

# Talking about Dying:

## From Anticipatory Care Planning to End of Life Care

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## What's the purpose of ACP?

- Clarifying the person's expectations, so that they can express preferences that are founded on good information.
- Ensuring that responses to future healthcare events respect the person's preferences and values
  - By statutory services, in-hours and out-of-hours
  - By family & friends
- Planning ahead may be to ensure future responses
  - Step up and escalate
  - Step back and evaluate
  - Step up and palliate – palliation is NEVER less care, even if it is sometimes less intervention

## Where do we start?

- 'Instead of/as well as/ now we've finished talking about your current care and medications today, I'd like to take some time to talk about how you would like your care to be in the future...'
- Do you have any concerns about what might happen to your health in the future?
- What's your best hope for the way your health will change as you get older/as your condition progresses?
- What's your worst dread about that?
- What would we need to do to make sure things turn out more like your best hope, and less like your worst dread?

Orientate the discussion to the person's priorities.

**'Is your goal these days...'**

**'...to live as long as possible?'**

- What are the milestones you hope to achieve?
- How realistic are they?
- Do you have a backup plan?
- Can you envisage a time or circumstances when that goal might change?
- Where would you set the balance between length of life and comfort/quality of living?

**'...to live as comfortably as possible?'**

- What does good quality of life mean for you?
- How can we improve or maintain your quality of life?
- Can you envisage circumstances when those goals might change?
- Where would you set the balance between length of life and comfort/quality of living?

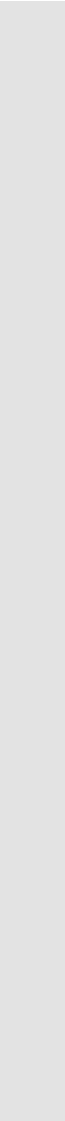
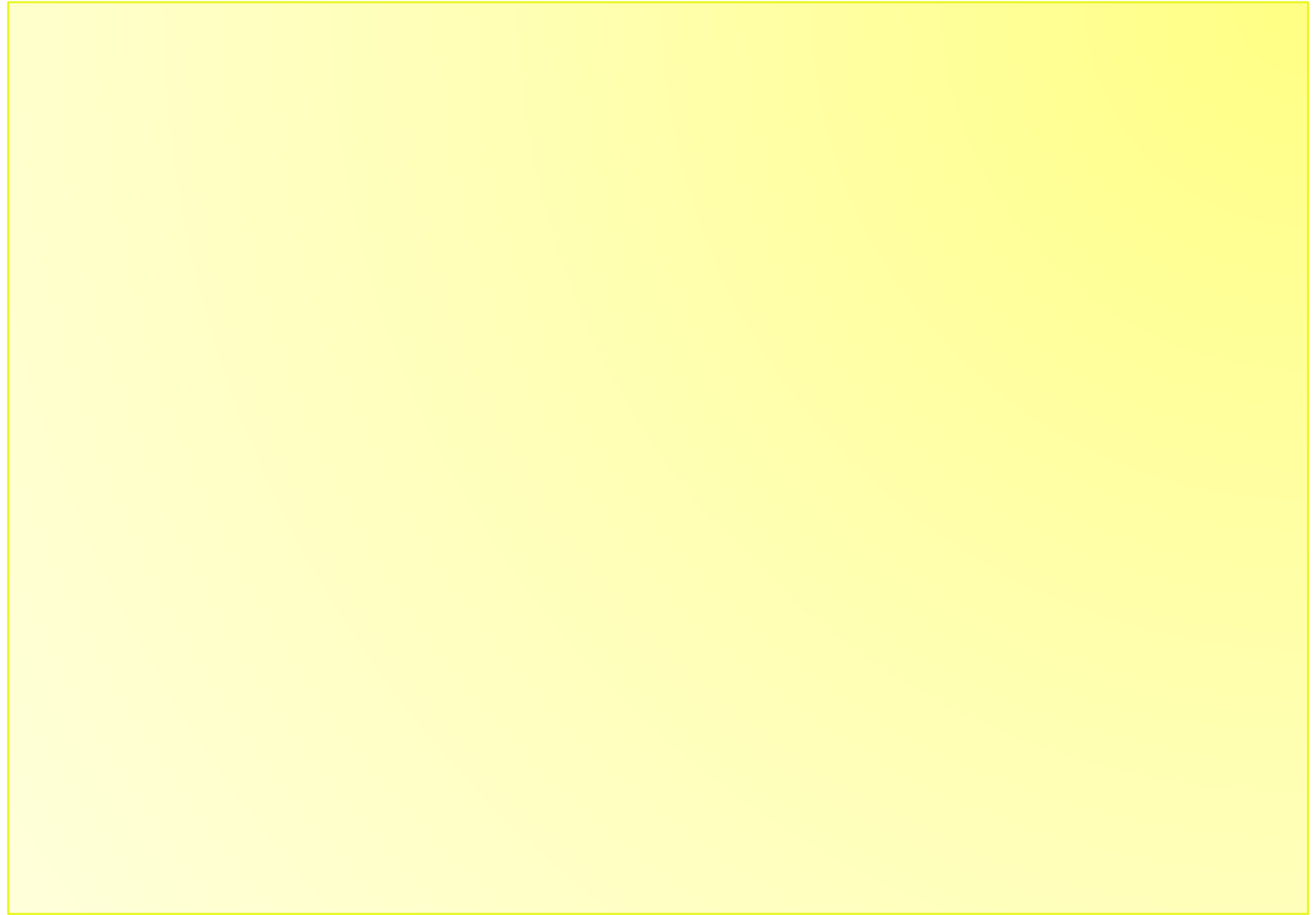
The paperwork:  
filling it in  
completely helps  
us all to stay on-  
message & remain  
focused on  
patient's values

- Local variations: ReSPECT; Deciding Right; GGC Clinical Portal
- Not only what NOT to do, but how to respond when required – a plan for anticipated emergencies
- Making sure the right people are aware:
  - Patient
  - Patient's first-line supporters: family, friends, res care staff, domi care staff – needs to bridge health & social care services
  - 'The daughter in Australia'
  - Usual medical advisers: PCT; LTCs team; onc team; MH team etc – may well have contributed to drafting the documents
  - OoH responders: 111, 999, GP, falls alarm responders

## When the person can't tell us their preferences and wishes...

- Best Interests decisions can be made. The decision maker might be
  - The person/people with PoA (LPA (H&W) E&W)
  - The prescriber of a medical intervention
  - The facilitator of a social intervention
- Helpful information about the person's values and preferences can be obtained from
  - The person – even if they lack capacity for this particular decision, they may well have an opinion
  - Previous statements of wishes
  - People who know the person well: family, friends, care staff, SW, clergy
  - An IMCA if there is doubt or conflict
- If a valid, applicable ADRT exists, it should be followed (must be E&W). If it is not fully applicable, it may be a guide to preferences and values for a BI decision.

Pause  
for  
Thought



The public  
understanding of dying:  
why we need to 'midwife'  
the deathbed



# MY RIGHT TO DIE IN DIGNITY

The public  
understanding  
of dying

Cancer mum denied  
chance to say goodbye  
'because doctors did  
not try to keep her alive'

# NHS HIT BY NEW HOSPITAL DEATHS COVER-UP

# LEFT TO DIE BY CALLOUS PARAMEDIC

# Our mum was drugged up and denied any food



# The public understanding of dying

- Misinformation
- Media distortion
- Soap opera/cinema trivialisation
- Lack of direct experience, or mistrust of own experience
  
- This is the space in which we are trying to deliver a service.
- This is a Public Health issue

# How we die 1

Changing energy levels; increasing sleep

Periods of being unrousable

Periods of being awake

Possible restlessness

Onset of unconsciousness

'Periodic Breathing' reflex

Respiratory noises

Slowing of respiration; pauses

Last breath usually 'nothing special'

# How we die

## 2

- Gradual process of normal dying is interfered with by discomfort/physical symptoms
- ACP needs to consider plans for possible symptoms depending on specific patient and their condition:
  - Bowel cancer: nausea; colic; constipation; diarrhoea; liver pain
  - Brain tumour: fits; headache; nausea; mobility challenges; agitation
  - Kidney failure: nausea; itch; changes in drug metabolism; delirium; fits; myoclonic jerks; CA
- Relief of symptoms will allow patient to settle: level of unconsciousness without symptoms may surprise the family so warn them what to expect.

# 'Midwifing' Dying

- Preparation: what to expect, options for place of care, who will provide care, what backup will be available
- Monitoring: familiarity with symptoms; planning for anticipatable emergencies; 'step up' as well as 'step back' plans
- Interventions: less 'treatment' and more 'care.'
- Deathbed accompaniment: narrating the process, explaining to patient and family, reassurance, pro-active symptom management, reactive symptom management
- Normalising normal dying
- Beginning the stories to be told in bereavement
- Every death an opportunity to educate

# Helpful phrases

- Tell me what you think is going on.
- Tell me what you expect to happen in the future.
- 'What if...' (avoids crushing denial)
- Treatment of X will restore you to how you were before X began: how were you then?
- You're at a crossroads.
- There are important decisions to be made today.
- What matters most to you right now?
- How much detail would you like me to give you? Is there someone you'd like to talk to with me? Someone you'd like me to talk to?
- Would you like me to describe how things are likely to happen? It's probably gentler than you're expecting.
- 'Sick enough to die.'
- 'If s/he could tell us, what would s/he say now?'

# Helpful phrases

- Tell me what you think is going on.
- Tell me what you expect to happen in the future.
- 'What if... ' (avoids crushing denial)
- Treatment of X will restore you to how you were before. How were you then?
- You're at a crossroads.
- There are important decisions to be made.
- What matters most to you?
- How much detail do you want to know? Is there someone you'd like to talk to with me?
- Would you prefer to know the worst things are likely to happen? It's probably gentler than you're expecting.
- 'Sick enough to...'
- 'If s/he could tell you what s/he would say now?'

When in doubt....

Summarise

Ask an open question



# Covid Complications

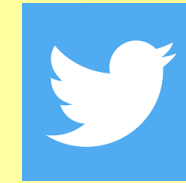
- Absence from deathbed: information vacuum will impact of grief and bereavement
- Decisions about non-escalation reported in media as 'rationing.'
- Decisions to remain in usual place of care reported in media as 'left to die.'
- Danger that 'ACP' will be mistaken for rationing or therapeutic nihilism
- Hard to campaign by saying 'It's not....'
- We need a clear, multi-stakeholder campaign that says ACP is about respecting people's right to know about their health and make plans for their future care based on respect for their preferences, values and wishes.

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Marshall,  
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Join the conversations:



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[www.withtheendinmind.co.uk](http://www.withtheendinmind.co.uk)