End of Life Care for People living with Frailty

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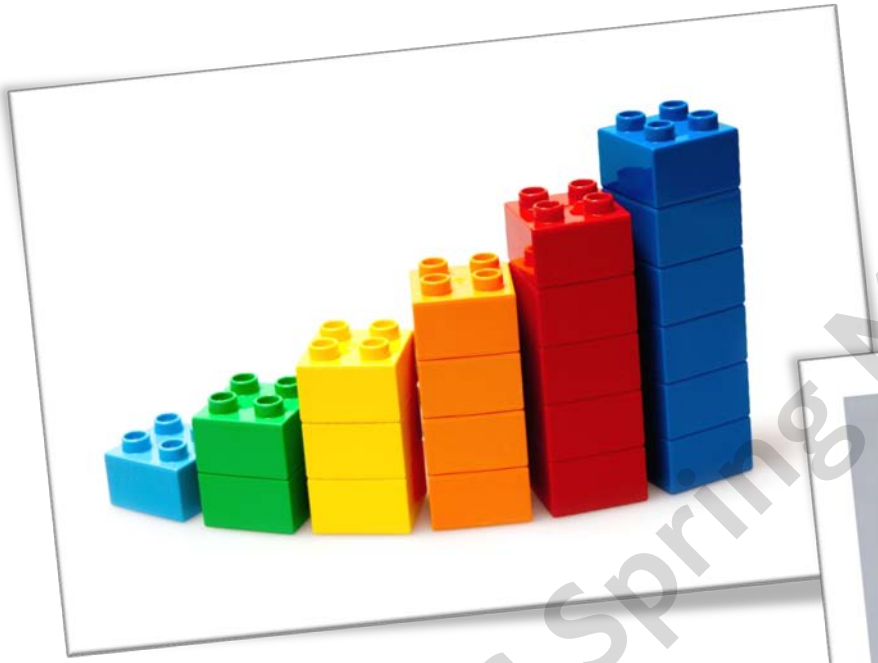
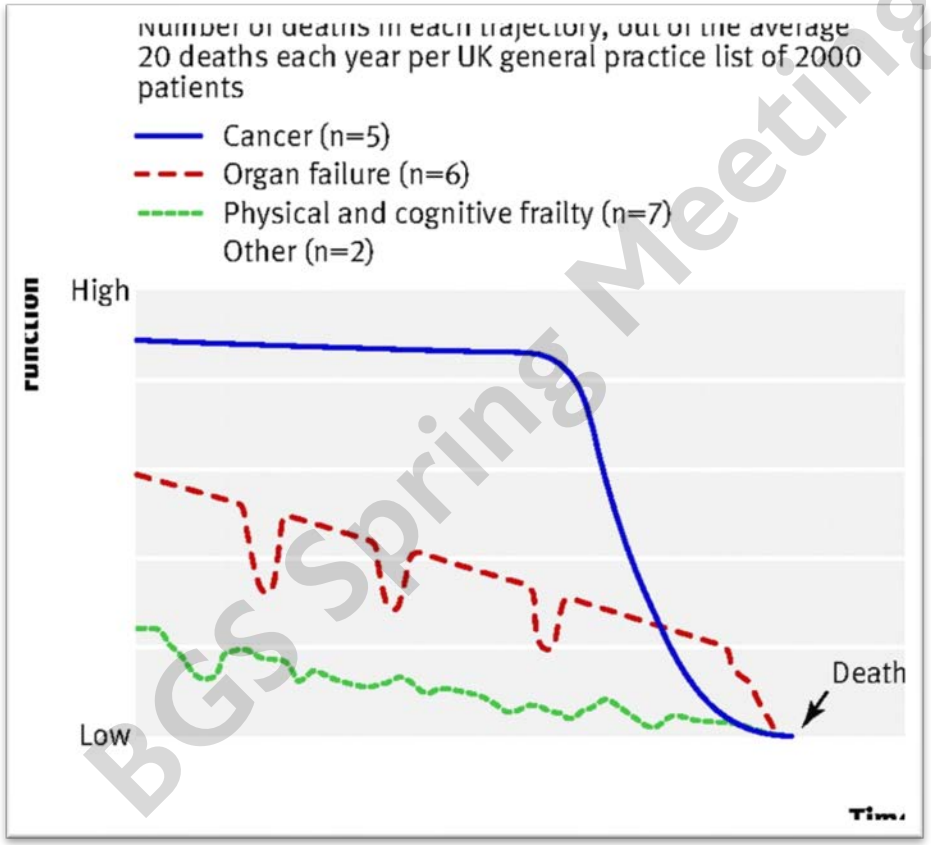
End of Life Care in Frailty



Building Blocks of Quality End of Life Care

- **R**ecognition
- **C**onversations
- **C**ommunication & coordination
- **S**ymptom Control
- **L**ast Days of Life Care
- **B**ereavement

1. RECOGNITION that End of Life is approaching



1. RECOGNITION that End of Life is approaching

Traditional EOLPC

- Recurrence disease
- Metastatic disease
- Failure to respond to chemo
- Steady decline in condition

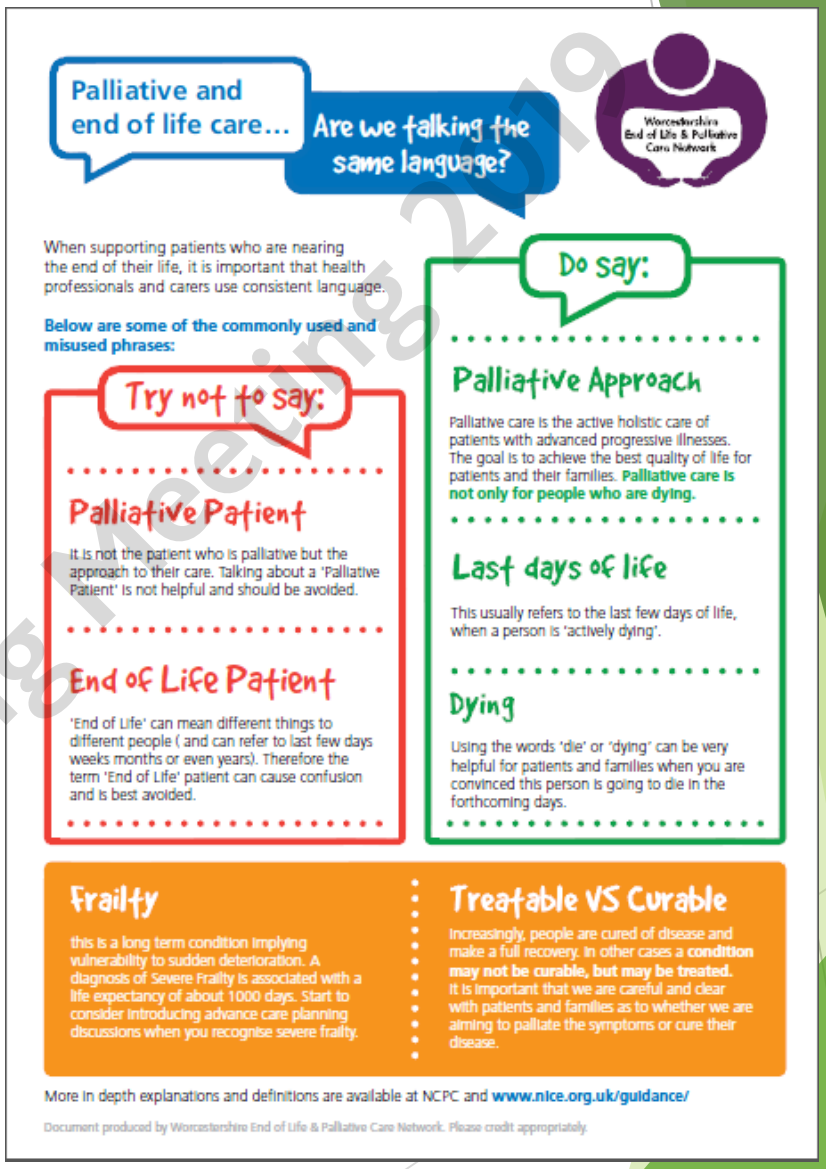
Frailty Related

- Diagnosis of Moderate/**Severe** Frailly
- Over 80s but CFS score important
- Over 85 and one or more acute admissions to hospital (45% mortality at 12m)

"Imminence of death among hospital inpatients: Prevalent cohort study" David Clark et al March 2014 Palliat Med

Language

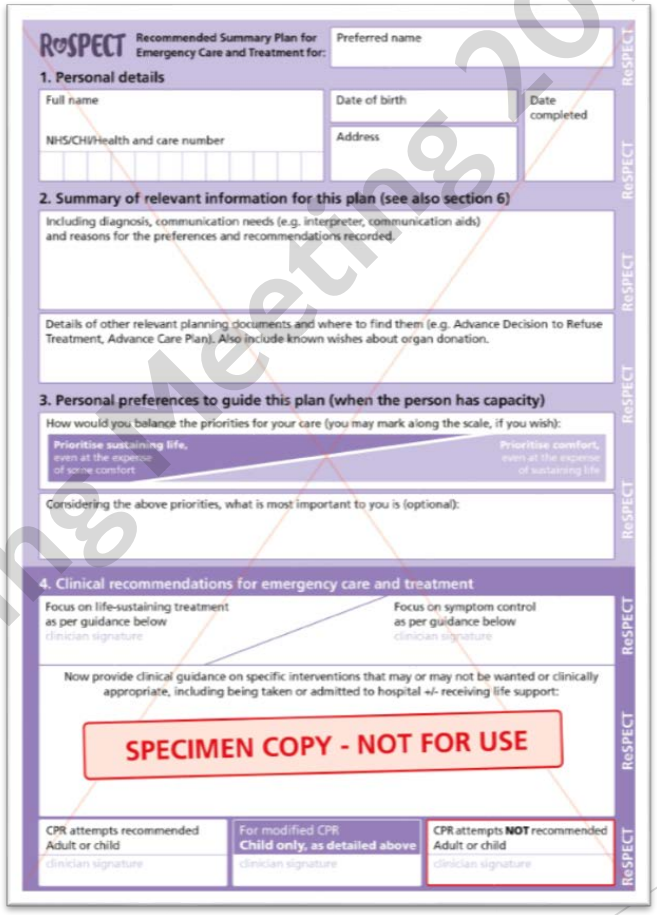
- ‘End of Life’
 vs Approaching the end of Life
- Palliative Approach
- ‘Last Days of Life’ if in the dying phase



2. CONVERSATIONS

Traditional EOLPC

- Patient
- Include Family members/Support network
- DNACPR –and escalation plans - ReSPECT
- Recording the conversation


ReSPECT Recommended Summary Plan for Emergency Care and Treatment for:

Preferred name

1. Personal details

Full name

Date of birth

Date completed

NHS/CHI/Health and care number

Address

2. Summary of relevant information for this plan (see also section 6)

Including diagnosis, communication needs (e.g. interpreter, communication aids) and reasons for the preferences and recommendations recorded.

Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.

3. Personal preferences to guide this plan (when the person has capacity)

How would you balance the priorities for your care (you may mark along the scale, if you wish):

Prioritise sustaining life, even at the expense of some comfort

Prioritise comfort, even at the expense of sustaining life

Considering the above priorities, what is most important to you is (optional):

4. Clinical recommendations for emergency care and treatment

Focus on life-sustaining treatment as per guidance below

clinician signature

Focus on symptom control as per guidance below

clinician signature

Now provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital +/- receiving life support:

SPECIMEN COPY - NOT FOR USE

CPR attempts recommended Adult or child

clinician signature

For modified CPR Child only, as detailed above

clinician signature

CPR attempts NOT recommended Adult or child

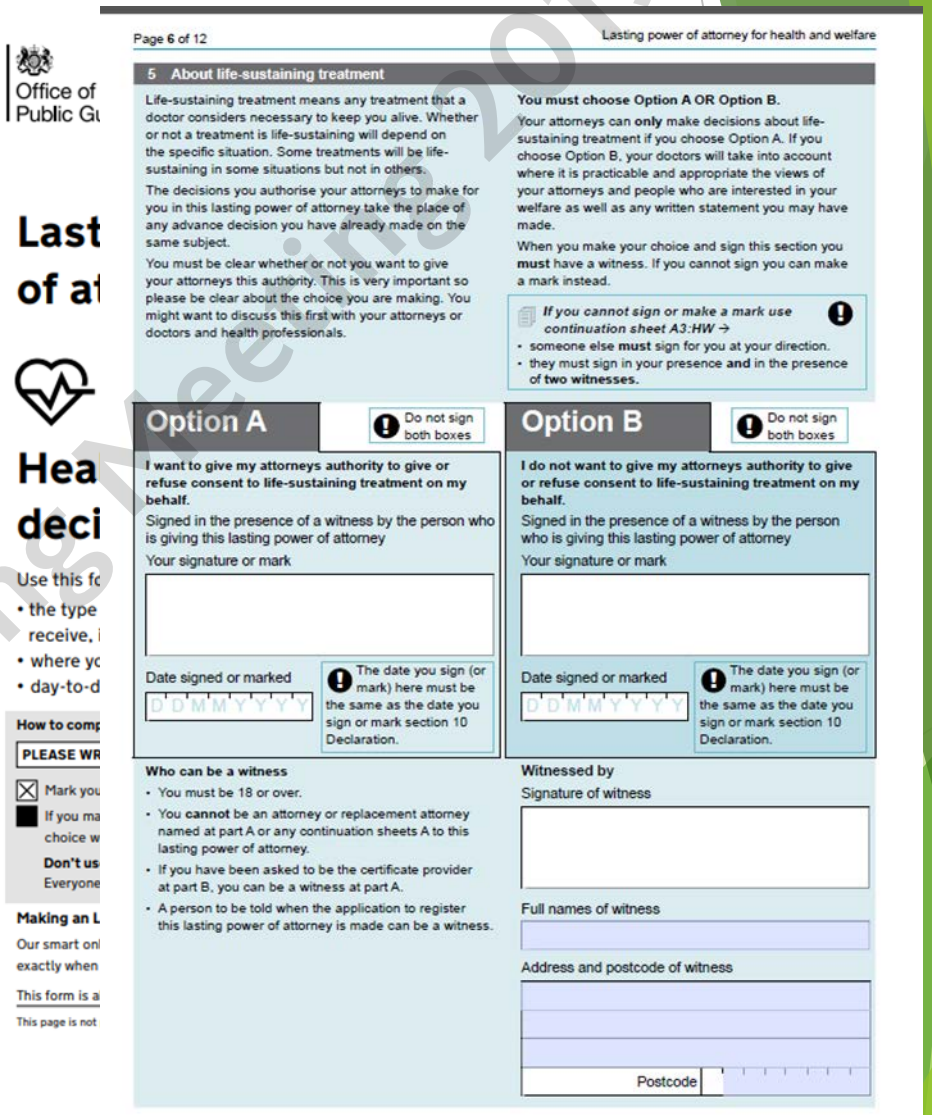
clinician signature

ReSPECT

2. CONVERSATIONS

Frailty

- Capacity issues
- Who is the decision maker?
- LPOA – for Health
- LPOA for Health with life sustaining decisions
- Need to see paperwork
- If not POA and no capacity need to d/w family/nok in order to make a Best Interest Decision



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Page 6 of 12 — Lasting power of attorney for health and welfare

5 About life-sustaining treatment

Life-sustaining treatment means any treatment that a doctor considers necessary to keep you alive. Whether or not a treatment is life-sustaining will depend on the specific situation. Some treatments will be life-sustaining in some situations but not in others.

The decisions you authorise your attorneys to make for you in this lasting power of attorney take the place of any advance decision you have already made on the same subject.

You must be clear whether or not you want to give your attorneys this authority. This is very important so please be clear about the choice you are making. You might want to discuss this first with your attorneys or doctors and health professionals.

You must choose Option A OR Option B.

Your attorneys can **only** make decisions about life-sustaining treatment if you choose Option A. If you choose Option B, your doctors will take into account where it is practicable and appropriate the views of your attorneys and people who are interested in your welfare as well as any written statement you may have made.

When you make your choice and sign this section you **must** have a witness. If you cannot sign you can make a mark instead.

If you cannot sign or make a mark use continuation sheet A3:HW →

- someone **else must** sign for you at your direction.
- they must sign in your presence **and** in the presence of **two witnesses.**

Option A — Do not sign both boxes

I want to give my attorneys authority to give or refuse consent to life-sustaining treatment on my behalf.

Signed in the presence of a witness by the person who is giving this lasting power of attorney

Your signature or mark

Date signed or marked D D M M Y Y Y Y

The date you sign (or mark) here must be the same as the date you sign or mark section 10 Declaration.

Option B — Do not sign both boxes

I do not want to give my attorneys authority to give or refuse consent to life-sustaining treatment on my behalf.

Signed in the presence of a witness by the person who is giving this lasting power of attorney

Your signature or mark

Date signed or marked D D M M Y Y Y Y

The date you sign (or mark) here must be the same as the date you sign or mark section 10 Declaration.

Who can be a witness

- You must be 18 or over.
- You **cannot** be an attorney or replacement attorney named at part A or any continuation sheets A to this lasting power of attorney.
- If you have been asked to be the certificate provider at part B, you can be a witness at part A.
- A person to be told when the application to register this lasting power of attorney is made can be a witness.

Witnessed by

Signature of witness

Full names of witness

Address and postcode of witness

Postcode

2. Topics of Conversation

- What matters to them – not what is the matter with them
- What are their expectations and fears?
- Wishes and priorities for future care?
- Advance Statements/ADRTs if capacity
- Escalation planning – clear statement of what NOT to do – ensuring statement 'even if life is at risk from Sepsis/Stroke/Heart Attack/Fit etc' – whilst ensuring comfort maintained
- What dying looks like = @drkathrynmannix

3. COMMUNICATION and COORDINATION

- Relatives
- Care Home/Dom Care Staff if relevant
- GP
  - Ambulance
  - OOH
  - EPACCS (Electronic Palliative Care Co-ordination Systems)
  - Enriched Summary Care Record

4. SYMPTOM CONTROL

Challenges:

- Knowing what the symptoms are
- Difficulty swallowing – ‘Cant swallow’
- Compliance with medication ‘Wont Swallow’
- Use of covert medication

4. SYMPTOM CONTROL

- Pain
- Nausea and vomiting
- **Constipation**
- **Breathlessness**
- **Fatigue**
- **Weight loss**
- **Artificial Nutrition and Hydration**

Pain : Opioid analgesia

- Start low go slow especially if opioid naïve
- Start or increase laxatives
- Avoid patches unless cant/wont swallow
- Avoid starting patches in last days of life
- Buprenorphine 5 = 120mg codeine and takes 4 days to reach full therapeutic level
- Fentanyl 12 = 40mg oral morphine which can be dangerous if opioid naïve
- If already have a patch –don't remove add injectable – and calculate total dose and rescue dose

Constipation

- Common
- Under diagnosed
- Overflow with impaction
- Examination examination examination
- Volume/tolerance/fluid intake

Breathlessness

- ~~Oxygen~~
- Fan
- Anxiolytics
- Morphine – oramorph 1.25-2.5mls prn

Fatigue and somnolence

- Very common as the end of life approaches and part of normal dying process
- Beware hypoactive delirium

Weight loss in Severe Frailty and Dementia

- Very common symptom
- Reduced appetite leading to reduced calorie intake
- Reduced ability to swallow
- (?) degree of catabolism

Options for intervention

- Investigations to exclude other causes
- high calorie diet - fortified drinks and snacks
- Oral nutritional supplements (?)
- PEG feeding (???)

Tips for the conversation with family members :

- Very common feature of the illness
- The urge to feed and to nourish is very strong
- What do they see as the future? What are their expectations?
- The individual is not ‘starving to death’ – but losing weight as part of their illness = like people who lose weight when dying of cancer
- They are not ‘suffering’ because of hunger - if they were hungry they would want to eat
- **Malnutrition vs Hunger**
- Its not a sign of neglect
- If agreement not to intervene –stop weighing

Anticipatory Medication

- Prescribe early – if writing a ‘not for escalation’ ACP
- Valid in the home for a long as drugs in date
- Administration sheet
- PRN doses only initially
  - Pain relief (1/6 of total opioid dose)
  - Anti secretory
  - Anxiolytic
  - (Antiemetic)
  - Oramorph

Anticipatory Medication

As required	Formulation	PRN Dose	Frequency	Max in 24hrs	Indication
HALOPERIDOL	5mg/5mls	0.5-1.5mg	Up to 2 hourly	10mg	Nausea and vomiting
HYOSCINE HYDROBROMIDE	400mcg/1ml	0.4mg	Up to 2 hourly	2.4mg	Noisy secretions
MIDAZOLAM	10mg/2mls	2.5-5mg	Up to half hourly	30mg	Agitation
MORPHINE	10mg/1ml		Up to hourly		Pain

Anticipatory Medication

Writing up anticipatory medication should be a trigger for:

- Robust Treatment escalation planning
- Stop all medication not giving symptomatic benefit
- Stop all routine investigations (QOF bloods, UnE in CKD etc)

5. LAST DAYS OF LIFE

- Timing is unpredictable

Useful Phrases:

- I cant be sure but I think this might be your/ her/his final illness
- I think they may be coming towards the end of their lives – but I might be wrong
- You are…. She/he is sick enough to die
- Under these circumstances – what are your/would be his/her priorities?
- Lets prepare for the worst, then hope for the best

CHC Funding

- CHC funding requires predictable decline over a few weeks – generally people with frailty do not qualify as they have an unpredictable trajectory and either aren't sick enough to rquire nursing support or deteriorate very rapidly and died suddenly.
- Applying for CHC fast track funding during an acute deterioration is challenging as recovery to baseline can be as fast and unexpected as decline.

Last days of life – symptom control

- Pain
- Breathlessness
- Agitation
- Secretions
- Mouth care
- Skin care/pressure areas

- **Hydration = Dehydration vs Thirst**

Clinically Assisted Hydration

NICE: Care of dying adults in the last days of life

When considering clinically assisted hydration for a dying person, use an individualised approach and take into account:

- whether they have expressed a preference for or against clinically assisted hydration, or have any cultural, spiritual or religious beliefs that might affect this documented in an advance statement or an advance decision to refuse treatment
- their level of consciousness
- any swallowing difficulties
- their level of thirst
- the risk of pulmonary oedema
- whether even temporary recovery is possible.

Subcutaneous Infusion ‘Hypodermoclysis’

- First described in 1913
- Used widely in 1940s and 50s
- Increasingly recognised as a way of maintaining comfort when oral intake is compromised through impaired swallow or tumours eg post CVA but person remains conscious and aware
- 1 litre in 24hrs
- Able to prescribe Sodium Chloride 0.9% infusion on FP10
- Simple kit – giving set/cannula
- Infuse by gravity no need for pump

6. BEREAVEMENT SUPPORT

Death Certification:

Severe Frailty of Old Age as a cause of Death

IN SUMMARY

- **Recognition** that Severe Frailty is an end of life state
- There are similarities but significant differences between dying of cancer and other single organ diseases vs dying with Frailty
- **Early Conversations, Advance care planning** and **anticipatory prescribing** are key to good outcomes

Any Questions?

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