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Finding the balance between holding on and letting go

Dying – the big unfixable

- Most people die from chronic disease, not a sudden event
- 70% of older patients present to the ED at least once in their last year of life
- Many have escalating attendances in their last weeks/days
- 30% of Australians die before age 75

Planning for death

- 40% of patients do not have capacity to make decisions at the end of life
- In 2014 only 14% of Australians had an Advance Care Plan/Directive
- In 2015, in patients older than 65 presenting to the ED
 - 26% of those from ACF had an ACD
 - o% of those from the community had an ACD
- 70% of people would like to die at home, but only 10% do

Managing death in the ED

- Australian Emergency Physician survey 2014
 - 84% felt uncomfortable providing care to the dying
 - 84% felt ED is not the right place to die
 - 65% felt futile treatment is frequently provided in ED
 - as limitations of care are not clearly documented
- Yet more and more people are presenting to the ED at the end of life

How do you know if EOL is approaching?

Patients with a serious, life-threatening illness and one or more of the following :

- Not Surprised You would not be surprised if the patient died in the next 12 months
- Bounce-Backs The patient makes more than one ED visit or hospital admission for the same condition within several months
- Uncontrolled Symptoms An ED visit is prompted by difficult-to-control physical or emotional symptoms
- Functional Decline There is decline in function or worsening of feeding intolerance,
 unintentional weight loss, or caregiver distress
- Increasingly Complicated Complex long-term care needs require more support

CriSTAL tool - predictors of death within 3 months

Case 1

- 77 yo woman from home with severe dyspnoea on a background of CCF and multiple other co-morbidities
- She is drowsy, hypoxic and confused
- The ambulance have brought an Advanced Care
 Directive which the patient signed 1 year earlier stating
 she does not want CPR or aggressive resuscitation
- The daughter arrives she demands that her mother have full treatment. She has never seen the advanced care directive and tries to tear it up

This is her ACD

- If I am in the terminal phase of an incurable illness:
 - I do/do not want cardiopulmonary resuscitation
 - I do/do not want assisted ventilation
 - I do/do not want artificial hydration.
 - I do/do not want artificial nutrition.
 - I do/do not want antibiotics unless needed as part of my palliative care.
- What will you do?

What will you do?

- Commence active treatment at the daughter's requests as she is the NOK
- Provide supplemental oxygen but no other active treatment in keeping with the patient's ACD
- Give antibiotics, oxygen and fluids but not further active intervention
- It depends......

Advanced Care Directives

- ACDs are a legally binding as an extension of an individual's right to consent, or refuse consent, to medical treatment
- ACDs need to be:
 - Relevant to the current clinical situation
 - Reflect the current views of the patient
 - Have been written when the person was competent

Requirements for a valid ACD

Common law	Statutory
capacity	capacity
without undue influence	without undue influence
	signed/dated & witnessed
must reflect current sentiment of person	for a current condition (Vic)

In cases of potential dispute:

- Supreme Courts of each State or Territory
 - Parens patriae jurisdiction
- Guardianship authorities and the guardians they appoint
- Health attorneys, enduring guardians and medical agents appointed by the patient
- Relatives or persons responsible under the relevant legislation

 Where there is genuine and reasonable doubt as to the validity of an ACD, the practitioner is justified by the 'emergency principle' in administering the treatment in question until the Court gives its decision

HOWEVER YOU ARE NEVER OBLIGED TO PROVIDE
 FUTILE TREATMENT

Futile Treatment / Non- beneficial treatment

 Treatment that gives no, or an extremely small, chance of meaningful prolongation of survival and, at best, can only briefly delay the inevitable death of the patient



POLICY

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Whilst doctors are generally not obliged to provide treatments that are considered medically futile, where possible it is important that the doctor discuss their reasons for determining a treatment to be medically futile with the patient (and/or the SDM, carers, family members) before deciding the treatment should not be offered



This is her ACD

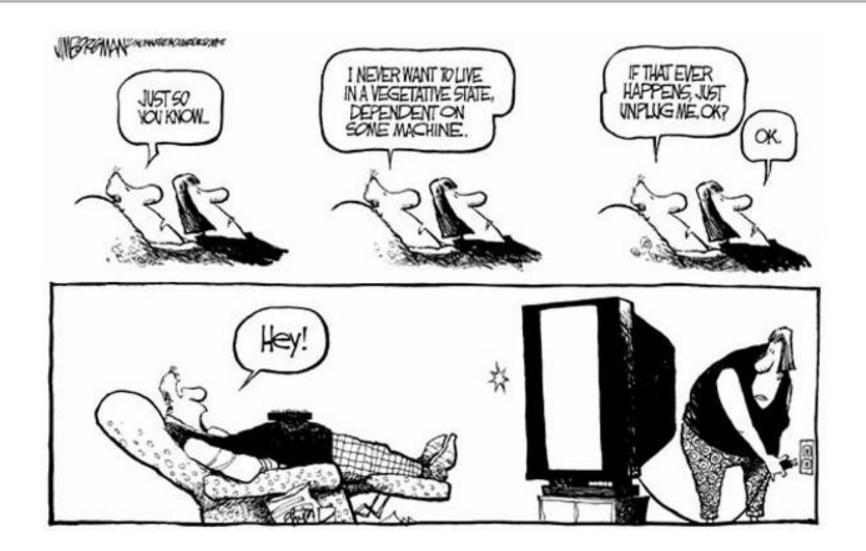
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This is her alternative ACD (dated one year earlier, signed & witnessed)

- I understand that I have a weak heart, weak kidneys and diabetes
- I understand that if my heart or kidneys gets worse I may become very short of breath due to fluid on my lungs or that my heart might stop beating and that either of these events may cause my death
- If either of these events occur, I do not want any unpleasant or invasive treatment such as a breathing machine, breathing tube or electrical shock to improve my breathing or make my heart beat again
- I do not want my life prolonged by artificial feeding or hydration
- I want my treatment to focus entirely on maintaining my comfort and dignity and request that medications be given to achieve this

92 yo demented patient from high level care facility, presents with acute stroke. ACD co-signed by a geriatrician

- Do not admit to Intensive care Unit Do not ventilate (except during and after surgery e.g. tube down throat and co with machine) OR Intensive Care (includes Surgical) Transfer to acute care hospital without hesitation Admit to Intensive Care Unit if necessary Ventilate if necessary Insert central line e.g. main arteries for fluids when other veins collapse Provide surgery, biopsies, all life support systems and transplant surgery Do everything possible to maintain life
 - Treated with thrombolysis, complicated by ICH, admitted to ICU.....



"Not for CPR – just fluids and antibiotics....."

- 92 yo woman from high level care facility,
 - advanced dementia
 - PEG tube in situ "for recurrent aspiration"
- T 38, O2 sats 88%, SBP 85/
- 2 similar presentations in past 6 months admitted under geriatrics and treated with IVAB for aspiration pneumonia
- Previously documented as "not for CPR"
- She has two children who visit infrequently, no formal guardianship plan or ACD
- What will you do?

What are you going to do?

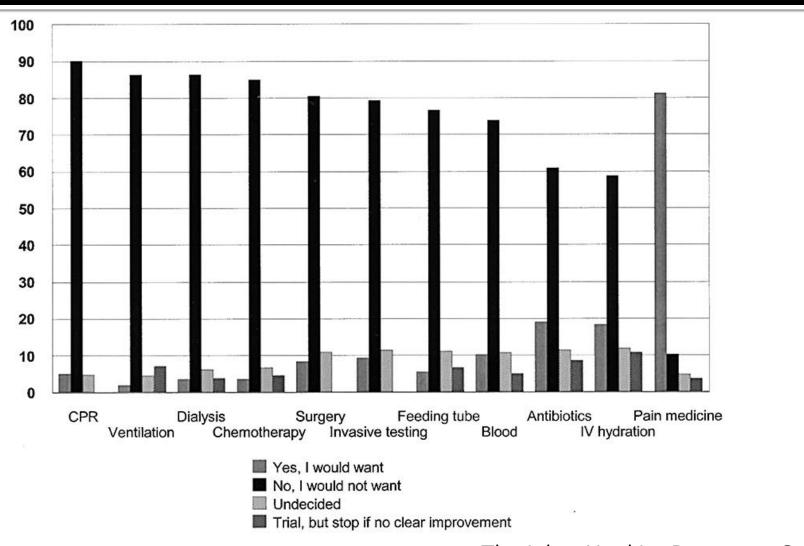
- The easy pathway admit her again under Geris for fluids and Abs
- Take a stand, send her back to the nursing home for palliation
- Talk with the family:
 - What would she want?
 - What do they want?
 - Are the close enough to be considered SDM?

Not for CPR – just fluids and antibiotics.....

- 90% of hospitalized patients with advanced cancer receive antimicrobials during the week prior to death
- 42% of nursing home residents with advanced dementia are prescribed antimicrobials during the last 2 weeks of life
- Approximately one-quarter of hospice recipients, for whom the intended goal of care is comfort, receive antimicrobials during the final weeks of life

- Antibiotics may provide some symptom relief for painful infections –
 but minimal evidence
- Antibiotics may prolong life for days to weeks in terminally ill patients but with greater suffering
- Antibiotics can:
 - Cause opportunistic infections
 - Drug interactions
 - Fluid overload
- 60% of doctors say that they wouldn't want antibiotics at the end of their own life!

What doctors want for themselves



The Johns Hopkins Precursors Study

Supplemental fluids

- Intravenous fluids do not relieve thirst
- In the dying patient, the majority never experience thirst, or only initially, and the thirst that occurs is easily alleviated by small amounts of fluids or ice chips given by mouth, and by lubricating the lips
- Loss of appetite is normal in the dying patient, hunger is rare

Other interventions to avoid

- Interventions should be based on symptom management unless curative intent
- Oxygen doesn't relieve dyspnoea unless hypoxic
- Death rattles are not relieved by antisialogues, best managed with positioning
- Good palliative care with symptom-focussed medication can prolong life longer than Abs/fluids and with greater QOL

Communication

- Talk to the family
 - "When a family says their father wants to live I try not to ignore it. I just say, 'Of course he does, we all want to live, but would he want to live like this?' People imagine they're going to live the way they did before they got sick, but that's not our choice right now"
- Talk to the patient (it makes you look human)

Establish goals of care

Helps avoid unwanted treatments and undue suffering

- Communicate prognosis clearly: "Hope for the best, prepare for the worst."
 - Explain your clinical assessment of what is wrong and what you expect the outcome will be
 - Make it clear if the process is not curable
- Engage the patient/surrogate by eliciting their goals of care with open-ended questions.
 - "What are you hoping for?" "What are you afraid of?" "What is important to you right now?"
- Choose words wisely
 - Avoid negative statements that may make the patient feel abandoned: "Do you want us to stop aggressive care?"
 - Highlight the patient's best interest: "We are here to ensure that you receive the treatment that is best for you and in line with your personal goals."
- Determine a treatment plan that is in line with the patient's wishes
 - Summarize your patient's goals & initiate a plan of action
 - Encourage the patient/surrogate to advocate for their wishes: "If you feel that the treatment you are receiving is no longer worthwhile, not enough, or causes you too much suffering, we can change our plan at any time."

Resolution

- Accept that opinions may differ
- Futility is subjective
- But the focus should be on what is best for the patient rather than what is best for the family
- Avoid conflict unless you feel the patient is suffering

Palliative care in the ED

- Improves quality of life and reduces costs associated with alternate treatments
- Improves satisfaction for patients and their families
- Improves outcomes, decreases length of stay,
 less use of intensive care units