

End of life care, Advance Care Planning and the Third Sector

Francis Ngale

End of Life Carers Project Manager



What we're going to talk about

- ✓ End of Life Care?
- ✓ Future care planning and
- ✓ What can we do?

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End of Life



Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes



Those patients whose death is expected within hours or days;



Those who have advanced, progressive incurable conditions;



Those with general frailty and co-existing conditions that mean they are expected to die within 12 months



Those at risk of dying from a sudden acute crisis in an existing condition; and



Those with life-threatening acute conditions caused by sudden catastrophic events.

Palliative Care

- Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness. It consists on
- providing relief from pain and other distressing symptoms;
- Affirming life and regarding dying as a normal process;
- Intending neither to hasten or postpone death;
- Integrating the psychological and spiritual aspects of patient care;
- Offering a support system to help patients live as actively as possible until death;
- Offering a support system to help the family cope during the patient's illness and in their own bereavement;
- Enhancing quality of life and may also positively influence the course of illness

Who may be involved in the care of a person in End of Life



NHS Continuing Healthcare	The Specialist Palliative Care Providers	Hospitals	District Nursing & Community Nursing Teams
Community Independent Services	Social Services & Care Workers	Macmillan Nurses	Pharmacy
Voluntary & Third Sector Organisations such as Age UK,...	GP	Faith & Spiritual bodies	Unpaid Carers & Family



End of Life Carers Project

The EOLC Project is a dedicated service for adult Carers providing unpaid care to a friend or relative who:

- Has been diagnosed with a terminal illness, or
- Is 80 or over, and has general frailty and/or co-existing conditions, or
- Is in a residential or nursing home



End of Life Carers Project

What it is all about

- EOL Carers Assessment**
- Advance Planning** (LPA, Will, ADRT, Funeral wishes, Organ Donation, future care wishers, etc)
- Bereavement Support**
- Grants & Income Maximisation**
- Advocacy**
- Workshops** (Will writing, Funeral wishes & Cost, Lasting Power of Attorney, Pensions, Benefit for older People, etc)

Of the total numbers of carers in the project, about 65% are aged 75 or over, including 21% aged 85 or older

Planning for the Last Years of Life: CHALLENGES

- ❑ **Talking about death is TABOO. We don't talk about dying and death - impacting on our end of life choices**
- ❑ **Lack of Awareness around End of Life Choices.**
- ❑ **Advance planning is still confined to clinical settings**

People in Britain risk not having their end of life wishes met. New ComRes market research released for Dying Matters Awareness Week 2016 found:

- **Just 35% of adults said they have made a will**
- **30% had let someone know their funeral wishes**
- **33% had registered to be an organ donor**



Planning ahead: 5 things to consider

- Consider legal and financial matters - Making a will; Power of Attorney; Inheritance
- Making choices – Preferred Place of Death, Where would you like to be cared for
- Advance Statements and Advance Decisions to Refuse Treatment
- Tissue, organ and body donations
- Planning your funeral



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What is Advance Care Planning?

- ❑ **Advance care planning is a way for someone to think, discuss, decide, document and share what matters most to them at the end of their life. This may include how they would like to be cared for, what treatments they don't want in the future, where they would like to die and anything else that is important to them.**

- ❑ **This process may lead to one or more of the following:**
 - ✓ an advance statement
 - ✓ an advance decision to refuse treatment (ADRT)
 - ✓ the appointment of a personal welfare Lasting Power of Attorney (LPA)

Advance Statement

- Written statement that sets down your preferences, wishes, beliefs and values regarding your future care.**
- You can make sure people know about your wishes by talking about them.**
- By writing your advance statement down, you can help to make things clear to your family, carers and anybody involved in your care.**
- An advance statement is not legally binding, but anyone who is making decisions about your care must take it into account.**





Advance decision to refuse treatment (ADRT)

- Also known as a living will, or ADRT or Advance Decision
- Is a decision you can make now to refuse specific treatments in the future.
- Unlike, the advance statement mentioned above, an advance decision to refuse treatment is legally binding, as long as it meets the necessary criteria for it to be considered valid and applicable

Lasting Power of Attorney

- ❑ A legal document, which allows YOU to choose a person or persons to make decisions on your behalf if you are ever unable to do so.
- ❑ Is designed to protect you if ever, you lose your mental capacity.
- ❑ There are two types:
 - Health & Welfare
 - Property & Finance
- ❑ How do you make a Lasting Power of Attorney?
 - Online (www.lastingpowerofattorney.service.gov.uk/home)
 - Using paper forms (To request the forms, email customerservices@publicguardian.gsi.gov.uk or call 0300 456 0300)
- ❑ It costs £82 to register each LPA with the Office of Public Guardian

Funeral Planning



Can be included in your Will or be documented in more detail by drafting your Advance Funeral Wishes.



This lists everything from your choice of burial or cremation to specific poems you would like to be read and by whom.



With funeral costs high and rising, many people faced with a sudden loss struggle to find an affordable send off for their loved ones.



Can help your loved ones understand your wishes, hence limiting unnecessary anxiety over funeral arrangements and expenses.

Will Writing

- ❑ Sometimes called a “last will and testament,” is a document that states your final wishes. It is read by a county court after your death, and the court makes sure that your final wishes are carried out.
- ❑ Writing a will allows people to plan what happens to their money and possessions after they die.
 - Free Wills Month (England and Wales) – runs usually in March and October in specific parts of England & Wales.
www.freewillsmoth.org.uk
 - Will Aid – runs in November. You usually have to book in advance, as spaces on the scheme are limited. There’s also a suggested minimum donation. www.willaid.org.uk

Any Questions?



- Do we have a role in Advance Care Planning?
- Thinking processes, how do we, organisationally, respond to death and Bereavement?



Registered charity (1097723)

Run the Royal Parks
Half Marathon
for **cn** carers
network

13 October 2019

For more information please contact
events@carers-network.org.uk
0208 960 3033

The image is a promotional poster for a half marathon. It features a blue background with a white question mark on the left. The text is in various colors: orange for 'Run the Royal Parks Half Marathon', green for 'cn carers network', and black for the date and contact information. A blue and green running shoe is at the bottom. The Carers Network logo is written in a grey, cursive font.