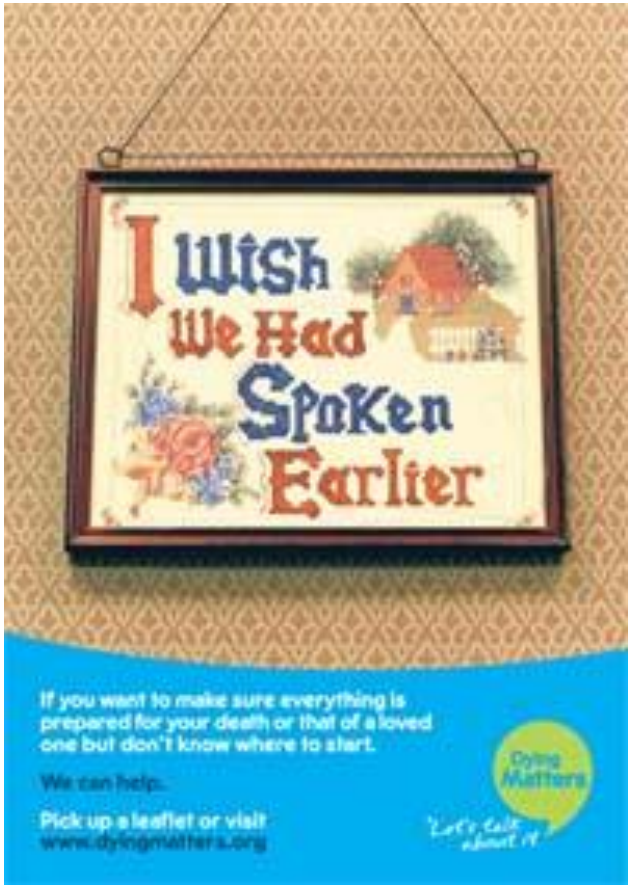
# Advance Care Planning

including DNACPR
(do not attempt cardiopulmonary resuscitation)
2019




#hello my name is…

Linda Rendle
linda.rendle@pilgrimshospices.org

Full reference list & links
to further resources available

www.pilgrimshospices.org

# Aim of session

The aim of this workshop is to improve confidence in end of life care discussions & to be familiar with the tools to support.

# Learning outcomes

- Identify differences between care planning & decisions made in advance.
- Understand the process of advance care planning, including importance of client choice & informed consent.
- Consider the benefits & challenges.
- Increase awareness of the key points of the DNACPR principles.
- Update on ReSPECT
- Explore importance of good communication skills & need for timely end of life conversations.

Certificate of attendance will be issued: this is not a certificate of competency

ReSPECT Recommended Summary Plan for Emergency Care and Treatment

Pilgrims Hospices

What matters to me is…..

Do people have an opinion about the treatment & care they want to receive?

Do we know what is best?

Do we always give everyone the opportunity to be to tell us what matters to them?

The Conversation Game ™


www.pilgrimshospices.org

‘Everyone dies, but uncertainty about how & when that will happen is inevitable’

*(Kimbell et al 2016)*

# End of life discussions

# What are the challenges?

*Useful articles – on factors influencing uptake of advance care planning*

*Lovell & Yates (2014)  Musa et al (2015)*

# Tools to help identify deteriorating health



## The Surprise Question

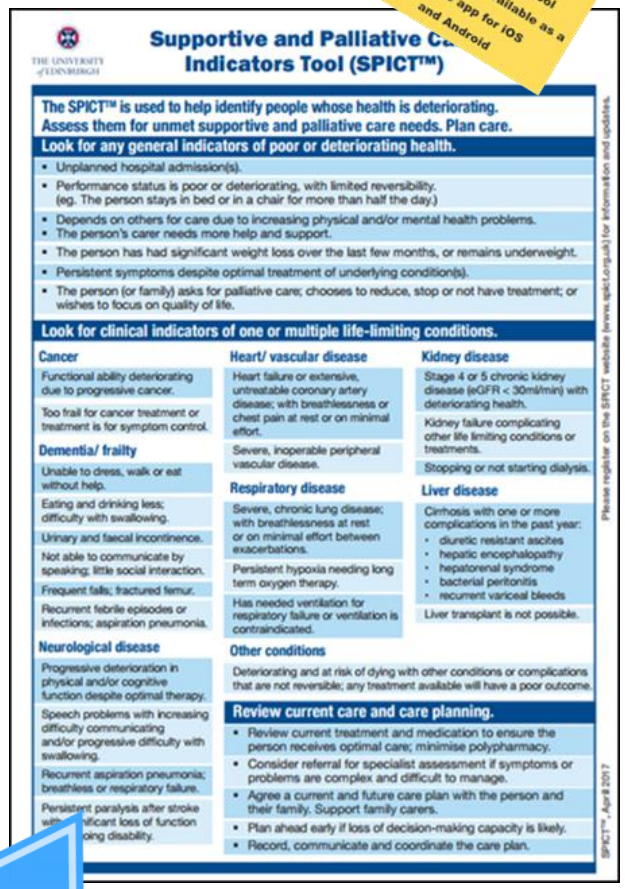
**'Would I be surprised if this person died in the next year?'**

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

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

*(Downer et al 2017)*

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



**Supportive and Palliative Care Indicators Tool (SPICT™)**

**The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.**

**Look for any general indicators of poor or deteriorating health.**

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- The person has had significant weight loss over the last few months, or remains underweight.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

**Look for clinical indicators of one or multiple life-limiting conditions.**

**Cancer**
- Functional ability deteriorating due to progressive cancer.
- Too frail for cancer treatment or treatment is for symptom control.

**Dementia/ frailty**
- Unable to dress, walk or eat without help.
- Eating and drinking less; difficulty with swallowing.
- Urinary and faecal incontinence.
- Not able to communicate by speaking; little social interaction.
- Frequent falls; fractured femur.
- Recurrent febrile episodes or infections; aspiration pneumonia.

**Neurological disease**
- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.
- Recurrent aspiration pneumonia; breathless or respiratory failure.
- Persistent paralysis after stroke with significant loss of function ...oing disability.

**Heart/ vascular disease**
- Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.
- Severe, inoperable peripheral vascular disease.

**Respiratory disease**
- Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.
- Persistent hypoxia needing long term oxygen therapy.
- Has needed ventilation for respiratory failure or ventilation is contraindicated.

**Other conditions**
- Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.

**Kidney disease**
- Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
- Kidney failure complicating other life limiting conditions or treatments.
- Stopping or not starting dialysis.

**Liver disease**
- Cirrhosis with one or more complications in the past year:
  - diuretic resistant ascites
  - hepatic encephalopathy
  - hepatorenal syndrome
  - bacterial peritonitis
  - recurrent variceal bleeds
- Liver transplant is not possible.

**Review current care and care planning.**
- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2017

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

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

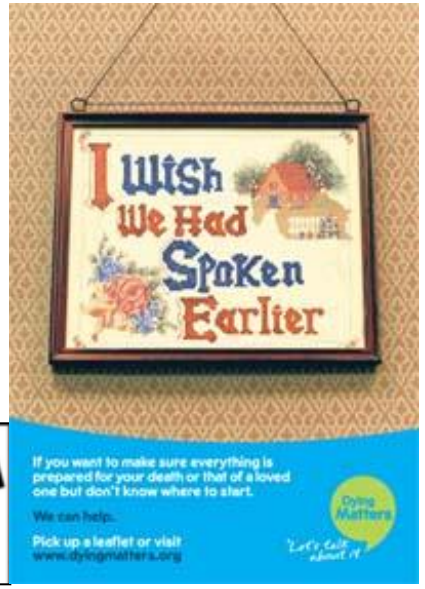
"I didn't want that!"

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

www.pilgrimshospices.org

# 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!

www.pilgrimshospices.org

# Concerns for the future


What matters to your patients/ residents?

Exploring options

Identifying wishes & preferences

# Potential outcomes of advance care planning discussions

- Patient may not wish to engage at the moment.
- May want to make an advance statement (of wishes or preferences). *Must be taken into account but not legally binding.*
- May want to make an advance decision to refuse treatment (ADRT). *Legally binding document which must be taken into account by clinicians.*
- May want to consider who they would like to be consulted on their behalf.
- May want to draw up a Lasting Power of Attorney (LPA).

# What does advance care planning discussion involve?

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*

# 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 & circumstances.
  - 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**

# 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

We will discuss CPR decision making (DNACPR later!

# Triggers for initiating or reviewing advance care planning discussion

- Patient initiates conversation.
- Diagnosis – progressive life limiting condition / LTC etc.
- Condition which is likely to result in loss of capacity (e.g. dementia).
- Change or deterioration in condition.
- Change in personal circumstances (move into care home, loss of family member).
- Routine review, appointment or when previously agreed review interval elapses.

*(Mullick, Martin in Kerry et al 2018)*

- Use uncertainty as an important trigger!
- Remember the tools to help identify end of life.

# 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…..

**Read – think – discuss - share**

Try practicing asking these questions to each other

Think about your communication skills

# Misconceptions about success of CPR


- Lay public tend to have unrealistic perception of outcome.
  *(Jones, Brewer,Garrison 2000)*
- Newspaper report survival rates (out of hospital arrests) significantly higher than medical literature.
  *(Field et al 2011)*
- Perception often related to impact of TV dramas.
- Basic knowledge of CPR can reduce but 'not eliminate the television effect'.
  *(Bulck 2002)*

*…with a cup of tea afterwards to help recover to full health!*

# How successful is cardiopulmonary resuscitation?

In the right context resuscitation can reverse the dying process, however:

- Rates of survival & complete physiological recovery following in-hospital cardiac arrest are poor.
- Chances of surviving to discharge from an arrest in hospital are fewer than 20%.
- Survival rates depend on cause of cardiac arrest, availability of expertise & equipment.
- Highest success rates are within coronary & intensive care units.

*National Confidential Enquiry into patient Outcome and Death (NCEPOD 2012)*

**∴ Individual circumstances need to be considered**

# What else do we need to consider?

- Success rate much lower for patients with life limiting conditions.
- We also need to consider what success is defined as!
  - What is a successful outcome from a cardiorespiratory arrest?

- CPR is invasive with risk of serious consequences
  - Fractures, damage to internal organs, hypoxic brain damage, undignified death.
- Frequent failure to consider resuscitation status.

*(Pitcher in Kerry et al 2018)*

- We cannot prevent the heart from stopping as part of the dying process.
- For this group CPR cannot prolong life but instead may prolong the dying process.

*NCEPOD (2012)*

# DNACPR decisions are sensitive & complex

## & not without debate or controversy


- Need to respect patient choice.
- Individual assessment for each case (no blanket policies).
- Safeguarding of vulnerable people.
- This is a sensitive matter and has come under scrutiny.

- Not always a consistent approach.

*(Freeman et al 2015)*

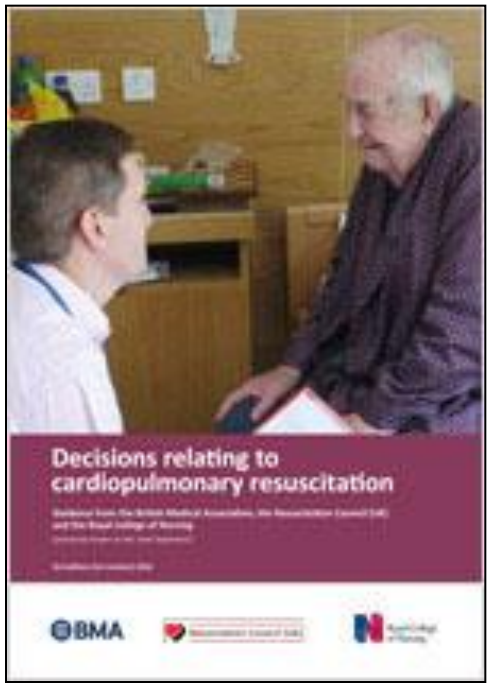
**Issues around DNACPR constantly developing**

- Guidance updated to reflect emerging issues.
- We will be discussing latest ReSPECT process later.

ReSPECT Recommended Summary Plan for Emergency Care and Treatment

# Updated current guidance

## Decisions relating to cardiopulmonary resuscitation 3rd edition (1st revision) 2016 - *BMA, RC (UK) & RCN*




Latest revision in response to public & professional debate about CPR decisions. Key ethical & legal principles remain the same, but places even greater emphasis on ensuring –

**high quality**
**timely communication,**
**decision making**
**& recording in**
**relation to decisions about CPR**

https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/

www.pilgrimshospices.org

# Why the need to consider CPR decision making?

# Are you aware of your local policy?

- All establishments that face decisions about attempting CPR should have a policy about CPR decisions.
- Needs to be readily available & understood by all relevant staff.
- & be available to the public.


Further changes are currently happening
Find out what is happening in your organisation
Review – review – review!

# Decision making process

- Responsibility always rests with most senior clinician currently in charge of patient's care.
- Good practice involves discussion with multidisciplinary team.
- Healthcare professional making decision must be competent to undertake discussion.

- Forms can only be completed by those who are permitted to do so.

- Some policies allow for suitably trained, assessed & fully competent senior nurses to complete DNACPR form if appropriate (may require countersigning).

# DNACPR forms

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

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

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

Adults over 16/18 years (some variation)

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

Watch out for ReSPECT

ReSPECT Recommended Summary Plan for Emergency Care and Treatment

# Sensitive discussions

- Patients may not wish to engage in discussion - this should be respected & documented **(including reason why).**
- Much greater emphasis on quality of communication & recording in updated guidance. *(BMA, RC (UK) & RCN 2016)*

- However we should not make assumptions.

"Although discussions on such sensitive issues are rarely easy, it is usually better to involve & consult people than exclude them for fear of causing upset"

*Claire Henry*
*CEO NCPC*
*(June 2014)*

# Potential challenges

- Patients cannot demand CPR if clinicians deem it would be futile (unsuccessful or may cause significant harm or burden).
- However sensitive explanation of why CPR is not an option is needed.
- These discussions may not be easy as explanation of the decision is required. It is not about offering choice when it is not considered an option, but instead requires careful sensitive explanation.
- Second opinion may be sought.
- Consider importance of consensual multidisciplinary decisions *(Imhof et al 2011).*

*See Section 5.4 BMA, RC, RCN (2016)*

# Decision making conversations &process….


What else can help?

# CPR decision making conversations

## What do patients, family & caregivers prefer?

- Discussions initiated by someone trusted (not just doctors – also nursing & AHP team)
- Most want family involvement, but some concerned about burden
- Timing very individualised but needs to be early
- Not on acute admission in busy environment
- Conversations to be honest, straightforward, empathetic. Avoid vague language. Consider level for understanding. Include discussion about goals & quality of life

*Hall et al 2018*

# What questions should healthcare professionals ask themselves?

Healthcare professionals competent in CPR decision making need to consider:

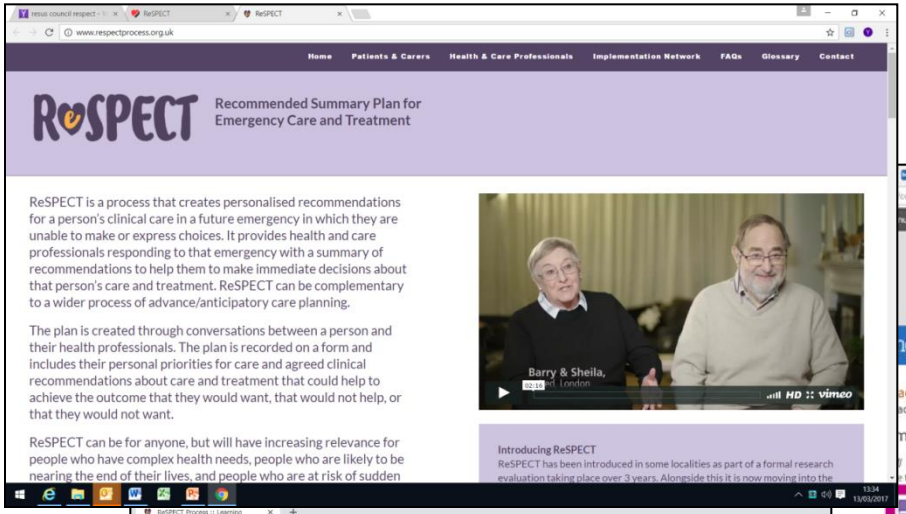
- Is a cardiac arrest likely?
- Is an attempt at CPR likely to be successful?
- Has the patient the capacity to be involved in decision making?

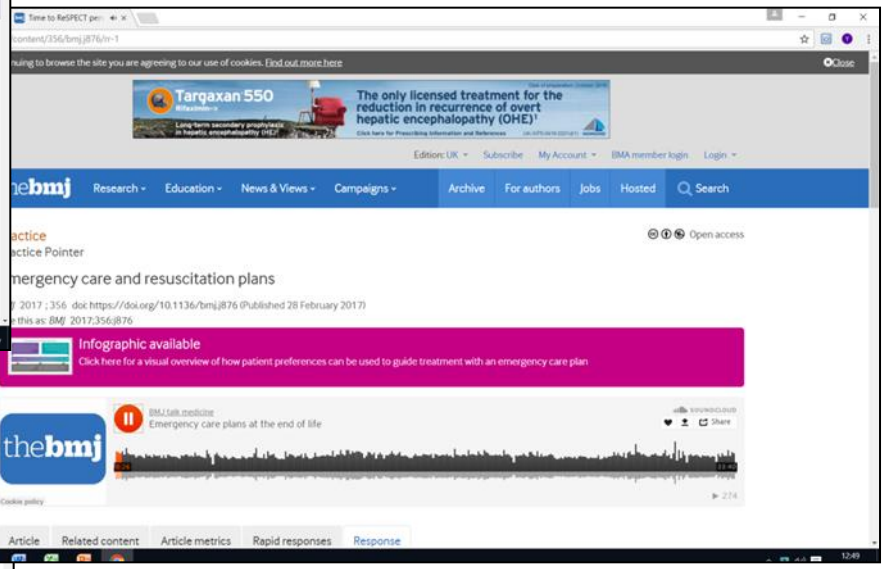

Mental Capacity Act (MCA 2005)

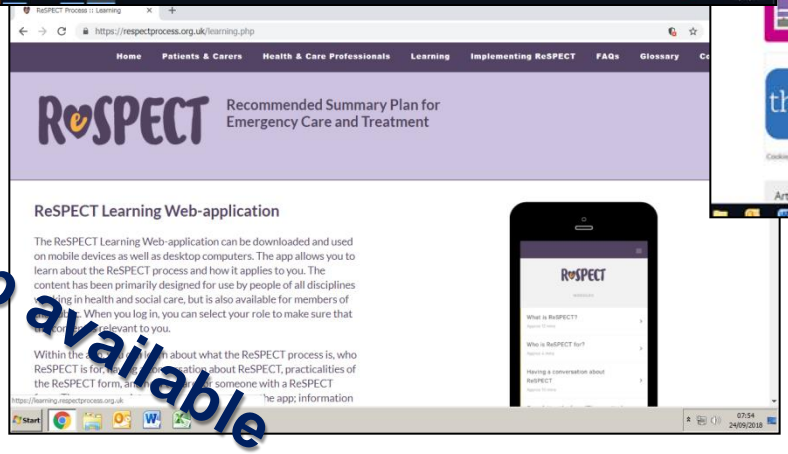
Pilgrims Hospices

ReSPECT Recommended Summary Plan for Emergency Care and Treatment

# ReSPECT




App available

www.pilgrimshospices.org

# 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

Pilgrims Hospices


# Finally

Remember

DNACPR orders only refer to cardiopulmonary resuscitation, not to any other treatments

*Unexpected deterioration should always be assessed and managed appropriately irrespective of DNACPR status*

Must not compromise any other aspect of care or treatment

*(Resus Council 2016)*

# Advance care planning
# What's the evidence?


Reference & resource handout available

www.pilgrimshospices.org

# 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?

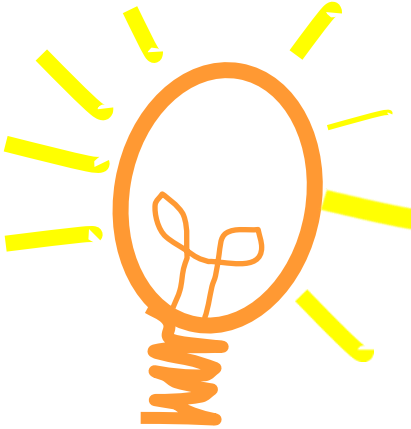
# Documentation


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)
- DNACPR form
- ReSPECT

**What do you use in your organisation?**

# Summary of top tips



- Embrace uncertainty - use as a trigger for discussion.
- Understand the impact of the terms we use.
- Do not assume everyone is fully aware.
- Use resources to help.
- Jump at any opportunity to further communication skills.
- Open and honest discussion.
- Listen for cues.
- Answer all questions and concerns.
- Include family and / or carers if possible.
- Remember not all will engage. ACP is voluntary.

- Watch out for further information on ReSPECT

ReSPECT Recommended Summary Plan for Emergency Care and Treatment

# Thought to take away

‘Uncertainty may in fact be more friend than foe.

An unpredictable but evident risk of deteriorating & dying should be a trigger for planning care with all people who have an advanced illness & in all care settings.’

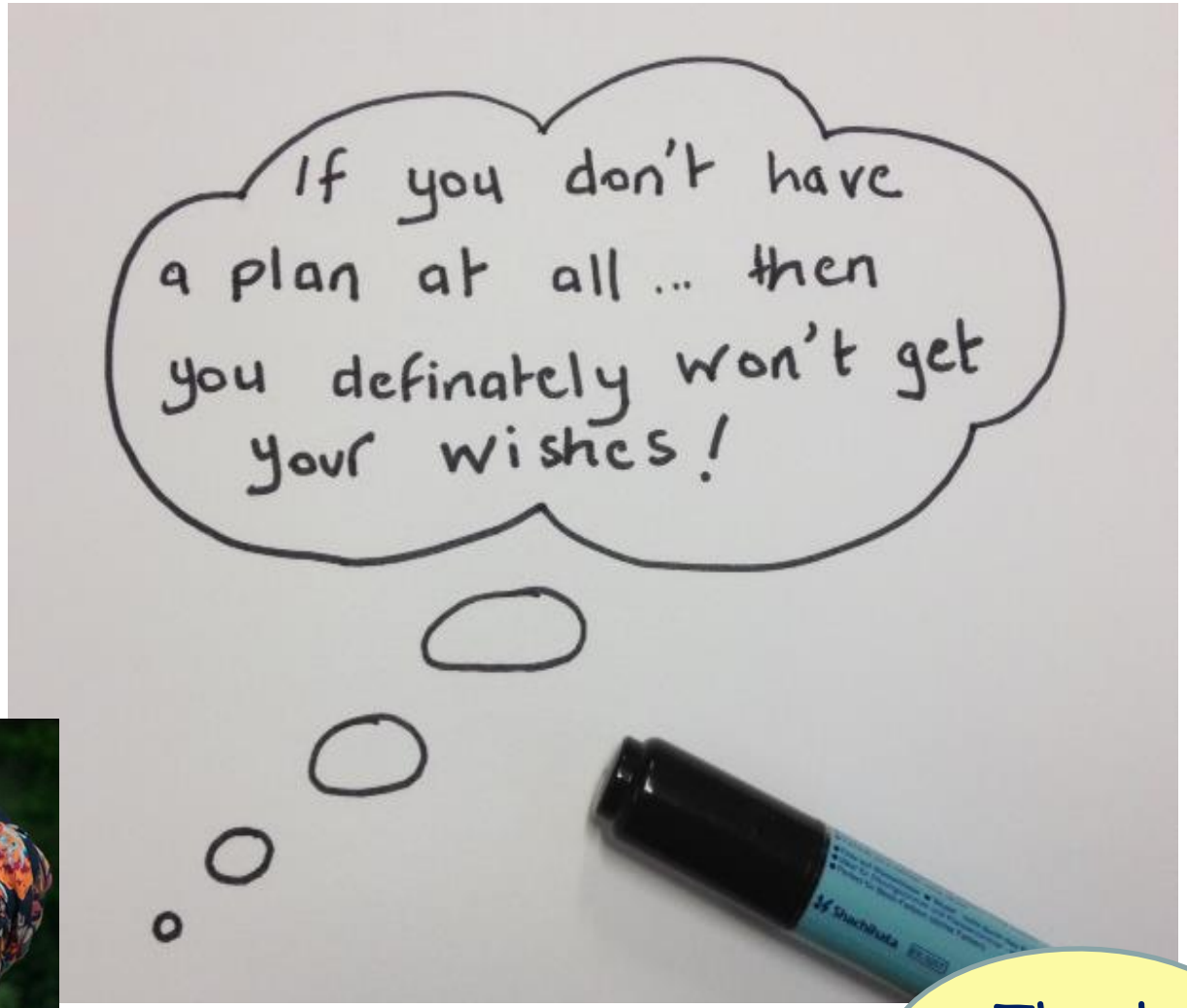
*(Kimbell et al 2016)*

Pilgrims Hospices

# hello

my name is…

Dr Kate Grainger




Thank you!

www.pilgrimshospices.org

# References & resources

Further more detailed list available

- 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
- fink™ Advance Care Planning https://finkcards.com/products/advance-care-planning
- Gold Standards Framework website http://www.goldstandardsframework.org.uk/
- National Council for Palliative Care - Difficult Conversations for Dementia http://www.ncpc.org.uk/difficult_conversations

# References & resources cont.


- 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
- NICE (2018) Care & support of people growing older with learning disabilities. https://www.nice.org.uk/guidance/ng96
- 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.