Advance Care Planning:

helping our patients to look ahead with hope

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What's your role in End of Life care?

- As a primary care clinician?
- As a DGH clinician in medicine, surgery, paeds, A&E?
- As a tertiary care clinician?
- As a commissioner of services?
- As a social care provider?
- As a health care manager?
- As a palliative care clinician?
- As a paramedic?
- As a member of a family/friendship group?
- As a human being?
- As somebody who will, in your turn, need End of Life Care?

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?

How do we plan ahead?

- We need to acknowledge disease progression
- We need to discuss diminishing returns of intervention
- We need to offer realistic plans for action when a patient feels less well
- The family needs to know the plan, and to understand it
- The plan needs to written jointly with patient/family
- The plan needs to take local services into account
- The possibility of dying, and how that will probably happen, needs to be discussed.

Advance Care Planning Progress

	Yes	No	GP aware
Patient is eligible for entry in GP Palliative Care Register?			
Patient is aware that ACP is appropriate?			
Possible future crises are planned for?			
Emergency Health Care Plan written?			
Patient has ADRT?			
Patient has nominated LPA and registered with OPG?			
Patient has agreed their current resuscitation status, which is:			
For CPR			
DNACPR			
If DNACPR, form has been completed & shared with GP & OOH services			
ReSPECT discussion has commenced?			
ReSPECT form is up to date?			

Dealing with uncertainty in Acute Medicine

- What's the diagnosis?
- What's making him/her so sick?
- What's reversible?
- How reversible?
- Is there an outcome worse than death?

- What does he/she know?
- What are his/her wishes?
- How much disability is s/he prepared to tolerate?
- What's more important to him/her, quality of life or length of survival?

Useful concepts

- Is death a possible outcome?
- What would 'dying well' look like?
- Parallel planning: restorative & EoL care at the same time
- Pre-sedation pause for communication

Helpful phrases

- "Sick enough to die…"
- "In case we can't reverse this…"
- "If s/he's sicker by tomorrow, what might we wish we had done today?"
- "What do you know about dying?"

The paperwork:

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

- Local variations: ReSPECT; Deciding Right; TEP etc
- 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 LPA (H&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 must be followed. If it is not fully applicable, it may be a guide to preferences and values for a BI decision.