The essence of humanity is never ‘me’, but ‘we’ ~ Jon Kabat-Zinn

Rebecca Lloyd

The Irish Hospice Foundation
Some day, we will all die, Snoopy!

True, but on all the other days, we will not.
Today’s webinar

• Introduction to talking, thinking and planning about end of life, dying and death
• Explore personal and professional beliefs
• Share experiences of talking to the public about End of life
OUR VISION

People facing death or bereavement would have the care and support they need.

OUR MISSION

To work for the best end-of-life and bereavement care for all.
We fund, deliver and enable a range of programmes and services

- Bereavement
- Healthcare
- Education & Research
- Advocacy & Public Engagement
Advocacy & Public Engagement

• We engage with media and policy makers to raise awareness of our work and maintain continued support.

• We change how people plan for end of life.

• We educate, inform and build public awareness and understanding that ‘Dying is everyone’s business’
The single biggest problem in communication is the illusion that it has taken place.

George Bernard Shaw (1856-1950)
The People’s Charter on Dying, Death and Bereavement in Ireland.

The Irish Hospice Foundation asked the people of Ireland what is needed for a good death and for healthy grieving. 
3,000 people say

**I want to live and die in an Ireland where:**

- Death is talked about and not hidden away.
- I can prepare for what lies ahead.
- I can get relief from pain, no matter where I am being cared for or what condition I have.
- I am treated as an individual and my wishes, choices and beliefs are respected.
- I, and the people who care for me, can get the practical services and support that we need.
- I can get information to understand what is happening to me.
- There is the support to help me cope with worries or distress.
- I can die, surrounded by people I love, in a calm and comfortable place. In my home, if at all possible.
- I am supported to stay in control of my own decisions.
- My dignity is respected and maintained to the end of my life, and after my death.

**For the people who matter to me, I want an Ireland where:**

- People understand grief and do not avoid thinking or talking about it.
- Family and friends are supported during a loved one’s illness and after their death.
- People get space and time to grieve, talk and remember.

Help us by rolling out the charter in your community, workplace, family or organisation. 
Have your say... You can do so at hospicefoundation.ie/haveyoursay
Are we talking enough ...?
Not always …

• ‘Some’ Doctors find it hard to talk to patients about death and dying and opt instead for continuing treatment

• Death is a “failure” rather than “normal”

• Societal expectation is to save lives at all cost

• Families often find it difficult to talk about dying – any sense of denying treatment/curtailing treatment is seen as “killing mum/dad” or “not doing all I could to save someone I love”
‘Death is a central problem for humanity, especially for ill people who face concrete and imminent concerns regarding it’

Havi Carel
Talking about death won’t make it happen.
But not talking about it steals us of choices and moments that will not come again.

All of us must (try) to be honest and unafraid to talk about death
Advance Care planning - to include Legal Directives

- New
- Death Education & Literacy
- Risk Reducing Care
- Early Screening
- Diagnosis
- Curative and Life Prolonging Care
- Palliative Care (Symptom Management)

Time

Death
Bereavement
It’s about doing things “with” people not “on people.

Alan Kellehear
27%
ADVANCE CARE DIRECTIVE

WHO WILL SPEAK FOR YOU IF YOU CAN'T SPEAK FOR YOURSELF?

11%
Making a Will

• Making a Will brings clarity to your intentions, for your assets and valuables, that you have created during your lifetime.

• If you don’t make a Will then your wishes or intentions cannot be carried out regardless of whether or not you have orally told people what you would want after you die.

• Go onto the Law Society website and fill in Client questionnaire (personal asset recorder)

• Find a solicitor - there are many pitfalls with DIY wills – (the Law society has a list of approved solicitors)
What happens if you don’t write a Will?

If you die without a will, the court will probate your estate, e.g. decide how your estate should be distributed.
Enduring Power of Attorney

• Is the naming a person or persons who would have the authority to make personal care (where you live, who you see, what you eat ..) and/or financial decisions for you in the event that at some time in the future you are unable to make those decisions for yourself.

• Currently are made with a solicitor & a doctor

• You DECIDE how much power you give to people

• EPA’s do not include End of life Health care decisions – for this you need an Advance Healthcare Directive (AHD)
What happens if I don’t have an EPA?

• If you lose capacity and you can’t manage your affairs, a judge will have to appoint someone to do so. This means you will become a ward of court, that is, someone appointed by the court will oversee your care and finances.
Advance Health Care Directive

- Make choices about ‘specific treatment’ you do NOT want to receive – even if that refusal may end in death
- Legally binding so must be signed and witnessed by two people (over 18 – one non family member)
- Only comes into effect if a person loses capacity (due to illness/coma/accident ..)
- Allows for you to nominate a Designated Healthcare Representative – authorised to carry out/ interpret your wishes
What happens if I don’t make an AHD?

- Family will be asked what they think you want (and may interpret to what they want)

- If family does not know what your wishes are, this might lead to family conflict and guilt over making the wrong decision

- You may receive treatment you don’t want
The most common problems people encounter following a death are:

- Regret
- I’m sorry I didn't’ know
- I didn’t get chance to ask
- I don’t know what she would have wanted
- I wish I knew...
We cannot stop people dying...
We can help them prepare...
Can you and your loved ones answer the following questions?
On a scale of 1 to 5, where do you fall on this continuum?

Let me die without medical intervention

Don't give up on me no matter what, try any proven and unproven intervention possible
If there were a choice, would you prefer to die at home, in a nursing home, a hospice or in a hospital?
Place of death in Ireland 2017 (CSO)

- Hospital: 49%
- Home: 23%
- Nursing Homes: 17%
- Elsewhere: 3%
- Hospices: 8%
Could a loved one correctly describe how you’d like to be treated in the case of a terminal/life limited illness?
Is there someone you trust whom you’ve appointed to advocate on your behalf when the time is near? (a healthcare representative)
Picture your final days ...

Who is around you?
What are you wearing?
Is there music playing?
Where are you?
What can you see, hear, touch, smell?
It all starts with a conversation and somewhere to write it all down

Think Ahead is a good place to start
What is Think Ahead?

A tool to help people think through & communicate their choices

A place to store, record & review:

End of life preferences
Top-level legal details (who our solicitor is, where our will is)
Our financial details (where we bank, insurance details)
A legal Advance Health Care Directive in line with (2015 Assisted Decision Making (Capacity) Act
Our Funeral wants and wishes
Why Think about end of life planning

- It as a kindness to others
- Having a conversation before a crisis is invaluable
- Help ourselves/others express any wishes, thoughts around end of life
- These wants and wishes – can then be used by those who love us and act on our behalf
Timing is essential

Before an event occurs

If there are any changes in our healthcare

Important events in others' lives that spur a conversation
How to start talking

- Talking honestly & openly creates a shared understanding
- Be aware that some people will be open to having conversations and others won’t be
- One step at a time...
- Find the right moment
- Be honest about how you feel and why you want to plan ahead/help someone plan ahead
We don’t really want to think and talk about death...

• This means that often, people aren't able to die in the way that they intended
• Some people die in a hospital when they would have preferred to be at home.
• Others are kept on life sustaining treatments way beyond the point they would have wanted.
• It's important to Communicate
Think Ahead is designed to help you:

- Keep control over your care
- Receive the care you want but not the treatments that you don’t want
- Give your loved ones peace of mind, not tough choices
- Give nominated people the ability to make the decisions you would want
- Have conversations about the things that are important to you
- Avoid family stress and conflict
Do everything that you can Doctor

that will not cause suffering or harm
What medical professionals need to think about

- When should we try to fix, and when should we not?
- Why do you think it is so difficult for Doctors and/or families to refuse or curtail treatment?
- Do you think that advancements in the medical field damage our ability to have a quality end of life?
- How do you walk the fine line between being hopeful and being unrealistic?
- What do we really expect of medicine?
What can you say?

• To your patient: What is of greatest concern to you right now?
• To a family/friends: They are sick enough to die
• To carers: The power of saying yes
“If we take ownership over our lives and eventual deaths, we can allow others to be powerfully present to our passing and not let it be lost in the chaos of indecision.

If doctors and nurses had clear direction from each of us—advance-care directives, clear power of attorney, healthcare representatives—and if our families knew our wishes for the type of care we want at our life’s end, if they knew what we want to happen to our body and how we want to be celebrated, the emotional and financial burden would significantly reduce”

Elizabeth Kubler Ross
By talking to one another, we can make the preparation and planning easier, even beautiful, whether it is an unexpected death or a slow waltz to the finish line

Michael Hebb
As with any journey,
who you travel with can be more important than your destination.
People will forget what you said. People will forget what you did. But people will never forget how you made them feel.

Maya Angelou