# A GP's approach to Quality End of Life and Palliative Care in Care Homes

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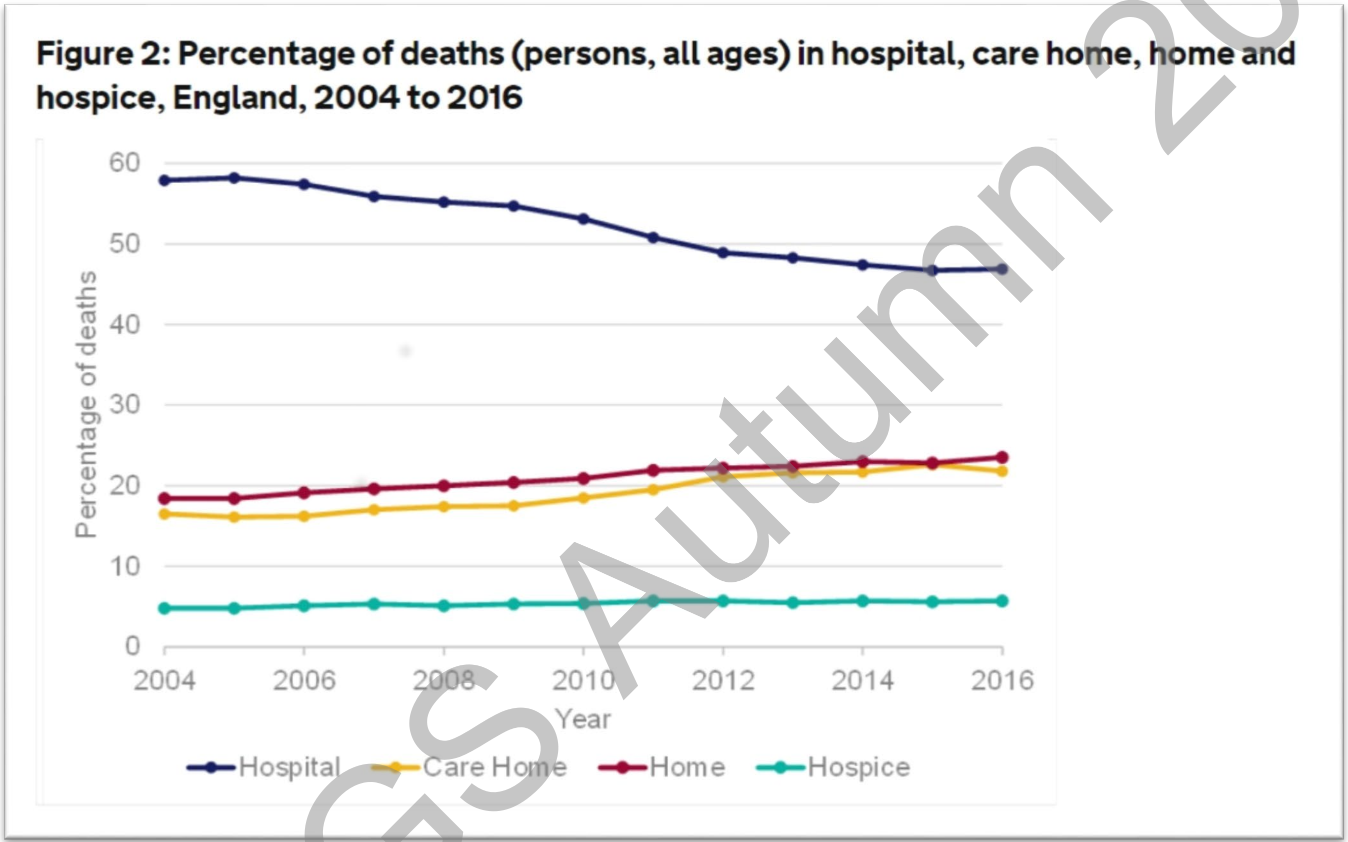
# My offices:

# Place of Death :



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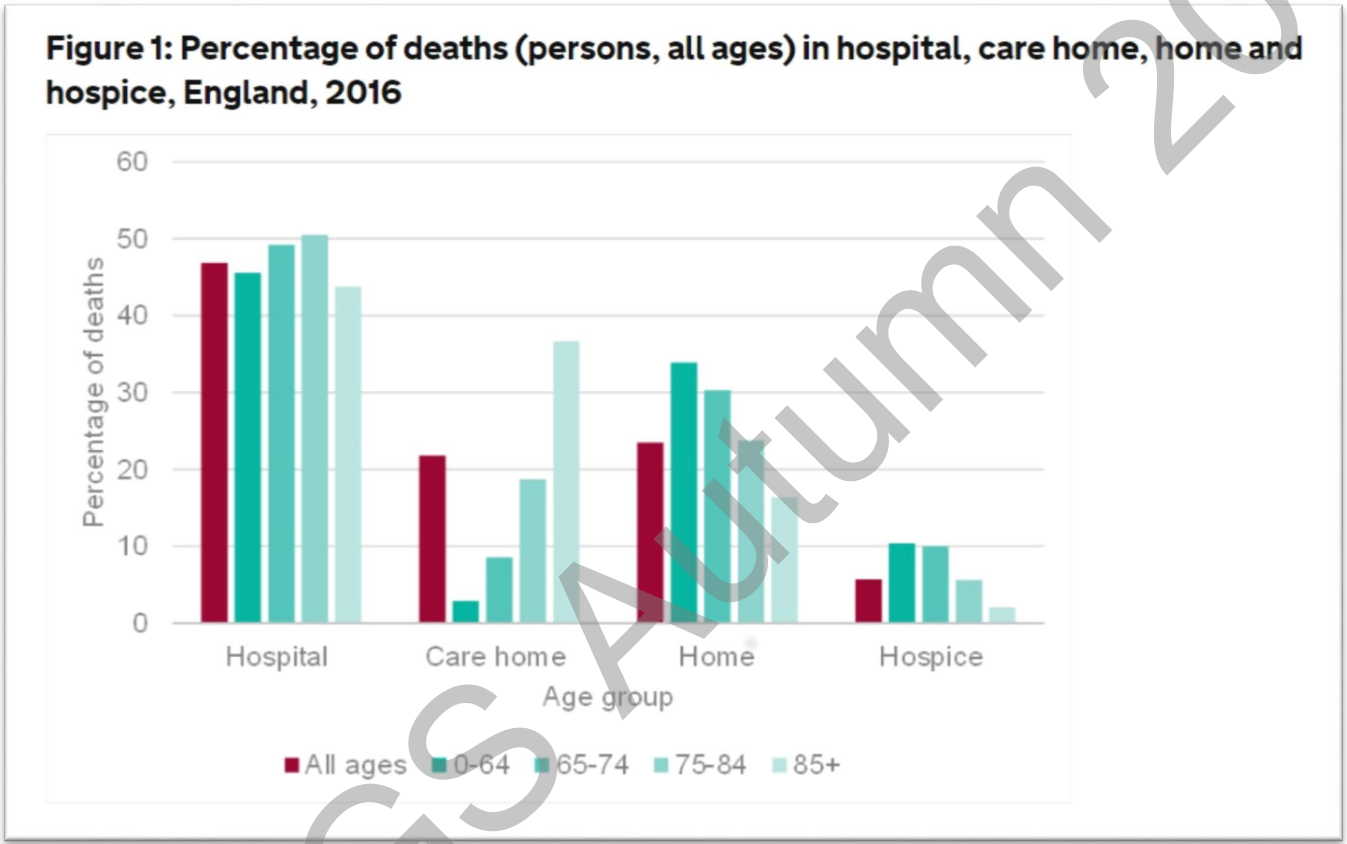



https://www.gov.uk/government/publications/end-of-life-care-profiles-february-2018-update/statistical-commentary-end-of-life-care-profiles-february-2018-update

# Place of Death :

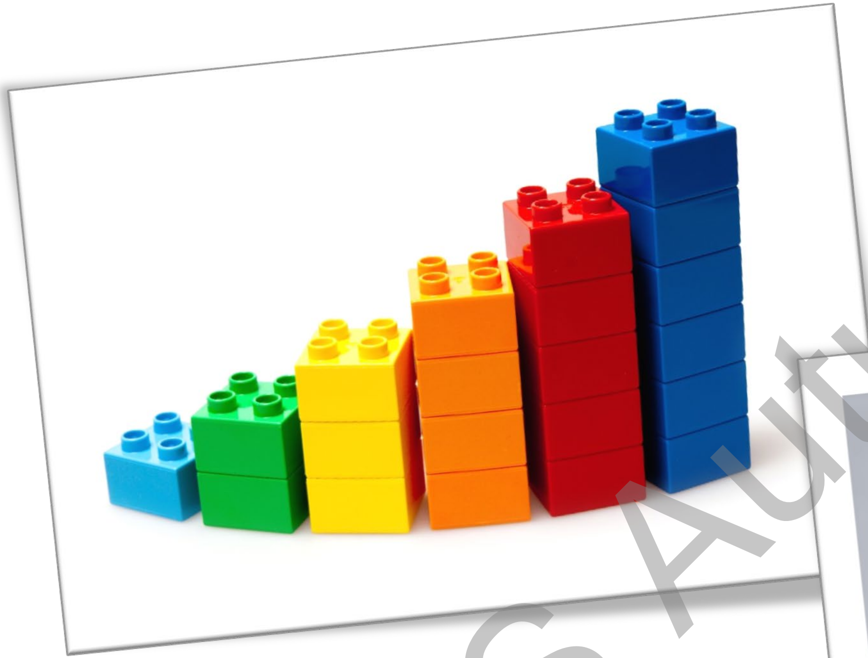
- Over 1/5 of all deaths occurred in care homes
- Over 1/3 of deaths in people aged 85+ occur in care homes.
- The majority of permanent care home residents die in a care home (70% in 2014)

End of life and Palliative Care associated with Hospice care but

- 2.1% of people aged 85 and over die in Hospices

Care Homes have become the hospices for people dying with Frailty

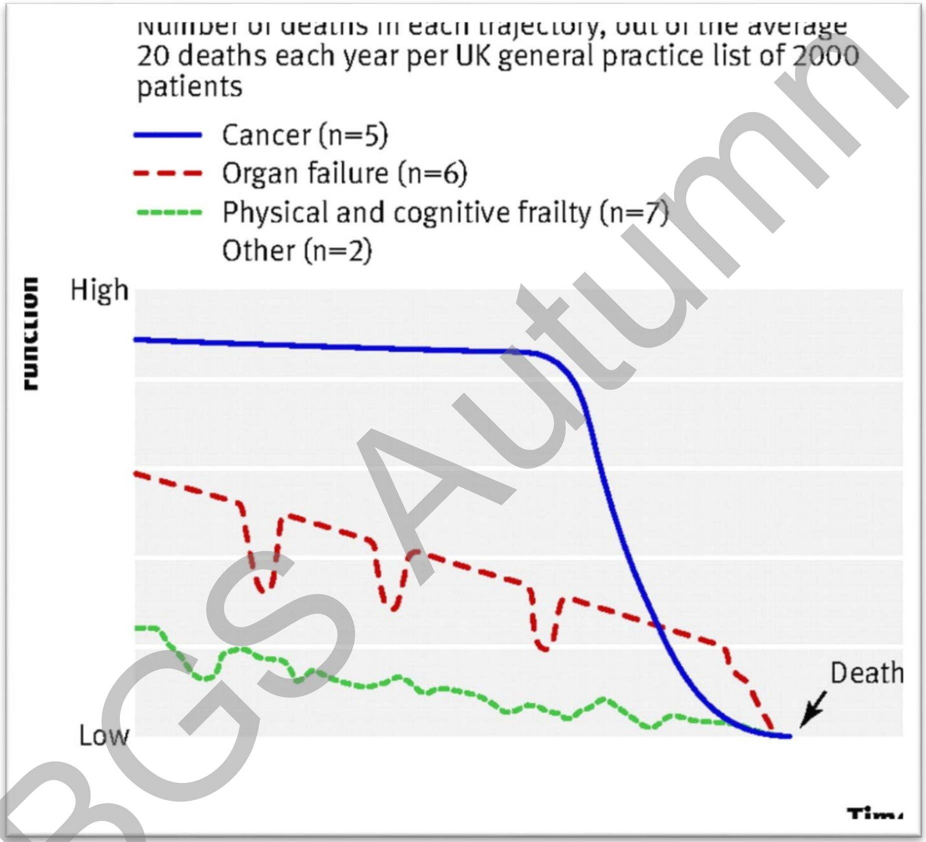
# Quality End of Life Care in Care Homes



# 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

## Care Home/Frailty

- When moving into a care home
- Following admission to hospital
- Terminology
- ‘is the patient End of Life?’

# Palliative and end of life care... Are we talking the same language?

Worcestershire End of Life & Palliative Care Network

When supporting patients who are nearing the end of their life, it is important that health professionals and carers use consistent language.

**Below are some of the commonly used and misused phrases:**

## Try not to say:

### Palliative Patient

It is not the patient who is palliative but the approach to their care. Talking about a 'Palliative Patient' is not helpful and should be avoided.

### End of Life Patient

'End of Life' can mean different things to different people ( and can refer to last few days weeks months or even years). Therefore the term 'End of Life' patient can cause confusion and is best avoided.

## Do say:

### Palliative Approach

Palliative care is the active holistic care of patients with advanced progressive illnesses. The goal is to achieve the best quality of life for patients and their families. **Palliative care is not only for people who are dying.**

### Last days of life

This usually refers to the last few days of life, when a person is 'actively dying'.

### Dying

Using the words 'die' or 'dying' can be very helpful for patients and families when you are convinced this person is going to die in the forthcoming days.

### Frailty

this is a long term condition implying vulnerability to sudden deterioration. A diagnosis of Severe Frailty is associated with a life expectancy of about 1000 days. Start to consider introducing advance care planning discussions when you recognise severe frailty.

### Treatable VS Curable

Increasingly, people are cured of disease and make a full recovery. In other cases a **condition may not be curable, but may be treated.** It is important that we are careful and clear with patients and families as to whether we are aiming to palliate the symptoms or cure their disease.

More in depth explanations and definitions are available at NCPC and **www.nice.org.uk/guidance/**

# 1. RECOGNITION that End of Life is approaching

- Admission to care home should prompt the start of Advance Care Planning Discussions
- Routine practice
- Opportunity to understand expectations of resident and family
- Revisit on a regular basis or as condition changes
- Return from Hospital – review ACPlanning
- ACPlanning - - DNACPR Escalation planning

# 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

NHS/CHI/Health and care number

Date of birth

Address

Date completed

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:

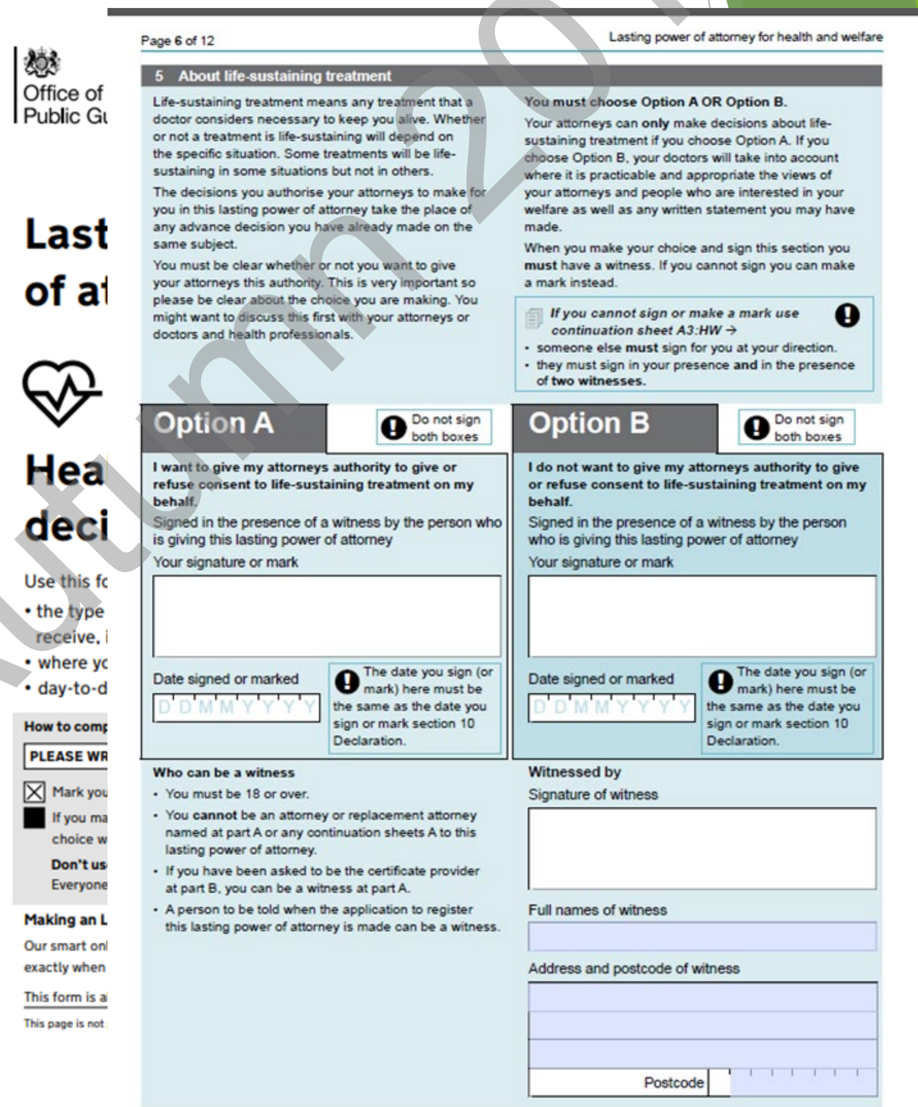
SPECIMEN COPY - NOT FOR USE

| | | |
|---|---|---|
| CPR attempts recommended Adult or child | For modified CPR Child only, as detailed above | CPR attempts **NOT** recommended Adult or child |
| clinician signature | clinician signature | clinician signature |

# 2. CONVERSATIONS

## Care Home/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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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
- What dying looks like = @drkathrynmannix

# 3. COMMUNICATION and COORDINATION

- Relatives
- Care staff
- Ambulance
- OOH
- Acute Providers
- EPACCS (Electronic Palliative Care Co-ordination Systems)

# 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

- Constipation
- Breathlessness
- Nausea and vomiting
- Skin Cancers
- Weight loss
- Pain

# Weight loss in Severe Dementia

- Very common symptom
- Reduced appetite leading to reduced calorie intake
- Reduced ability to swallow
- (?) catabolic state

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 :

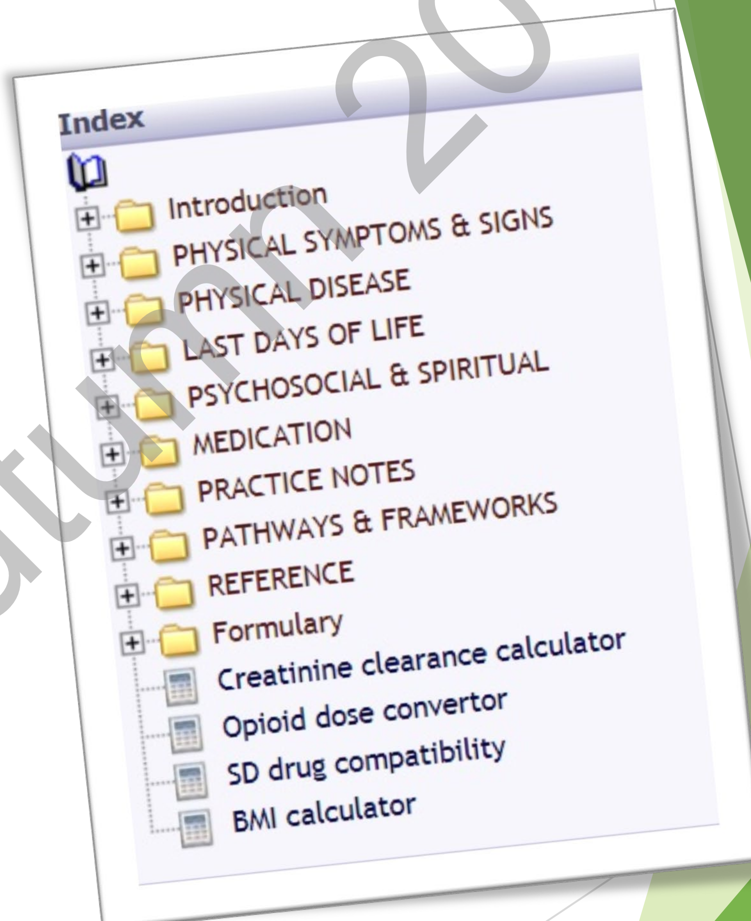
- Very common feature of the illness
- The urge to feed and to nourish is very strong
- What do they see as the future? What are their expectations?
- The individual is not ‘starving to death’ – they are losing weight as part of their illness = like people who lose weight when they are dying of cancer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

# Pain : Opioid analgesia

- Start low go slow especially if opioid naïve
- Start or increase laxatives
- 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 fatal if opioid naïve
- If already have a patch –don’t remove add injectable – and calculate total dose and rescue dose

# Calculation of dose equivalence

- Palliative Care Adult Network Guidelines
- http://book.pallcare.info/



# 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
- Stopping all medication not giving symptomatic benefit
- Stop all routine investigations ( QOF bloods, UnE in CKD etc)

# 5. LAST DAYS OF LIFE

- Timing is unpredictable

# Last days of life – symptom control

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

- **Hydration**

# 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

# 5. Last days of life

- Residential vs Nursing
- Equipment Availability – syringe drivers – profiling beds

# Education of Staff

- Delivery of training and education adhoc
- Lack of recognition of commissioners that end of life care is happening in Residential as well as Nursing homes
- No specific requirement for EOL and PC training in contracts
- CQC requirements vague
- Provision of available training an open market with no apparent quality control
- Affordability of available training
- Opportunity to improve the situation through collaboration in STP areas – to support shared education and training across all health and social care providers – ( eg Worcestershire Integrated Network for training )

# IN SUMMARY

- **Recognition** that the vast majority of people in Residential and nursing homes are approaching the end of their lives
- **Advance care planning** and **anticipatory prescribing** are key to good outcomes
- Quality and availability of staff **education and training** needs to be reviewed
- We need to celebrate the good work already being done in care homes

# Daughter of a resident who died recently:

"The care that my mum received at the end of her life …. was better than the care that Dad received when he died in the hospice last year"



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