A GOOD DEATH…?

PALLIATIVE & END OF LIFE CARE UPDATE
GP RETAINERS

30th November 2018

Euan Paterson

Palliative & End of Life Care (P&EoLC) Update

- Agenda
  - Definitions – palliative care & end of life care
  - Trajectory
  - What are the differences between P&EoLC and other care?
  - 10 Cs & 1 E of care of the dying
  - What does the GP bring to P&EoLC?
  - Anything else…?

Palliative & End of Life Care

- What are we talking about?
  - What is palliative care?
  - What is end of life care?
  - Which patients should receive palliative & end of life care?
- What does the GP bring to palliative & end of life care?

What is WHO talking about?

‘Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’

World Health Organisation

What is Proust talking about?

‘We say that the hour of death cannot be forecast, but when we say this we imagine that hour as placed in an obscure and distant future. It never occurs to us that it has any connection with the day already begun or that death could arrive this same afternoon, this afternoon which is so certain and which has every hour filled in advance.’

Marcel Proust

In Search of Lost Time

What is Chuck talking about?

‘Marla doesn’t have testicular cancer. Marla doesn’t have Tb. She isn’t dying.

Okay in that brainy brain-food philosophy way, we’re all dying, but Marla isn’t dying the way Chloe is dying’

Chuck Palahniuk

Fight Club

What is the GMC talking about?

'…patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

(a) advanced, progressive, incurable conditions

(b) general frailty and co-existing conditions that mean they are expected to die within 12 months

(c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition

(d) life-threatening acute conditions caused by sudden catastrophic events.

…also applies to those extremely premature neonates whose prospects for survival are known to be very poor…and to patients in a persistent vegetative state for whom a decision to withdraw treatment may lead to their death.'

General Medical Council, 2010

What am I talking about?

‘Palliative care is for the individual who realises that their own inevitable mortality is now of relevance to them such that it merits consideration. This is frequently due to either their perception of death’s relative imminence or the belief that some new disease or combination of diseases will inevitably be the cause of their death – both of these will be hugely variable.’

ScotPHN Palliative and end of life care in Scotland, 2016

The 10 Cs (and 1 E) of Care of the Dying

C 1	Consider dying as a possibility
C 2	Competence
C 3	Compassion
C 4	Capacity
C 5	Communication
C 6	Current needs
C 7	Ceilings of treatment and intervention
C 8	Care planning
C 9	Care in the last stages of life
C 10	Continuing care
E	Essence

C1 Consider dying as a possibility

- Consider ‘dying’ as a diagnosis!
  - Probability / possibility / uncertainty

C1 Consider dying as a possibility

- Consider ‘dying’ as a diagnosis!
- What primary disease(s) do they suffer from?
  - Mesothelioma
  - Prostate cancer
  - Renal failure & dialysis
  - 93 year old with multi-morbidity & dementia
  - COPD

C1 Consider dying as a possibility

- Consider ‘dying’ as a diagnosis!
- What primary disease(s) do they suffer from?
  - Mesothelioma
  - Prostate cancer / **Malignant Spinal Cord Compression**
  - Renal failure & dialysis / **decision taken to stop dialysis**
  - 93 year old with multi-morbidity & dementia / **15% weight loss in 6m**
  - COPD / **LTOT & 4 admissions in last year**

C1 Consider dying as a possibility

- Consider ‘dying’ as a diagnosis!
- What primary disease(s) do they suffer from?
- Personal trajectory
  - How are they at this moment?
  - How were they?
  - How rapidly are they changing?

C1 Consider dying as a possibility

- Consider ‘dying’ as a diagnosis!
- What primary disease(s) do they suffer from?
- Personal trajectory
- Would you be surprised…?
- Whoever YOU feel should be included!
- Consider all above plus:
  - (Gold Standards Framework register)
  - SPICT / GSFS prognostication guidance?
  - Chronic disease registers?
  - Care Home patients??
  - Housebound patients???

THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT™)

The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- The person has had significant weight loss over the last few months, or remains underweight.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping or not starting dialysis.

Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

Other conditions

Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.

Review current care and care planning.

- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.

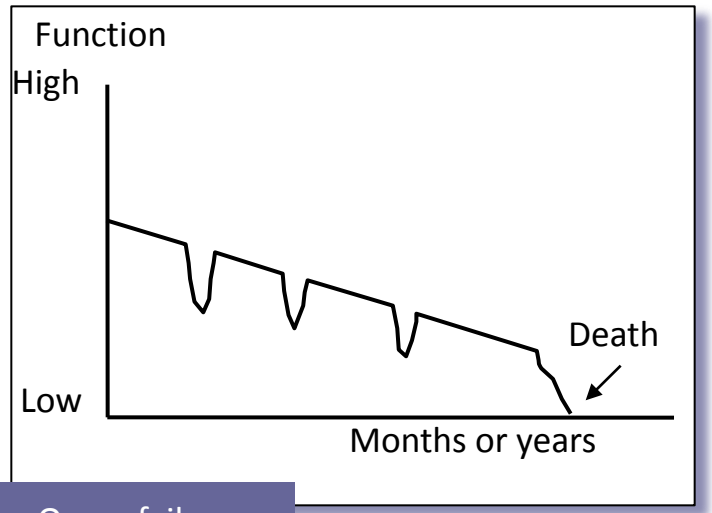
Please register on the SPICT web site (www.spict.org.uk) for information and updates.

SPICT™, April 2017

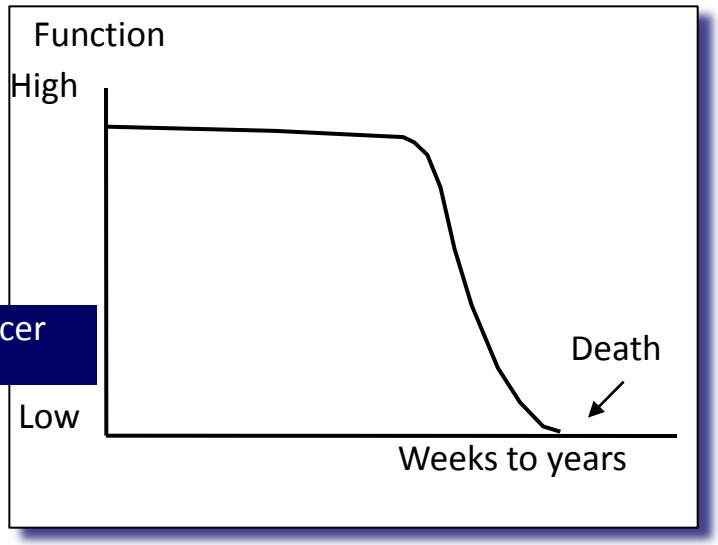
Trajectory

- Phases
  - Ante-natal
  - Birth
  - Gradual accrual of ‘disease’
  - Critical mass
  - Aggressive treatment
  - Complex
  - Prodromal
  - Last stages of life
  - Death
  - Legacy

Trajectory

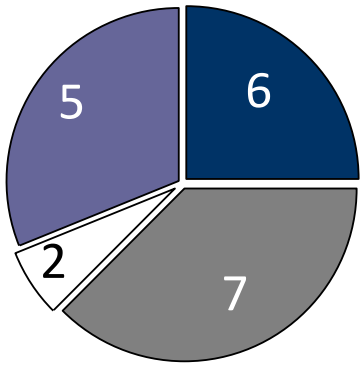


Organ failure

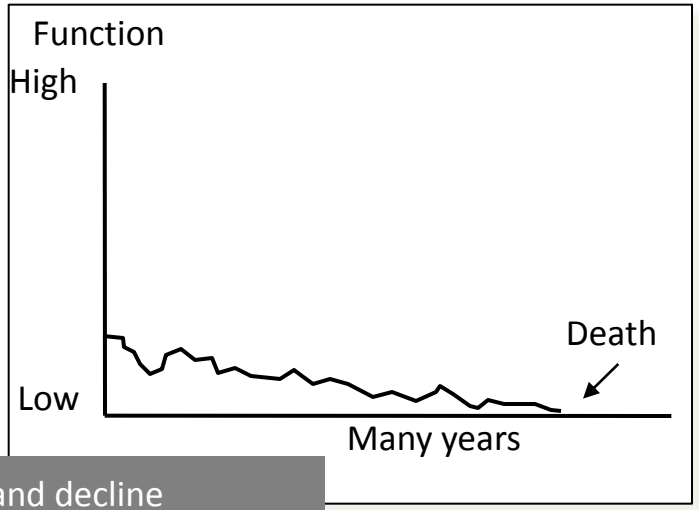


Cancer

GP has 20 deaths per list of 2000 patients per year



Acute



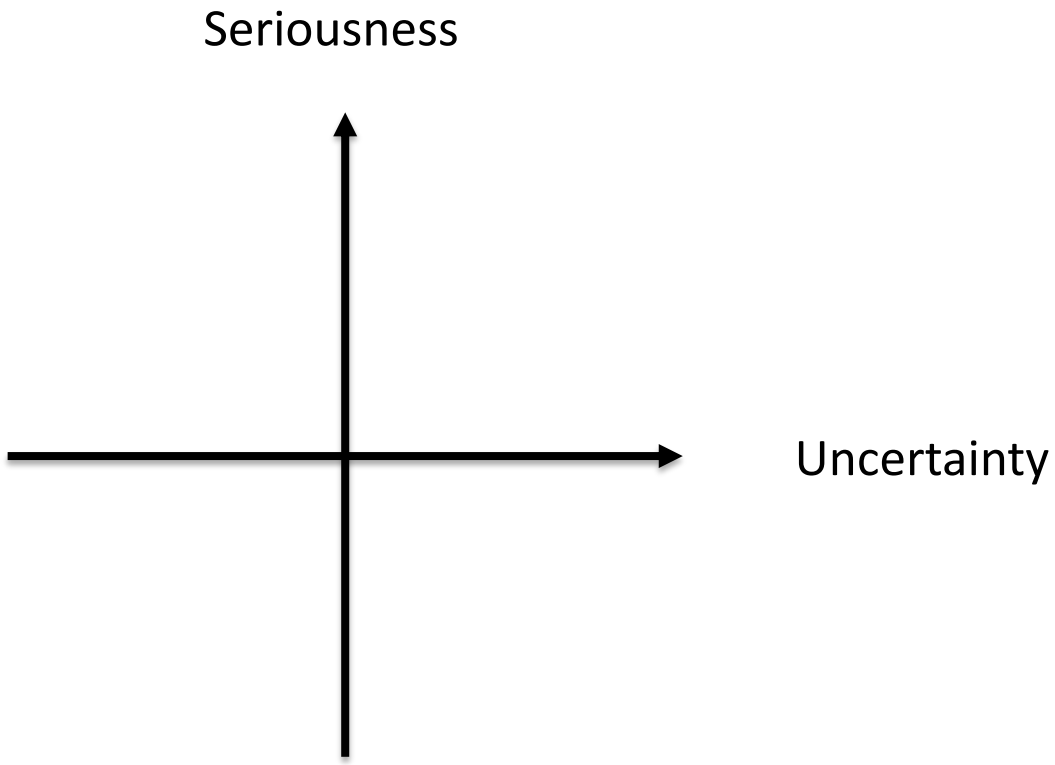
Dementia, frailty and decline

Trajectory

- Critical factors
  - Disease burden
  - Disability
  - Dependency
  - Treatment aims
  - Response to treatment
  - Awareness of enormity
  - Acceptance of enormity
  - Time frame
  - Possibility / Probability
  - Uncertainty

Trajectory

- The Index of Concern



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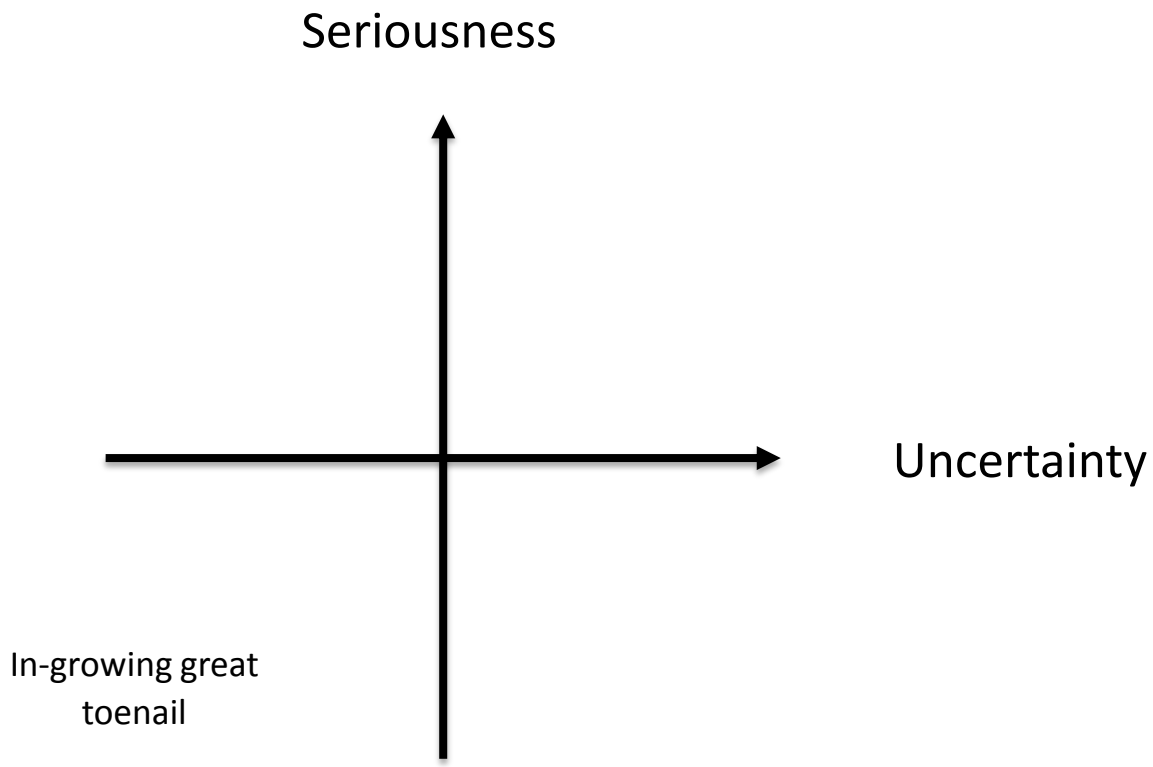

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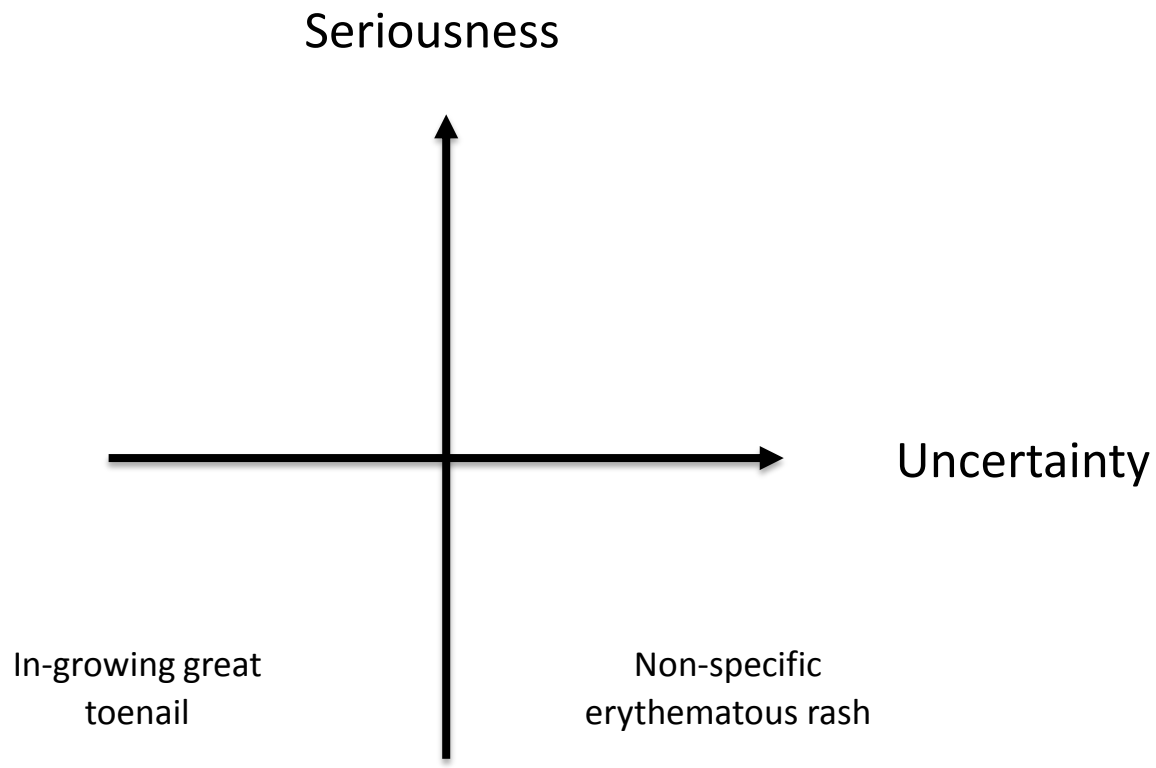

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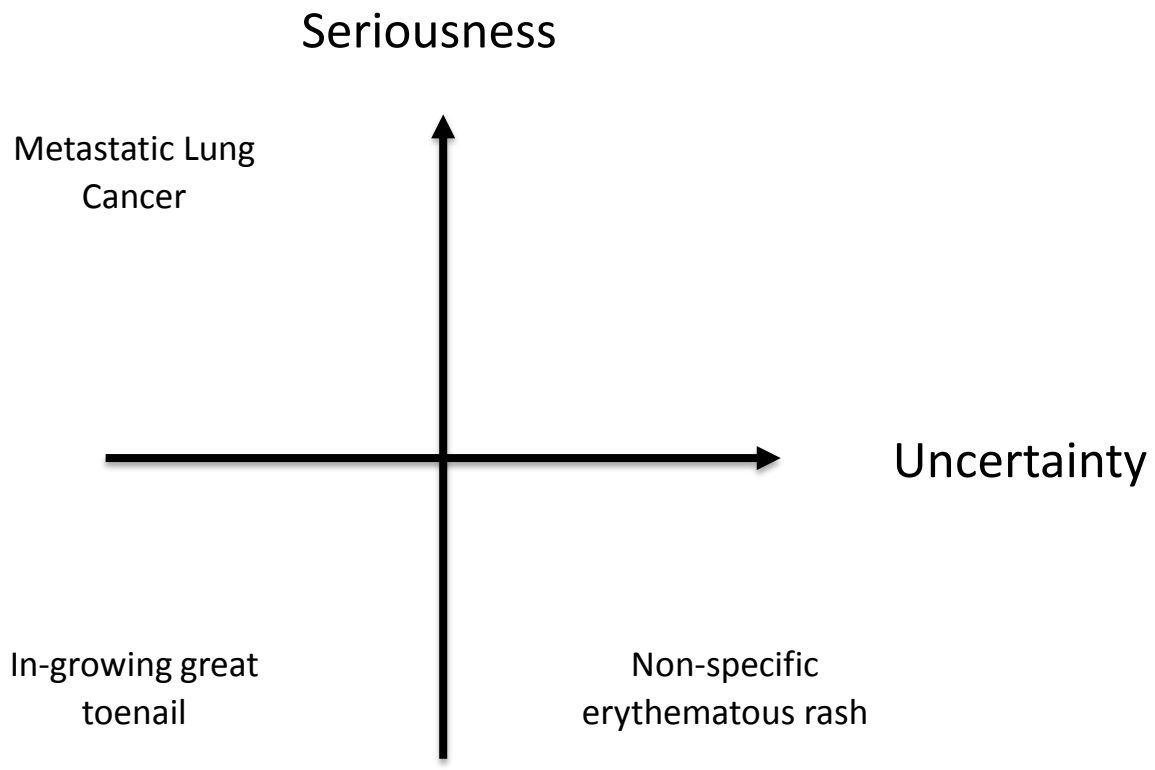

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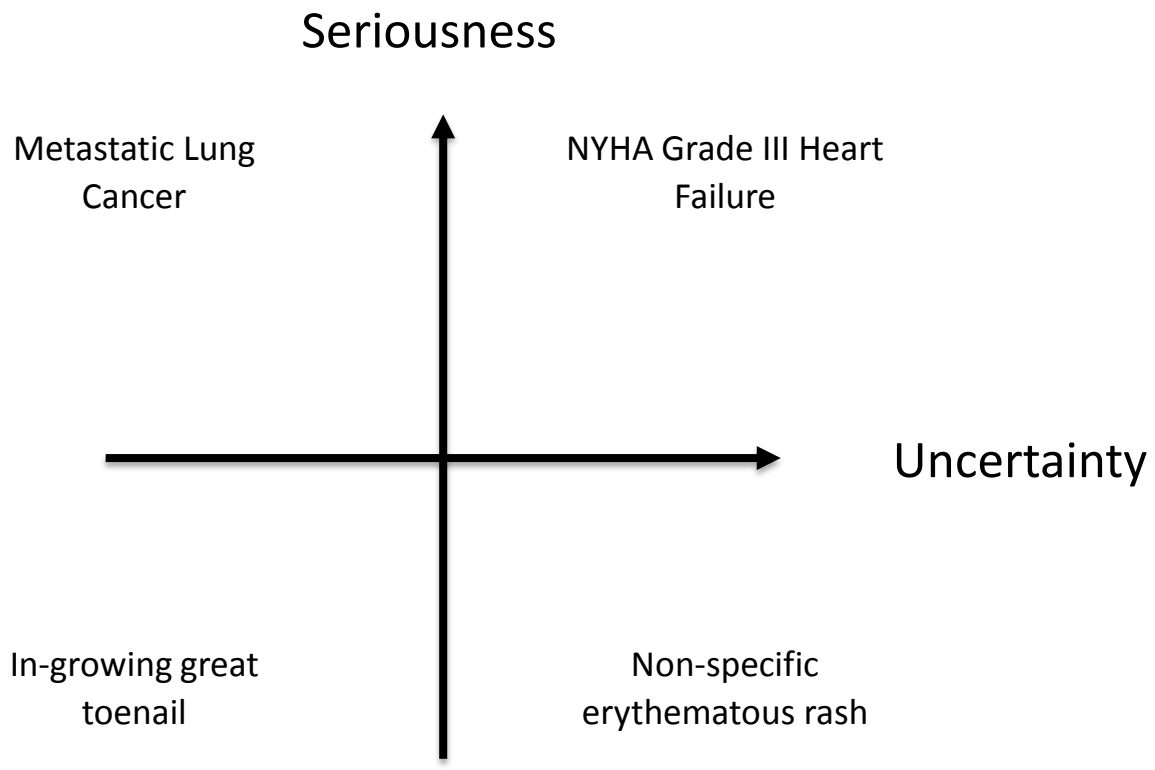

What are the differences between palliative care and all other care?

What are the differences?

- Aim
  - Plan A: Active treatment aimed at disease process / life prolongation
  - Plan B: Active treatment aimed at a good and dignified death

What are the differences?

- Aim
- Specific communication / planning issues
  - My Thinking Ahead & Making Plans
  - (Key Information Summary)
  - (Prescribing)
  - Verification of Expected Death
  - eMCCD

What are the differences?

- Aim
- Specific communication / planning issues
- Enormity – the ‘Index of Concern’
  - Really important for patient and loved ones (and us)
  - One shot at it…

What are the differences?

- Aim
- Specific communication / planning issues
- Enormity – the ‘Index of Concern’
- Time cost
- Ceilings of treatment and intervention

What are the differences?

- Ceilings of treatment and intervention e.g.
  - Transplant
  - Dialysis / ventilation / cardiac devices
  - Surgery
  - Chemotherapy / radiotherapy
  - CPR

Discussing DNACPR

- Know the patient and their context
- Be clear about benefit/burden balance of CPR (Rx)
- (Consider benefit/burden balance of discussion)
- Consider who should discuss
- Consider when to discuss
- Often less difficult earlier in disease
- Small chunks and check… (BBN)
- Aim is to Allow a Natural Death
- **Discussion on CPR should be part of wider discussion**
- **Compassion!**

Key points of DNACPR

- The decision to offer CPR is a medical matter
- The decision to offer CPR has nothing to do with quality of life
- If CPR is likely to be futile do not offer it as a treatment option
- Patient / family view is only relevant if CPR is an option
- If success anticipated – CPR decisions need to be discussed
- If success not anticipated – patient needs to be informed of the decision not to offer CPR
- Relatives should not be asked to 'decide' unless patient lacks capacity & relative has legal powers (if success anticipated)
- Discussion on CPR should be part of wider discussion
- Compassion!

What are the differences?

- Ceilings of treatment and intervention e.g.
  - Transplant
  - Dialysis / ventilation / cardiac devices
  - Surgery
  - Chemotherapy / radiotherapy
  - CPR
  - Antibiotics I/V
  - Admission or transfer
  - Blood tests (arterial, venous, capillary)
  - Nutritional support
  - Hydration / S/C fluids
  - Antibiotics oral
  - Routine positional change

Palliative & End of Life Care

- What are we talking about?
  - What is palliative care?
  - What is end of life care?
  - Which patients should receive palliative & end of life care?
- What does the GP bring to palliative & end of life care?

The 10 Cs (and 1 E) of Care of the Dying

C 1	Consider dying as a possibility
C 2	Competence
C 3	Compassion
C 4	Capacity
C 5	Communication
C 6	Current needs
C 7	Ceilings of treatment and intervention
C 8	Care planning
C 9	Care in the last stages of life
C 10	Continuing care
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C 1 – Consider dying as a possibility

- Consider:
  - What primary disease(s) do they suffer from
  - Personal trajectory
  - Would you be surprised…?
  - Gold Standards Framework register
  - SPICT / GSFS prognostication guidance?
  - Chronic disease registers?
  - Care Home patients??
  - Housebound patients???

C 1 – Consider dying as a possibility

- Some early considerations
  - (Critical illness insurance)
  - (Locum insurance)
  - Life insurance
  - Will
  - Power of Attorney
    - Continuing
    - Welfare
  - Burial or cremation?
  - Music for your funeral…

C 2 – Competence

- Our own!
- Do we have enough knowledge & skills?
  - Diagnostic accuracy
  - Knowledge of condition, natural history, interventions
  - Communication skills
- Do we have enough experience?
- Do we need help?
- Who / where can we get help from?
  - Primary Care colleagues
  - Specialist Palliative Care
  - Hospital colleagues

C 3 – Compassion

- Later…!

C 4 – Capacity

- Does the patient have capacity?
- If not do they have a legally appointed representative e.g. PoA or Guardian?
- Other medico-legal aspects
  - Consent (KIS)
  - Advance Decision to Refuse Treatment (ADRT)

C 5 – Communication

- Who needs to know?
- What needs to be known?
- How can we make communication better?

C 5 – Communication

- Who needs to know?
  - Patient / family / loved ones
  - ‘Professionals’
    - e.g. Partners, Nurses, OOH, Pharmacy, SAS, Acute, Specialists, Social Workers, Social Carers, Reception staff, Faith leader…

C 5 – Communication

- What needs to be known by ‘professionals’?
  - Clinical issues
    - Diagnosis / prognosis / treatment options
  - All the other ‘professional’ views!
  - Patient / family / loved ones views
    - What is important to them?
    - What do they want?
    - What do they not want?
    - Who else do they want involved?
    - (Are these all the same?)
  - An ‘Advance Statement’

C 5 – Communication

- An Advance Statement
  - Statement of values
    - E.g. what makes life worth living
  - What patient wishes
    - E.g. aggressiveness of treatment; place of care; place of death; admission
  - What patient does not want
    - E.g. PEG feeding; SC fluids; CPR; admission
  - Who they would wish consulted

C 5 – Communication

- What needs to be known by patient / family / loved ones
  - Professional views
    - Possibility / probability of death
    - Prognostic uncertainty
    - What we know or suspect
    - What we are concerned about
    - What the plans are
    - (Are these the same?!)
  - That you care!

C 5 – Communication

- How can we make communication better?
  - Gathering
    - Using our vast communication skills!!
    - My Thinking Ahead & Making Plans (MTA&MP)
      - What's important to me just now
      - Planning ahead
      - Looking after me well
      - My concerns
      - Other important things
      - Things I want to know more about e.g. PoA / CPR
      - Keeping track

C 5 – Communication

- How can we make communication better?
  - Gathering
    - Using our vast communication skills!!
    - My Thinking Ahead & Making Plans (MTA&MP)
  - Sharing
    - Record it!
    - MyACP
    - In conversation – telephone / face to face
    - Letters / email
    - Key Information Summary (KIS)

C 5 – Communication

- What is KIS for?
  - Information transfer
    - In hours GP to OOH GP
    - GP to District Nurse
    - Primary Care to A&E / Acute Receiving Units
    - Primary Care to Scottish Ambulance Service
    - Primary Care to Specialist Palliative Care
  - Prompts for proactive care
  - Anticipatory Care Planning
  - All data stored in one place

C 6 – Current needs

- Physical
  - Symptom relief
  - Bowel / bladder care
  - Oral care
  - (Hydration)
- Psychological
- Personal
  - Social
  - Spiritual / Existential (the inner self)

C 7 – Ceilings of treatment and intervention

- Some ceilings
  - Transplant
  - Dialysis / ventilation / cardiac devices
  - Surgery
  - Chemotherapy / radiotherapy
  - CPR
  - Antibiotics I/V
  - Admission or transfer
  - Blood tests (arterial, venous, capillary)
  - Nutritional support
  - Hydration / S/C fluids
  - Antibiotics oral
- But NEVER of care!

C 8 – Care Planning (Anticipatory)

- Probable / what is likely to happen
- Possible / what might happen
- Review communication (C 5)
  - Patient views / wishes
  - Loved ones views / wishes
  - Professional views
  - Congruence?

C 8 – Care Planning (Anticipatory)

- Probable / what is likely to happen
- Possible / what might happen
- Review communication (C 5)
- Review current needs (C 6)
  - Physical
    - Symptom relief
    - Bowel / bladder care
    - Oral care
    - Hydration
  - Psychological
  - Personal
    - Social
    - Spiritual (the inner self)

C 8 – Care Planning (Anticipatory)

- Probable / what is likely to happen
- Possible / what might happen
- Review communication (C 5)
- Review current needs (C 6)
- Review ceilings of treatment and intervention (C 7)
- Review prescribing
  - What is essential
  - What is not needed
  - What to do with those in between
  - Just in case? (what might be needed?)
  - Route (S/C?)
  - Syringe pump?

C 8 – Care Planning (Anticipatory)

- Probable / what is likely to happen
- Possible / what might happen
- Review communication (C 5)
- Review current needs (C 6)
- Review ceilings of treatment and intervention (C 7)
- Review prescribing
- Review processes
  - (DNACPR)
  - Registered Nurse Verification of Expected Death (RN VoED)
  - KIS update

C 8 – Care Planning (Anticipatory)

- Probable / what is likely to happen
- Possible / what might happen
- Review communication (C 5)
- Review current needs (C 6)
- Review ceilings of treatment and intervention (C 7)
- Review prescribing
- Review processes
- Plan for ‘care in the last stages of life’ (C 9)

C 8 – Care Planning (Anticipatory)

- Prodromal phase
  - Plan A: Active treatment aimed at disease process / recovery
  - Plan B: Active treatment aimed at a good and dignified death
  - Acknowledge the uncertainty
  - Gradual / sudden shift away from possibility of improvement
  - Death now inevitable
  - Plan B is the only option…
  - Care in the Last Stages of Life

C 9 – Care in the Last Stages of Life

- Care planning (C 8)
  - Probable / what is likely to happen
  - Possible / what might happen
  - Review communication (C 5)
  - Review current needs (C 6)
  - Review ceilings of treatment / intervention (C 7)
  - Review prescribing
  - Review processes
  - Plan for death
    - Does everyone know that just Plan B?
    - Is everyone prepared?
    - Does everyone know what to do?
    - And what not to do…?
    - eMCCD

C 10 – Continuing care

- Bereavement support
  - Ensure ALL practice staff know
  - Consider
    - Adding details to key relatives records
    - Contacting bereaved relative(s)
    - Informing other GP practices if bereaved not registered with practice
  - Consider possible need for additional support

Palliative & End of Life Care

- What are we talking about?
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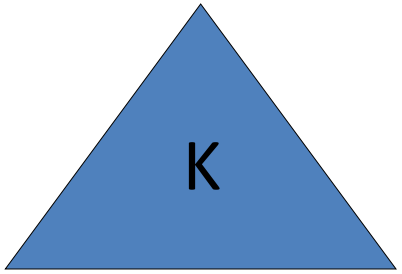
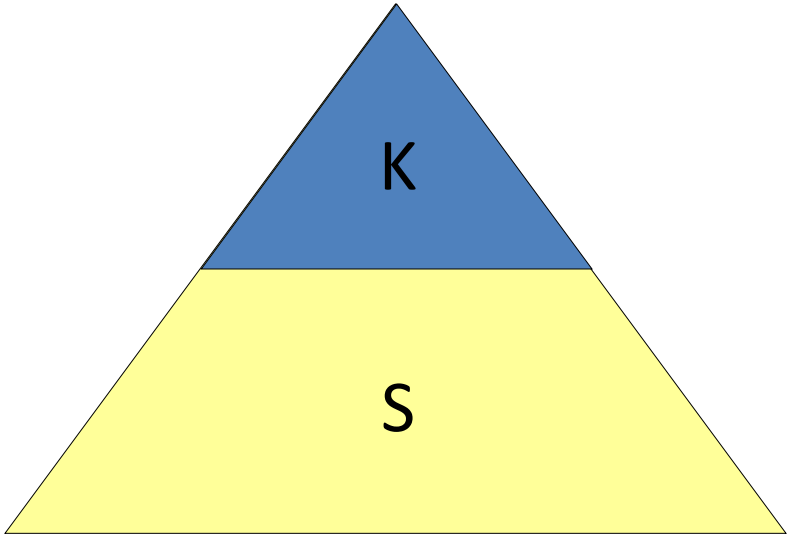
Knowledge



Skills



What does the GP bring to P&EoLC?

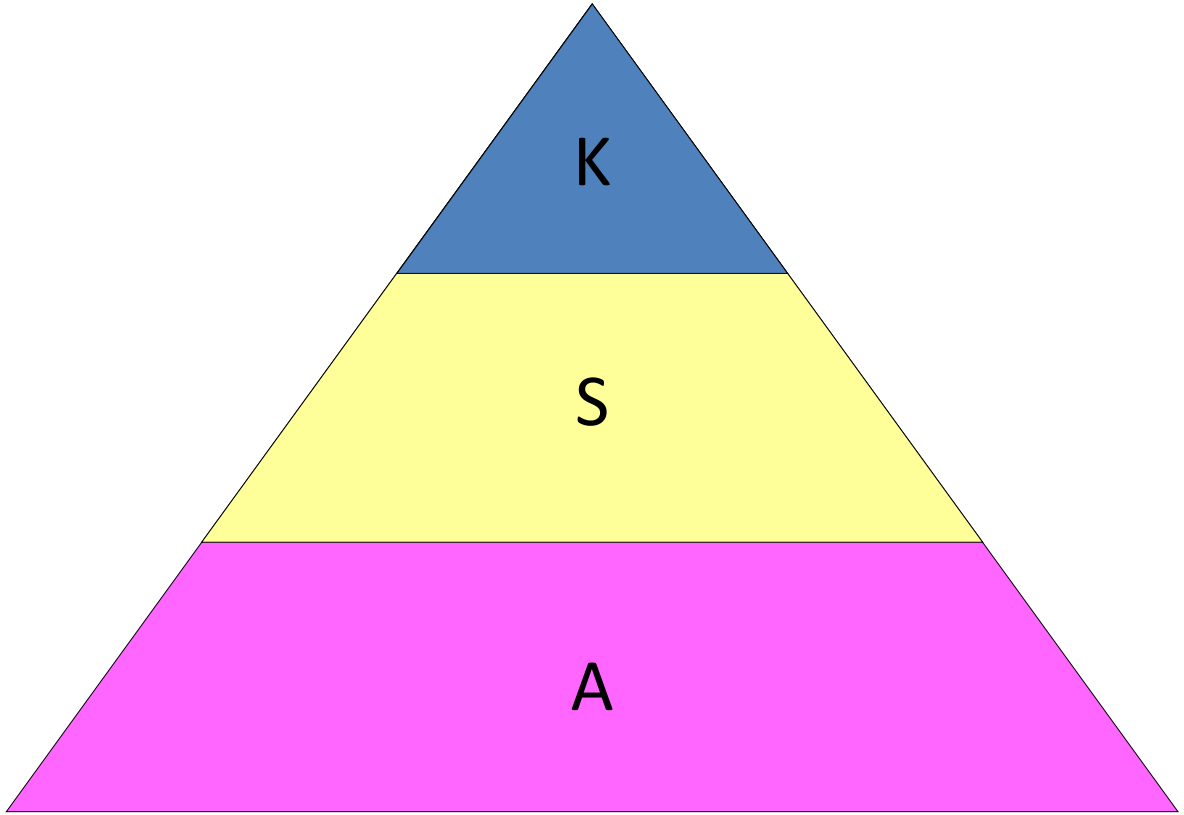
- Treating role
  - Diagnostician
  - Treatment planner
  - Decision maker
  - Decision ratifier
- Pre-morbid awareness
  - Narrative & biography

What does the GP bring to P&EoLC?

‘Ask not what disease the person has but what person the disease has’

Sir William Osler

Attitudes



The 10 Cs (and 1 E) of Care of the Dying

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C 3 Compassion

C 4 Capacity

C 5 Communication

C 6 Current needs

C 7 Ceilings of treatment and intervention

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C 9 Care in the last stages of life

C 10 Continuing care

E Essence

What does the GP bring to P&EoLC?

- Treating role
  - Diagnostician
  - Treatment planner
  - Decision maker
  - Decision ratifier
- Pre-morbid awareness
  - Narrative & biography
- Healing role

Professor Kieran Sweeney's account of his care

https://www.youtube.com/watch?v=3TignNvHNx4

C 3 – Compassion

Participation in another's suffering

Oxford English Dictionary

A strong feeling of sympathy and sadness for the suffering or bad luck of others and a wish to help them

Cambridge Dictionary

'An acknowledgement that a person or individual is suffering or unhappy and having the intention to take action to address that.'

John Gillies

C 3 – Compassion

- Treating role
- Pre-morbid awareness
- Healing role
  - Showing that we care!
    - Be polite and courteous
    - Make it personal
    - Show interest
    - Give your time (even when you have very little!)
    - Add ‘little touches’
    - Unbidden Acts of Human Kindness(!)

E – Essence

‘The intrinsic nature or indispensable quality of something, especially something abstract, which determines its character.’

Oxford English Dictionary

‘A property or group of properties of something without which it would not exist or be what it is.’ (Philosophy)

Oxford English Dictionary

The ‘Essence’ of General Practice

‘General practice was pushed into defining itself at its own margins, leaving its very centre, its specific priorities, unfathomed by both critics and spokesmen.’

Carl Edvard Rudebeck

The ‘Essence’ of General Practice

- Undifferentiated presentation
- Un-diagnosing
- Toleration of uncertainty

The ‘Essence’ of General Practice

‘Specialists aim to reduce uncertainty, explore possibility and marginalise error

Generalists aim to accept uncertainty, explore probability and marginalise danger’

Marshall Marinker

What does the GP bring to P&EoLC?

- Treating role
- Pre-morbid awareness
- Healing role
  - Showing that we care
  - Explaining and normalising
  - Affirming and validating
  - Understanding

What does the GP bring to P&EoLC?

‘The consultation is the patient’s forum for coming to understand her illness; not merely a rational understanding, but an understanding which involves the emotions and which contributes to the growth of the individual.’

Peter Toon

What does the GP bring to P&EoLC?

- Treating role
- Pre-morbid awareness
- Healing role
  - Showing that we care
  - Explaining and normalising
  - Affirming and validating
  - Understanding
  - Supporting and empowering
  - Witnessing

What does the GP bring to P&EoLC?

‘To be with people at the edge of the human predicament, to understand them when they were there and, to some extent, to let them understand me being with them at that point.’

Kieran Sweeney

What does the GP bring to P&EoLC?

- Treating role
- Pre-morbid awareness
- Healing role
  - Showing that we care
  - Explaining and normalising
  - Affirming and validating
  - Understanding
  - Supporting and empowering
  - Witnessing

What does the GP bring to P&EoLC?

‘He (Sassall) is acknowledged as a good doctor because he meets the deep but unformulated expectation of the sick for a sense of fraternity.’

John Berger & Jean Mohr

A Fortunate Man

KIS

What is KIS for?

- Information transfer
  - In Hours GP to OOH GP
  - Primary Care to A&E / Acute Receiving Units
  - Primary Care to Scottish Ambulance Service
  - Primary Care to Specialist Palliative Care
- Prompts for proactive care
- Anticipatory Care Planning
- All data stored in one place
- Structure for lists / meetings / etc
- Palliative care DES

What does KIS contain?

0 - Consent

1 : Demographics

2 : Current situation

3 : Care & Support

4 : Resuscitation & Preferred Place of Care

5 : Palliative Care

0 - Consent

- KIS Upload decision
- Patient consented?
- Apply Special Note
- KIS Review date

1 : Demographics

- Patient Details
- Practice Details
- Usual GP
- Patients Emergency Contact Number
- Carers
- Next of Kin
- Access Information

2 : Current Situation

- Medical History
- Self Management Plan(s)
- Anticipatory Care Plan
- Single Shared Assessment
- Oxygen
- Additional Drugs Available at Home
- Catheter and Continence Equipment at Home

3 : Care & Support

- Agency Contact
- Moving and handling Equipment at Home
- Syringe Driver (sic)
- Adults with Incapacity Form
- Power of Attorney
- Guardianship with Welfare Decision Making Powers

4 : Resuscitation & Preferred Place of Care

- Preferred Place of Care
- DNACPR
- CYPADM

5 : Palliative Care

- Palliative Care Register
- OOH Arrangements
  - Discussed with patient / carer
  - GP sign death certificate
  - GP should be contacted OOH / Contact Number(s)
- Patient's / Carer's understanding
  - Diagnosis
  - Prognosis
- Palliative care and Treatment

DNACPR

DNACPR – Framework

- Step 1 – Is cardiac or respiratory arrest a clear possibility for the patient?
  - No
    - End of process
  - Yes
    - Step 2

DNACPR – Framework

- Step 2 – Is there a realistic chance that CPR could be successful?
  - No
    - Patient should be informed unless felt to pose too great a risk of physical or psychological harm. Reason must be documented
    - Those close to patient should be informed (confidentiality)
    - If patient lacks capacity and has welfare attorney or guardian then they should be informed
    - If patient lacks capacity then those close to them should be informed. If this cannot be done then reasons must be documented
    - If DNACPR decision is not accepted then a second opinion should be offered
  - Yes
    - Step 3

DNACPR – Framework

- Step 3 – Does the patient lack capacity and have an advance decision specifically refusing CPR or have a welfare attorney or guardian?
  - Yes
    - If applicable and valid advance decision then this must be respected
    - If welfare attorney or guardian they must be consulted
  - No
    - Step 4

DNACPR – Framework

- Step 4 – Does the patient lack capacity?
  - Yes
    - Discuss with those close to patient to guide ‘patient’s best interests’
    - Decision rests with senior clinician
  - No
    - Step 5

DNACPR – Framework

- Step 5 – Is the patient willing to discuss his/her wishes regarding CPR?
  - No
    - Respect and document their refusal
    - Discussion with those close to the patient may guide decision (confidentiality issues)
    - Decision rests with senior clinician.
  - Yes
    - The patient must be involved in deciding whether or not CPR will be attempted

DNACPR – Decision making

- Is there a realistic chance that CPR could be successful?
  - What do we mean by ‘success’?
    - Sit up and have a cup of tea…
  - Population that we are considering
    - Candidate for admission to HDU?
  - Facilities available
  - People available

Introducing the subject of DNACPR

- Communication
- Breaking bad news
  - Narrowing the information / knowledge gap
  - We know something we think they need to know!
    - CPR would be futile or
    - CPR would not be futile and so do they want it?
  - How much do they actually know?
  - How much more, if any, do they want to know
  - When do they want to know
  - Who do they want to tell them

Discussing DNACPR

- Know the patient and their context
- Be clear about benefit/burden balance of CPR (Rx)
- (Consider benefit/burden balance of discussion)
- Consider who should discuss
- Consider when to discuss
- Often less difficult earlier in disease
- Small chunks and check… (BBN)
- Aim is to Allow a Natural Death
- **Discussion on CPR should be part of wider discussion**
- **Compassion!**

Getting CPR raised

- By patient and carer
  - Spontaneously
  - Prompted
    - Another professional e.g. the hospital said…
    - ‘My Thinking Ahead & Making Plans’

Getting CPR raised

- By us (in the course of a more general discussion)
  - How do you feel you are doing?
  - Where would you like to be cared for?
  - And if things got worse…?
  - How do you see the future?
  - Are there any things you'd like to avoid?
  - Etc etc etc…
- By us (more pushy…)
  - If you're really keen to be kept at home then…
    - …what to do if there was a sudden change in your condition
    - …what to do if your heart was to stop

CPR – the subject matter

- General
  - What it means
    - Allow a natural death
  - Likelihood of success
  - Whether ‘people’ would wish it
- Individual
  - In your case…
- ‘Fine line’
  - Awareness raising, BUT
  - Clinical decision has already been made

What DNACPR is not about

- Anything other than CPR
- Any other treatments e.g. antibiotics
- Feeding
- Fluids

- Highlight everything else that we can still do

DNACPR – Practicalities

- Completing the DNACPR form
- Where should form be kept
- When to update form
- Patient transfer
- Communication
  - Patients home
    - Patient
    - Family / loved ones
    - OOH Services
    - Scottish Ambulance Service
    - Others?

DNACPR – key points

- The decision to offer CPR is a medical matter
- The decision to offer CPR has nothing to do with quality of life
- If CPR is likely to be futile do not offer it as a treatment option
- Patient / family view is only relevant if CPR is an option
- If success anticipated – CPR decisions need to be discussed
- If success not anticipated – patient needs to be informed of the decision not to offer CPR
- Relatives should not be asked to 'decide' unless patient lacks capacity & relative has legal powers (if success anticipated)
- Discussion on CPR should be part of wider discussion
- Compassion!

Pain

Pain

- Causes
  - Disease
    - E.g. direct invasion, organ distension, pressure on surrounding structures
  - Treatment
    - E.g. constipation, chemotherapy, radiotherapy
  - Debility
    - E.g. pressure sores
  - Unrelated pathology
    - E.g. arthritis, osteoporosis, vascular disease, dyspepsia

Pain

- What do you need to know?
  - Severity
  - Site
  - Character
  - Radiation
  - Onset e.g. when, suddenly, gradually?
  - Precipitant
  - Constant or intermittent?
  - Effect on sleep?
  - Aggravators e.g. Movement / posture / breathing / coughing / eating
  - Relievers e.g. Keeping still / rest / sleep / posture
  - Associated symptoms e.g. SOB / N&V / urine or bowel upset?

Pain

- What can you do?
  - Assessment is the key
  - Consider what type of pain it is e.g.
    - Bone – worse on pressure, stressing bone, weight bearing
    - Nerve – burning, shooting, tingling, jagging, altered sensation, dermatomes
    - Liver – hepatomegaly, R upper quadrant pain
    - Colic – intermittent, cramping
    - Raised intracranial pressure – headache, nausea, worse lying down / morning
    - Episodic / incident – sudden onset, precipitant
  - Prescribe an anti-emetic when staring an opioid e.g. haloperidol / metoclopramide
  - Prescribe a laxative when starting an opioid

Pain

- Drug treatment
  - Use the analgesic step ladder
    - Prescribe paracetamol and add stronger analgesic to this
  - Codeine / dihydrocodeine 10mg orally ≈ morphine 1mg orally
  - Morphine should be the first line oral opioid
  - Morphine 10mg orally ≈ oxycodone 5mg orally
  - Morphine 10mg orally ≈ morphine 5mg SC ≈ diamorphine 3mg SC
  - Fentanyl – seek specialist advice as only for stable pain / large dose equivalence range / slow to reach 'steady state'
  - Alfentanil / hydromorphone / methadone – seek specialist advice
  - NSAIDs can be very useful for some pains e.g. Naproxen for bone pain
  - Adjuvant therapy particularly for neuropathic pain e.g. amitriptyline, gabapentin, pregabalin, RXT

Pain

- Good practice points
  - Remember CD prescription requirements
    - Form of preparation
    - Strength of preparation
    - Dose must be included for all preparations ‘as directed’ is not sufficient
    - Total quantity in words and figures
  - Avoid prescribing opioids with decimal points!

Nausea & vomiting

Nausea & Vomiting

- Causes
  - Regurgitation – obstruction of oesophagus
  - Impaired gastric emptying
    - e.g. opioids, anticholinergics, locally advanced cancer, autonomic neuropathy (e.g. diabetes, Parkinson's, alcohol)
  - Chemical / metabolic
    - e.g. drugs, extensive cancer, infection, hypercalcaemia, uraemia
  - Bowel obstruction
    - e.g. constipation, extensive cancer
  - Cerebral disease
  - Vestibular system
    - e.g. motion, brain stem disease
  - Chemotherapy / radiotherapy

Nausea & Vomiting

- Causes (cont.)
  - Other
    - e.g. anxiety, fear, smell, organ failure, gastroenteritis
  - Unknown – perhaps 50%(!!)

Nausea & Vomiting

- What do you need to know?
  - Nausea, vomiting or both?
  - Pattern
    - e.g. when, frequency, persistence, how quickly after eating, what time of day, what makes it worse, what helps, how do they feel after vomiting, do they feel full?
  - Medication
  - Bowel function
  - Headache
  - How ‘ill’ are they?
  - Fever?
  - Other diseases?
  - How are they ‘within themselves’?

Nausea & Vomiting

- What can you do?
  - Look for symptom clusters e.g.
    - N&V, constipation, abdominal distension, pain
    - Vomiting (more than nausea), morning headache
    - Persistent nausea, little relief from vomiting
  - Pick up possible serious problems e.g.
    - Obstruction
    - Cerebral disease
  - Treat constipation
  - Avoidance e.g.
    - Smells, movement
  - Ensure good fluid intake
  - Good mouth care

Nausea & Vomiting

- What about drug treatments?
  - Treat the cause e.g. hypercalcaemia
  - Treat the neural pathway – just TOO complicated for tonight!
    - Drug / metabolic – haloperidol, metoclopramide
    - Gastric stasis – metoclopramide
    - Obstruction – cyclizine, hyoscine, dexamethasone, octreotide
    - Cerebral – dexamethasone, cyclizine
    - Motion – prochlorperazine, cyclizine
    - Chemotherapy – ondansetron
    - Unsure / (desperate!!) – levomepromazine
  - Think about other treatments e.g. steroids, radiotherapy
  - Consider route – S/C or PR may well be needed
  - Don’t use metoclopramide/domperidone with cyclizine

Shortness of breath

Shortness of Breath

- What causes SOB?
  - Cancer
    - e.g. tumour infiltration / SVCO / pleural effusion / lymphangitis / abdominal distension
  - Organ failure
    - e.g. heart failure / COPD / interstitial lung disease / cystic fibrosis
  - Neuromuscular
    - e.g. MND
  - Debility
    - e.g. PTE / respiratory secretions
  - Incidental
    - e.g. chest infection / asthma / anaemia / arrhythmia / anxiety / fear / panic

Shortness of Breath

- What do you need to know?
  - When?
  - Onset
    - e.g. when / suddenly / gradually
  - Aggravators
  - Relievers
  - Any associated features
    - e.g. fever / sputum / haemoptysis
  - Oxygen saturation
  - Overall condition and place on disease trajectory

Shortness of Breath

- What can you do?
  - Remember that SOB is both frightening & difficult to treat
  - Recognise / treat crises
    - e.g. PTE, SVCO
  - Recognise and explore anxiety / fear associated with breathlessness / disease / situation
  - Relaxation
  - Physiotherapy
  - Avoid!
  - Fan
  - Open window

Shortness of Breath

- What about drug treatments?
  - Treat the treatable e.g.
    - Chest infection
    - Bronchospasm
    - Cardiac decompensation
    - Pleural effusion
  - Relieve anxiety
    - Benzodiazepine e.g. lorazepam S/L
  - Treat breathlessness
    - Bronchodilators
    - Steroids e.g. trial of dexamethasone
    - Opioids (low dose)
    - Nebulised saline 0.9%
  - Oxygen (only if low oxygen levels)

Shortness of Breath

- What about drug treatments? (cont.)
  - Treat respiratory secretions
  - Possible sedation in last stages of life

Agitation – anxiety & delirium

Agitation – Anxiety

- What causes anxiety?
  - Organic
    - e.g. Symptoms, drugs, drug withdrawal (including nicotine)
  - Fears
    - e.g. illness related, money, family, loss of role
  - Psychiatric ill health
  - ‘Deep meaning’ issues
    - e.g. fear of loneliness, fear of death, lack of meaning

Agitation – Anxiety

- What do you need to know?
  - If they are the same as usual i.e. they are NOT confused
  - What are they like?
    - e.g. how do they deal with things, where ‘are’ they, what do they want, what do they fear?
  - Personal attributes
    - e.g. coping strategies (humour, denial, acceptance)
  - Personality
    - e.g. optimistic, self-confident, pragmatic

Agitation – Anxiety

- What can you do?
  - Establish if anxiety or confusion
  - Reinforce attributes, correct misconceptions, encourage ‘own coping strategies, use vague / open questions
  - Listen / support / reassure / ‘be with’
    - Though all potentially quite tricky in the OOH situation

Agitation – Anxiety

- What about drug treatments?
  - Benzodiazepines
    - e.g. diazepam, lorazepam
  - Neuroleptics
    - e.g. haloperidol. levomepromazine
  - Antihistamine
    - e.g. hydroxyzine

Agitation – Delirium

- What causes delirium?
  - Raised intra cranial pressure
  - Drugs & drug withdrawal
  - Metabolic – encephalopathy, biochemical upset
  - Infection
  - Stroke
  - Nutritional
  - Urinary retention / constipation
  - Fatigue
  - Anxiety / depression
  - Environment – excessive / unfamiliar stimuli
  - Dementia

Agitation – Delirium

- What do you need to know?
  - If they are NOT the same as usual!
  - Look for
    - Memory impairment,
    - Disorganised thinking
    - Reduced attention
    - Disorientation
    - Change in psychomotor activity
    - Disturbance of sleep
    - Altered mood
    - Altered perception (hallucinations)
    - Motor signs
  - If there are any signs of the causes on the previous slide!

Agitation – Delirium

- What can you do?
  - Establish if anxiety or confusion
  - Correct the correctable
  - Investigations (admission?)
  - Listen / support / reassure / ‘be with’
    - Though all potentially quite tricky in the OOH situation

Agitation – Delirium

- What about drug treatments?
  - Neuroleptics
    - e.g. haloperidol, levomepromazine

Crises

Malignant Spinal Cord Compression

- Early symptoms
  - Severe local spinal pain (8/10)
  - Pain in upper or mid spine
  - Pain worse at night and/or on straining
  - Radicular pain
- Early signs
  - Spinal tenderness

Malignant Spinal Cord Compression

- Late symptoms
  - Weakness
  - Sensory disturbance
  - Autonomic problems (bladder / bowel)
- Late signs
  - Weakness / difficulty walking / ‘off legs’
  - Sensory loss
  - Incontinence
- Management
  - Urgent admission as flat as possible (unless too frail for aggressive management)
  - Dexamethasone 16mg/day

Malignant Spinal Cord Compression

- Management
  - Discuss with on-call registrar at BOC
  - Urgent admission – lie as flat as possible
  - (unless felt to be too frail for aggressive management)
  - Dexamethasone 16mg/day

Name:
DOB/CHI:
Consultant:

NHS
West of Scotland Cancer Network

Health board: **XXX**

Sometimes when people have cancer it can cause the nerves in the spine to be squeezed. This is quite rare. It is very important to pick it up quickly as the earlier treatments are started, the better the result usually is.

Symptoms to watch out for:

- Back pain in one bit of your back that is severe, distressing or different from your usual pain.
- Pain that is like a band squeezing your chest.
- A new feeling of weakness of the legs or difficulty walking.
- Numbness or pins and needles in your toes, fingers or over buttocks
- Problems passing urine or controlling your bowels.

PLEASE TURN OVER

If you have any of the symptoms on the front of this card:

- Speak with a doctor, nurse or paramedic as soon as is practical (within 24 hours).
- Tell them that you have cancer, are worried about your spine and would like to see a doctor.
- Show the doctor this card.
- Try to bend your back as little as possible.

For Doctor / Health Care Professional

- This patient has metastatic cancer and is therefore at risk of malignant spinal cord compression (MSCC).
- If they have any of the symptoms on the front of this card then please consider MSCC as a possible diagnosis and discuss further management with XXXXXXX by phoning XXXXXX.
- If after discussion MSCC remains a possibility please
    - Give them Dexamethasone 8mg twice daily (unless contraindicated).
    - Advise them to lie flat as much as is practical until seen at hospital.

Hypercalcaemia

- Symptoms
  - Nausea & vomiting
  - Thirst / polyuria
  - Constipation
  - Fatigue
  - Pain
  - Anorexia
  - Confusion / drowsiness
  - Headache / dehydration
- Signs
  - Difficult to distinguish from general deterioration
- Management
  - Admission for investigation (adjusted calcium), rehydration and bisphosphonate – unless too frail for aggressive management

Superior Vena Caval Obstruction

- Symptoms
  - Feeling of fullness in head
  - Breathlessness (worse lying flat)
  - Headache (worse bending forward)
  - Visual disturbance
- Signs
  - Oedema of face, neck, arms and hands
  - Dusky colour of skin
  - Distended superficial veins
  - Breathlessness (worse lying flat)
- Management
  - Urgent admission
  - Dexamethasone 16mg/day

Raised Intracranial Pressure

- Symptoms
  - Persistent headache worse in the norning
  - Vomiting
  - Seizures
- Signs
  - Raised BP
- Management
  - Dexamethasone 16mg/day
  - Symptom relief
  - Admission for investigation / diagnosis / further management

Terminal Agitation

- Management
  - Exclude or relieve treatable causes if possible e.g.
    - Urine retention
    - Faecal impaction
    - Poor symptom relief
    - Opioid toxicity
  - If opioid toxicity suspected reduce dose by 50% and observe
  - Midazolam 5mg S/C bolus as required
  - If effective consider midazolam S/C infusion

Bleeding

- Haemoptysis
  - Consider cause
  - Treatment
    - Steroids
    - Antifibronolytics
    - Antibiotics
    - Suction
    - Admission?
- Catastrophic haemoptysis
  - Position sitting forward well supported
  - Towels (dark)
  - Midazolam

Bleeding

- Haematemesis
  - Consider cause
    - Tumour erosion
    - Drug side effect
  - Treatment
    - Treat cause
    - Admission?
- Catastrophic haematemesis
  - Position sitting forward well supported
  - Towels (dark)
  - Midazolam

- Carotid artery erosion
  - Position sitting forward well supported
  - Towels (dark)
  - Midazolam