Principles & Practice in End of Life Care
Non-registered practitioners 2019

Advance Care Planning

#hello my name is… Linda Rendle
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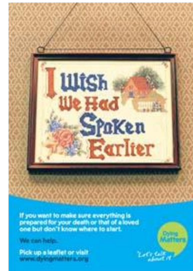


Learning outcomes

- Explore importance of good communication skills & need for timely end of life conversations.
- Identify differences between care planning & decisions made in advance.
- Increase ability to engage confidently in end of life conversations.

Macmillan Cancer Support 2017

Macmillan cancer Support 2018

If people (including us) do not discuss death & dying openly, how are we going go know what people may want?

….or what about things people don't want?

"I didn't want that!"

Commissioned by Dying Matters – this short film highlights the importance of making end of life wishes clear.

http://dyingmatters.org/page/i-didnt-want-that

Advance care planning

Advance care planning is about giving people the opportunity to:
- think about
- talk about
- be involved in

decisions about what matters to them.

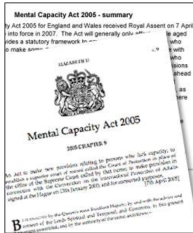
Plan Ahead

When….?

while they have capacity for making decisions.
Can help people have their voice heard when they can no longer speak for themselves.
Remember it is a voluntary process.

Mental Capacity Act is key!

Mental Capacity Act (MCA 2005)


Mental Capacity Act 2005 - summary

Mental Capacity Act 2005

2005 CHAPTER 9

Advance care planning needs to be considered when the person is well enough to take part in the discussion.

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Advance care planning discussion

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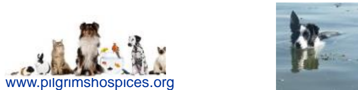
What might advance care planning discussion include?

- Understanding about illness & prognosis.
- **Options for treatment** & care to find out wishes or preferences (this may include preferred place for care & death).
- Values, beliefs & personal goals.
- Advance refusal of specific treatments (ADRT).
- Lasting Power of Attorney - health and welfare &/or property and financial affairs.
- DNACPR decision making (waiting until someone has a cardio respiratory arrest is too late for the discussion!).

What else can you think of?



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Advance decision to refuse treatment (ADRT)

- If an individual wishes to make an ADRT – appropriate guidance must be followed (previously known as living will or advance directive).
  - Legally binding.
  - Must relate to specific medical treatment.
  - Must be put in writing, signed & witnessed if relates to life sustaining treatment (& must clearly state 'even if my life is at risk as a result').

See ADRT fact sheet 3

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Lasting Power of Attorney (LPA)

This has replaced Enduring Power of Attorney

- Can chose someone to have legal authority to make decisions on your behalf.
  - Decisions concerning property &/or personal welfare.
  - Only health & welfare attorneys can make healthcare decisions (decisions about life sustaining treatments must be specified).
  - Only used when capacity is lost.
  - An LPA must be in a prescribed form & registered with the Office of the Public Guardian.

For further info visit their website
- http://www.justice.gov.uk/about/opg

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Documentation?

Discussion may result in a record of patient's wishes:
- Advance statement of wishes & preferences
- ADRT (advance decision to refuse treatment)
- LPA (Lasting Power of Attorney)

What do you use in your organisation?

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Has the healthcare professional got time? What do I say?

Is it OK to talk about the future? What if I say the wrong thing? What if I upset her?

Is it OK to say I'm am scared?

What if I open a can of worms? Will I know the answers? I don't really have time

Knowle House practice

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Picking up on cues

- Verbal or non-verbal hints about possible underlying concern.
- Evidence suggests that cue-based consultations take less time.

(Levinson et al in Silverman, Kurtz, Draper 2013).

Never make assumptions

ASK

Examples from practice?

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The Conversation Game™

What matters to me is……..

What's the conversation game?

"I now know why this conversation matters"

A simple, evidence-based tool to start the conversation for
- Staff and systems
- Individuals and families
- Patients and carers
- Community events

Supports patients, family and staff to explore and communicate quality of life wishes or preferences for the best possible end of life care.

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Advance care planning What's the evidence?

Reference & resource handout available

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Compassion in Dying 2018

Although these conversations can be emotionally demanding …. they can bring people closer & many find rewarding.

Can help you make informed decisions, & give peace of mind knowing others understand what is important to you.

Principles of the Mental Capacity Act 2005, must underpin advance care planning.

Allows you to express who you are & what is important to you

Focuses on what matters most to the person.

It is not a 'one-off' plan making session.

Potential for reducing unwanted, futile invasive treatments or hospital admissions. Enables better planning of care…. more person-centred

It allows people to be more in control of living their life with their conditions.

NHS England 2018

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Thomas 2018

Tools to help identify deteriorating health

The Surprise Question

'Would I be surprised if this person died in the next year?'

This could be a useful prompt to consider advance care planning discussion.

This question is just a starting point & should not be used alone.

The SPICT tool can help us to identify people with declining condition.

Supportive and Palliative Care Indicators Tool (SPICT™)

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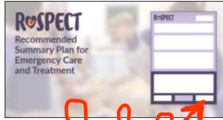

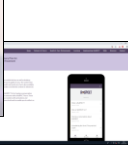

ReSPECT Learning Web-application

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DNACPR forms

Valid forms – accepted across geographical & organisational boundaries, including transfers.

Remains valid from date of signing unless review date has been specified. However - review should occur whenever circumstances change.

Visit the Resuscitation Council (UK) for latest recommended standards for recording decisions about CPR (2016)

Adults over 16/18 years (some variation)

N.B. minor variations in format of forms between Trusts

Watch out for ReSPECT

Why the need to consider CPR decision making?

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ReSPECT

Are you aware of the ReSPECT process??

This may be coming soon to our locality so be ReSPECT ready!!!

ReSPECT is a process that creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices. It provides health and care professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment. ReSPECT can be complementary to a wider process of advance/anticipatory care planning.

Check out their website http://respectprocess.org.uk/

Take a look at some of the resources they provide (see below

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What is your role in advance care planning

- **All** health & social care staff should be open to discussion brought up by an individual.
- If the individual wishes, their friends & family may be included in discussions.
- Remember process is voluntary, but look for opportunities.
- With the individual's agreement discussions should be documented, regularly reviewed & communicated to key people involved in care.
- Staff require appropriate training to enable to communicate effectively.

What else can help?

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Starting the conversation

If I become more unwell….

"Thinking, talking, deciding & writing down what's important to you at the end of life can be difficult. Sometimes we don't want to talk about it, know what to discuss, or when to begin the conversation."

These think cards may provide some ideas of how to help start, share or continue advance care planning conversations.
See what you think…..

Try practicing asking these questions to each other

Think about your communication skills

Read – think – discuss - share

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Triggers – initiating or reviewing ACP discussion

- Patient initiates conversation.
- Diagnosis – progressive life limiting condition / LTC etc.
- Condition with predictable disease trajectory likely to result in deterioration - loss of capacity.
- Change or deterioration in condition.
- Change in personal circumstances (move into care home).
- Use uncertainty as an important trigger!
- Remember the tools to help identify end of life.

Putting it all together

- Opening the conversation
- Exploring your options
- Identifying your wishes & preferences
- Refusing specific treatment if you wish
- Identifying who you would like to be consulted on your behalf
- Appointing someone to make decisions for you using a Lasting Power of Attorney
- Letting people know your wishes

Adapted from Dying Matters (2017) Planning for your future care

Reminders

- Good communication skills can create opportunities & allow people to let you know **what matters to them.**
- 'Patients have goals & priorities……. besides living longer'. *Bernaki & Block 2014*
- **Do not forget to look for opportunities!**

#hello my name is…

Dr Kate Grainger

Thank you!

References & resources

- Conversation Game™ - www.conversationsforlife.co.uk
- Compassion in Dying - Planning Ahead: my treatment & care https://compassionindying.org.uk/library/planning-ahead-treatment-care/ (2018)
- Dying Matters – Time to talk https://www.dyingmatters.org/sites/default/files/user/Leaflet%2011_WEB.pdf
- e-ELCA – end of life care for all http://www.e-lfh.org.uk/programmes/end-of-life-care/ (look up communication sessions)
- fink™ Advance Care Planning https://finkcards.com/products/advance-care-planning
- National Council for Palliative Care - Difficult Conversations for Dementia http://www.ncpc.org.uk/difficult_conversations

References & resources cont.

- Macmillan (2018) Missed Opportunities https://www.macmillan.org.uk/_images/missed-opportunities-end-of-life-advance-care-planning_tcm9-326204.pdf
- NHS England (2018) My future wishes Advance Care Planning (ACP) for people with dementia in all care
- NHS Improving Quality - Planning for your future care https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/12/EoLC-Planning-for-your-future-care.pdf
- ReSPECT Learning Web-application https://respectprocess.org.uk/learning.php
- Supportive & Palliative Care Indicators Tool (SPICT™) https://www.spict.org.uk/
- Thomas, K, Lobo, B. Detering, K. (2018), *Advance Care Planning in End of Life Care,* Oxford: OUP.