Dying Matters: so let's talk about it!

*Helping people to talk about and plan for their end of life care*

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“Dying is not only a physical event – it is the conclusion of a life defined in its nature, content and connections within a society and its cultures that are every bit as important as the mechanism of how dying happens.”

More Care Less Pathway (2013)
“There needs to be a greater understanding of how people who are dying, and their relatives and carers experience care at the end of life; and greater understanding of the social and health effects of different experiences of dying on individuals and on their families..”

One Chance to Get it Right (2014)
Why is this important?

• We are all living longer, and need to make the most of our lives without fearing what will happen in the end.
• Most people say they would prefer to be cared for and die in their own home, but most die in hospital.
• People who have discussed and shared their wishes stand a much better chance of having these fulfilled.
• Getting your affairs in order gives you and your family peace of mind and gives you a chance to say goodbye, heal old rifts.
It's not just about you - it is everybody's business (Out of the Shadows Alzheimer's Society)

“How people die remains in the memory of those who live on.”

Dame Cicely Saunders
54% of complaints regarding hospital care were related to care surrounding death:

“In many cases, families received contradictory or confusing information from different staff caring for a relative. In others, relatives felt that they were unprepared for the death or had no time to arrange for family members to be present”

(The Health Care Commission 2007)
Talking about death and dying..

• More than half of people have been bereaved in the last 5 years (54%), with a third think about dying every week and 11% think about it daily and yet it remains a big taboo for many to talk about..
• Its worse than talking about money, religion, politics or immigration, but better than talking about sex, well we are British!
• People have concerns about quality of care (59%), being a burden (82%) and about what would happen to family after their death (74%) with 35% saying they would not be able to afford a funeral if someone close to them died tomorrow, 28% would not know what authorities to notify and 24% would not know how to organise the funeral itself
• It has an impact in bereavement as well with only 25% of the bereaved feeling they received the support they needed from their employer

Com Res/Dying Matters (2012)
http://dyingmatters.org/page/i-didnt-want-that
We need to be brave..

• We need to know what questions to ask
• We cannot help the staff caring for us unless we are brave enough to ask difficult questions ourselves:
  – about our own health (or those we care for)
  – about our own care (or those we care for) and
  – about our own needs (or the needs of those we care for), otherwise someone else may make the decisions for us..
The easy bit – making your will

• Much easier to look after our possessions, but only three in 10 people in the UK have a will – how many here have?
• In 2011 the Treasury gained £53m from people who died intestate - without a will
• The year before it was £76m
The hard bit – everything else!

• Talking about it at work or home
• Planning for it for yourself or another
• Making sure you get the care and support **YOU** want for yourself or for those you love..
“Communicating with dead people is easy. Communicating with live people is hard!”
What do we need to talk about?

• **How we want to be cared for** – only 27% have asked a family member about their wishes and only 31% have discussed their own
• **To write this down** so that it our wishes can be referred to if we are unable to express them – just 8% have done this
• **Write a will** – only 37% have written a will
• **To think about organ donation** – only 31% have registered for a donor card
• **How about GPs?** Only 35% of those asked had initiated an end of life care planning discussion with their patients and only 33% of GPs have asked a family member about their wishes with only 35% have discussed their own (7% have written them down), 56% have written a will and 48% have registered for a donor card

Com Res/Dying Matters (2012)
"... and after periods of denial, anger, bargaining, depression and finally acceptance... they lived happily ever after."
When could we talk about it..

Life changing events:
• Mortgage
• Marriage/partnership
• When children arrive
• Retirement planning
• Will writing
• Illness of self or others
• Bereavement
What is advance care planning?

• It is an *on-going process of discussion, decision making and documentation*

• It is an opportunity for the *person to think about how they wish their current and future care to look*, and to discuss *their wishes* with the people who are closest to them and those who provide their care if they wish

• In Norfolk this is called the **Thinking Ahead pack**
What is in the Thinking Ahead pack?

• The content is adapted to individual needs
• It is a communication tool
• Contents may include:
  – An Advance Care Plan
  – Information leaflets about advance care planning and do not attempt resuscitation decisions
  – Leaflets about local supportive services
How do you do an advance care plan?

An advance care plan provides a structure for your thinking about your preferences as you near the end of your life:

- Where you want to be cared for
- Aspects of care that you are concerned about
- Treatments you do or don’t want to have
- People who you wish to be there, or don’t!
- Who will look after the cat..
- You can change your mind, its an evolving process

For Yourself
For Someone Else
For you and your family
When Someone has Died
www.bereadyforit.org.uk
How do you help someone else to do an advance care plan?

- Listen
- It takes time: to think about and discuss
- You can record but only when the person wants to do so

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What about..

- Do not resuscitate
- Advance decisions to refuse treatment
- Lasting powers of attorney

For Yourself
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So how can we be ready for it?

Start the conversation:
• At home
• At work
• As a neighbour
• As a member of your community
• There are lots of resources available

For Yourself
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When Someone has Died
www.bereadyforit.org.uk
Be ready for it: Checklists and useful information

Finding the emotional support you need

If you are affected by a life limiting illness
Everyone responds differently to having a life limiting illness, and every individual will need different information, support and advice. It may be helpful to talk through any questions you may have.

It is natural to feel sad or upset: you may, or may not, want to talk to your family and friends about how you feel. You might find it helpful to consider counselling, which you can arrange through your GP. Alternatively, you can call one of the local information and support services directly who will be able to help you through the difficult times.

Your family and friends will also be experiencing a range of feelings and may also need support.

If someone you know is affected by a life limiting illness or may have died
People react in different ways following the loss of someone close. Feelings may include a sense of regret, fear, anger, denial, despair, relief, depression, guilt or numbness. However it feels, the grief is unique to each bereavement and grieving is something that will happen at its own pace. Your need for
"The last thing she said to me was, 'Would it kill you to apologize'?”
Before I die I want to.....

"Cruise round the Greek Islands"
From Joan
So what do you need to do to be ready?

For Yourself
For Someone Else
For you and your family
When Someone has Died

www.bereadyforit.org.uk
How to contact us

maggie.parsons@nhs.net
GYWCCG.nspca@nhs.net
Homework

• Stephen Cave – Immortality: The quest to stay alive
• Irvin D Yalom – Staring At The Sun: Being at peace with your own mortality: Overcoming the Terror of Death
• Kate Granger’s blog
Tea and mortality

"In my experience, when people talk about death and dying, all their pretences disappear. You see people's authenticity and honesty among strangers. Although it might sound really weird and wonderful to say you attend a death cafe, it just feels very normal."