PROGRESS WITH THE DYING MATTERS COALITION
“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
OUR GREATEST FEAR

How scared are you of the following happening to you?

- Dying in pain 83%
- Being told you are dying 67%
- Dying alone 62%
- Dying in hospital 59%

Compare with:

- Going bankrupt 41%
- Divorce/end of a long-term relationship 39%
- Losing their job 38%

Comres 2011
TABOOS HAVE CONSEQUENCES

- Deciding not to talk is just that – a decision....
- Our carers may not know what we want:
  - Shower or bath
  - Marmite or marmalade
  - Mozart or Motorhead
  - Own home or care home
- Our families may not know what we wanted
- If we don’t discuss, anticipate and plan, it makes unplanned “crisis care” and hospital admission more likely

www.dyingmatters.org
THE CHALLENGES

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. 70% of people would like to die at home, but over half of all people die in hospital

www.dyingmatters.org
THE DYING MATTERS COALITION

- 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 17,000 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
WORDS USED TO SAY DEATH OR DYING

www.dyingmatters.org
THE FUTURE

- Dementia incidence to rise from 822,000 to 1 million by 2025
- People are living longer, numbers of people dying have declined, but will rise soon to 586,000 by 2030
- Lack of capacity in hospitals/hospices will increase demand in the community: homes, care homes, and other settings
- New types of care & support services are needed to ensure good end of life care
- How can we campaign for something we don’t talk about?
- How can we plan, if we don’t talk?
Research and Insight

- Nat Cen Quant Survey
- ICM Omnibus Quant Survey
- NFP Synergy Qualitative research
- GP baseline from ComRes Kings Fund
- Regional surveys and qualitative data
- Nottingham Literature review

www.dyingmatters.org
**Why we don’t talk about dying**

- Death is a long way off:
  - 47% of men
  - 43% of women

- I am too young to think about it:
  - 19% of men
  - 16% of women

- 20% of 75+

- 3% of 75+

www.dyingmatters.org
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

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

www.dyingmatters.org
TARGET AUDIENCES

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

Well off

Less well off

Poor Social Networks

www.dyingmatters.org
DYING MATTERS PROJECTS WITH NCPC

Working with schools & hospices

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

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

“I look forward to the kids coming, I don’t often get a chance to speak to people from that generation”

“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”

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

www.dyingmatters.org
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

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

Outputs
• Local network of engaged organisations
• Supporting materials encourage future planning
• Local events during 2012/13
• Higher local profile for DM

Impact
• More people’s wishes are met
• Improved end of life care

www.dyingmatters.org
DYING MATTERS GP PILOT PROJECT

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

www.dyingmatters.org
DYING MATTERS SUCCESS 2011/12

- **Dying for a Laugh**, produced in partnership with NHS Bolton, won two How-Do Public Services Communications Awards
- **Awareness Week 2012** saw 200+ members run events
- **Materials** popular – over 200,000 sent out
- **Find your 1% campaign** – over 400 GPs signed up
- **Connecting online** – nearly 4,000 twitter followers and 1,500 Facebook likes, and a 230% increase in page views on www.dyingmatters.org
- Working with older **LGB&T** people on their access to, and experience of, end-of-life care
TALKING ABOUT DYING WON’T MAKE IT HAPPEN

Some tips:

- Be direct
- Acknowledge it’s not an easy subject for many people
- Be clear what is possible and available
- Be sensitive to cues
- Listen to what people are saying
- Allow people time to reflect
- Be prepared to talk about it more than once
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*
WHAT’S IN A WILL?

- Cash, home, assets
- Personal mementoes
- Funeral directions
- Disposal of the body
- Last wishes

Emotional:
- Relationships
- Lost relatives
- Closure/farewell

www.dyingmatters.org
PUTTING YOUR HOUSE IN ORDER

5 things:

- Make a will
- Make a funeral plan
- Start planning for your future care and support
- Sign up as an organ donor
- Make sure your loved ones know your plans

www.dyingmatters.org
What can people do?

Planning for a ‘good death’ can include...
- Legal and financial matters
  - Making a will, insurance, cost of funeral
- Preferences
  - Type and place of care
  - Advance decisions
- Funeral arrangements
- Leaving a memorial or legacy
- Organ donation
- Preparations for bereavement
  - What would you like people to know before you go?

Subjects you might want to talk about

In the checklist below are some of the areas that people often leave it too late to discuss. Some may be more important to you than others. If you want to know more about any of these areas, then go to the Dying Matters website www.dyingmatters.org or phone 0800 21 44 66

- The type of care you would like towards the end of your life
- Where you’d like to die
- How long you want doctors to keep treating you
- Funeral arrangements
- Care of dependents – children or parents, for example
- Organ donation
- How you’d like to be remembered
- Worries you have about being ill and dying
- What you’d like people to know before you die
- How you feel about people

A Dying Matters resource
This is difficult. Preparing for end of life is a process we dip in and out of.

If you had a stroke tomorrow…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?

Preferred Priorities for Care
- http://www.endoflifecareforadults.nhs.uk

www.dyingmatters.org
What are you doing for Dying Matters Awareness Week 13 – 19 May 2013?
WHAT YOU CAN DO

- 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

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