# NATCEN SURVEY RESULTS

## Attitudes

- Women talk than men but few of either gender talk about it
- Talking about many issues dip in the middle years
- 75+ talk but conversations are not common
- Dying with Dignity is what most have talked about (respectful care and support)

## Preferences

- *'too young'* and *'death is a long way'* off decline with age
- older people say that *'Other people do not want to talk to me about my death'*
- The trigger to is: *"To make life easier for family and friends"*
- People prefer to talk to families and friends 35%, followed by GPs 31%

# KEY PERFORMANCE INDICATORS AND TARGET GROUPS



## Indicators – by 2014

- 75% aged 55-75 very/fairly comfortable talking about death (baseline: 70%)
- 39% aged 55-75 discussed wishes (baseline: 34%)
- 32% aged 55-75 written plan for end of life (baseline: 28%)
- 38% of GPs discussed their care if don't have long to live

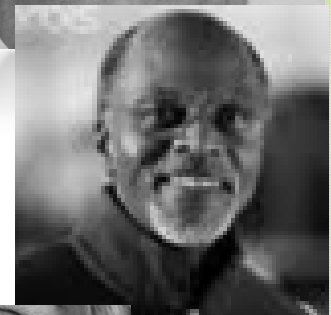
## Target Groups

The less well off with poor social networks from:

- 55 – 65 years
- 65 – 75 years

And

- GPs



# RESOURCES AND MATERIALS

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## We have Produced

- **Materials** to encourage conversations
- **Toolkits** to support awareness raising activities
- **Website** with information on dying, death & bereavement
- **Video** 'Party for Kath'
- **Lesson plan** for schools



## We have also...

- Held an **Awareness Week**
- **GPs** – improving end of life conversations with patients
- **Community Programme** – local awareness raising
- **Involving people** –
  - BME, disabled, homeless, traveller groups



[www.dyingmatters.org](http://www.dyingmatters.org)

# DYING MATTERS PROJECTS WITH NCPC

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## 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"*

[www.dyingmatters.org](http://www.dyingmatters.org)



On going media, internet, social networks, special projects and events (Schools, theatre, youth, LGB etc)

- Community Group Members**
- Local Hospices
  - Care Home
  - Housing Associations
  - Funeral Directors & Solicitors
  - Local Age Concern, NPC & other pensioner orgs
  - Local Authorities
  - Schools
  - Faith & belief Groups
  - GPs
  - Bereavement groups
  - PCTs, SHAs

November Awareness Raising Activities

Community Champion / Peer Educator

Promotion to coalition members via newsletters, web etc.

Support pack and communications tool kit



National Profile Raising Activities (supported locally)

- Outputs**
- Higher local profile for DM
  - Appropriate early planning materials to support PPC & future planning including ACP
  - Events during 2010/11
  - DM Leaflet distribution
  - Speeches at key events

- Outcomes**
- More conversations leading to more planning
  - More coalition members



## DYING MATTERS GP PILOT PROJECT

**Aim:** Support GPs in conversations with patients & relatives about dying & death

**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 will, 42% have discussed organ donation and 23% have discussed their funeral plans**



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# EVALUATION RESULTS



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- 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



# PLANNING FOR THE END OF LIFE



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- **Peer Educator Project**
- **Aim**
  - To work in collaboration with key stakeholders<sup>1</sup> to develop resources to inform advance care planning for older people.
- **Objectives**
  - Identify resources required to inform advance care planning for older people and to increase communication skills among practitioners and users
  - Collate and publish a resource pack to help address these needs



# IF YOU HAD A STROKE TOMORROW...

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...WHAT WOULD YOU WANT PEOPLE TO  
KNOW?

- Bath or shower?
- Mozart or Meatloaf?
- Marmite or marmalade?
- Allergic to cats?
- Where you would want to be?
- Outside or in?



## 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?

## PLANNING FOR A 'GOOD DEATH'

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

*Lady Lazarus  
by Sylvia Plath*



# WHAT YOU CAN DO

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Join Dying Matters Today...  
Sign up for FREE at  
[www.dyingmatters.org](http://www.dyingmatters.org)

- Become a local champion raise awareness in your community
- Get your organisation involved in an event on 1 November to mark Mexican Day of the Dead
- Join in the Awareness week  
May 16 – 22 May 2011



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