ANTICIPATORY CARE PLANNING

(in the context of palliative care…)

www.palliativecareggc.org.uk
Professional >> Education >> Local Education Providers >> GP evening meetings

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Experience

- What things led to ‘good deaths’?
- What things led to ‘bad deaths’?

Anticipatory Care Planning (ACP)

- 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?

Who 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

Who 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

Who 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 is Scottish Public Health 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 to 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

How do we decide?

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

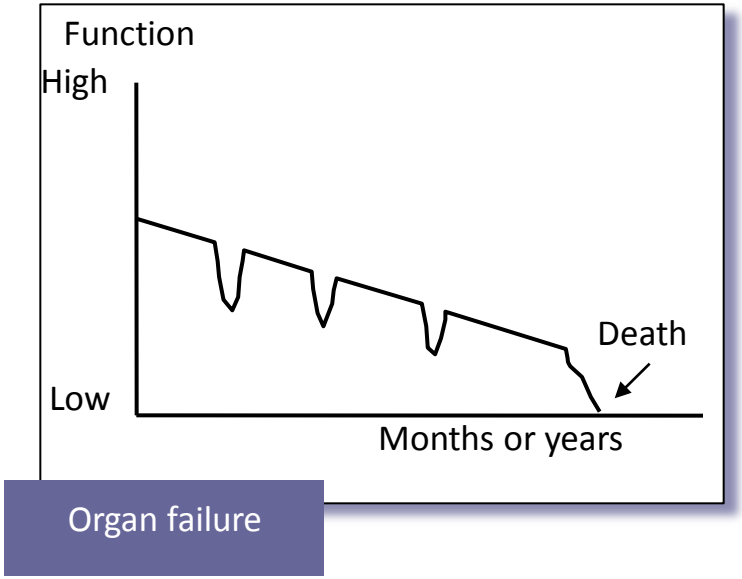
How do we decide?

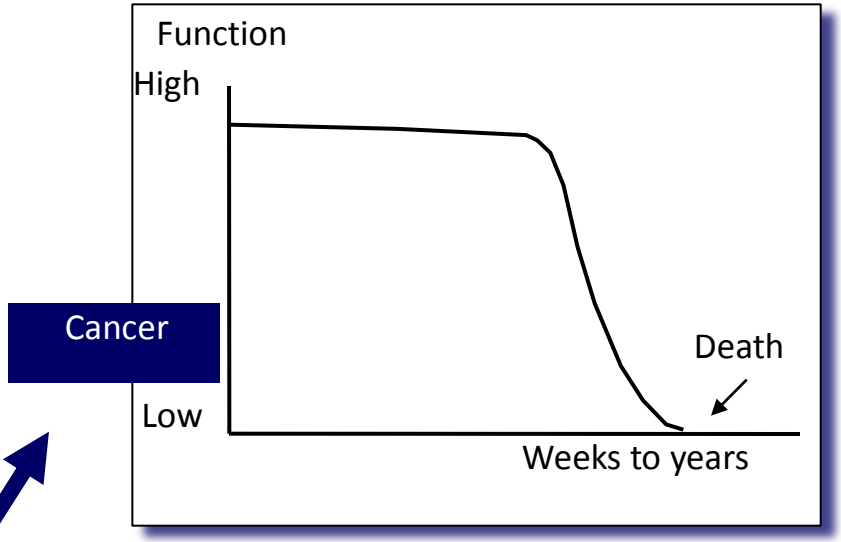
- Consider ‘dying’ as a diagnosis!
- What primary disease(s) do they suffer from?
  - Mesothelioma
  - Prostate cancer
  - Renal failure & dialysis
  - 93 year old with multi-morbidity & dementia
  - COPD

How do we decide?

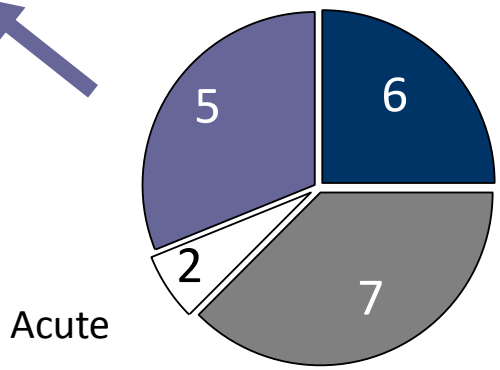
- Consider ‘dying’ as a diagnosis!
- What primary disease(s) do they suffer from?
  - Mesothelioma
  - Prostate cancer / **Malignant Spinal Cord Compression**
  - Renal failure & dialysis / **decision taken to stop dialysis**
  - 93 year old with multi-morbidity & dementia / **15% weight loss in 6m**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

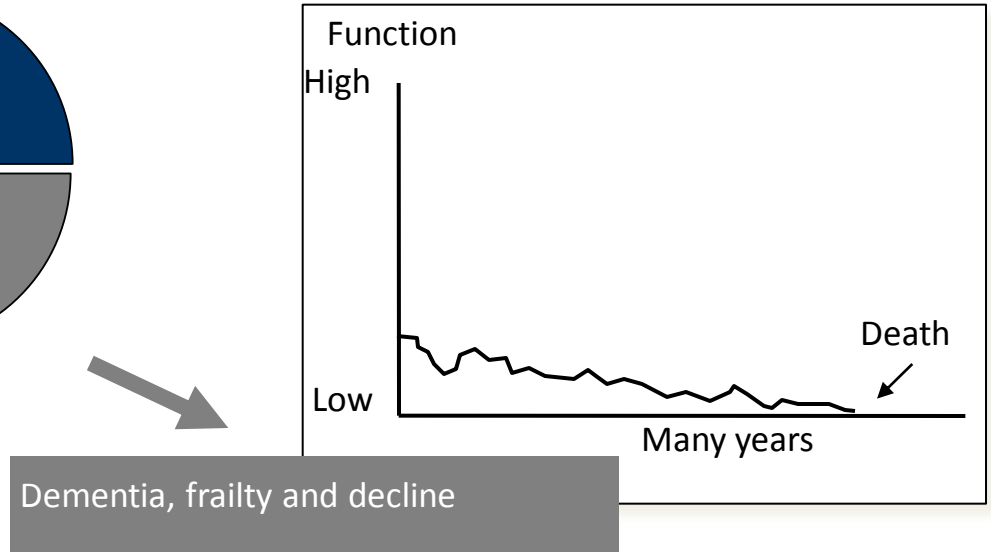
Numbers and Trajectories





GP has 20 deaths per list of 2000 patients per year





Trajectory

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

Trajectory

- Phases
  - Ante-natal care
  - Birth
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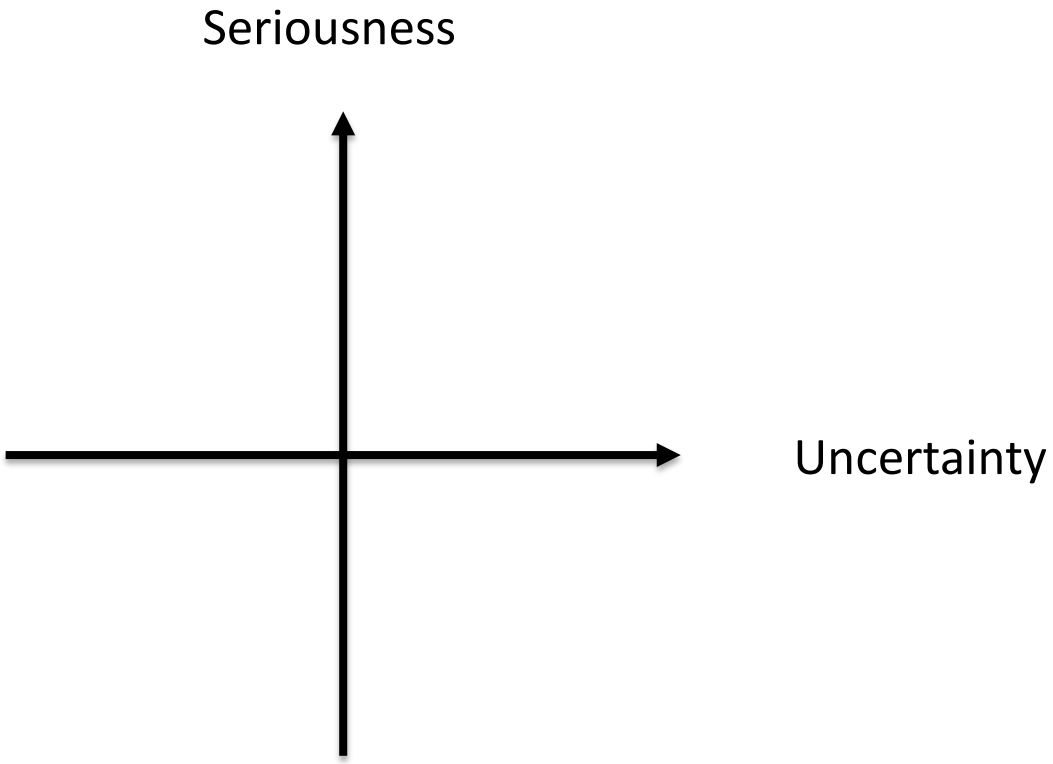
Trajectory

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

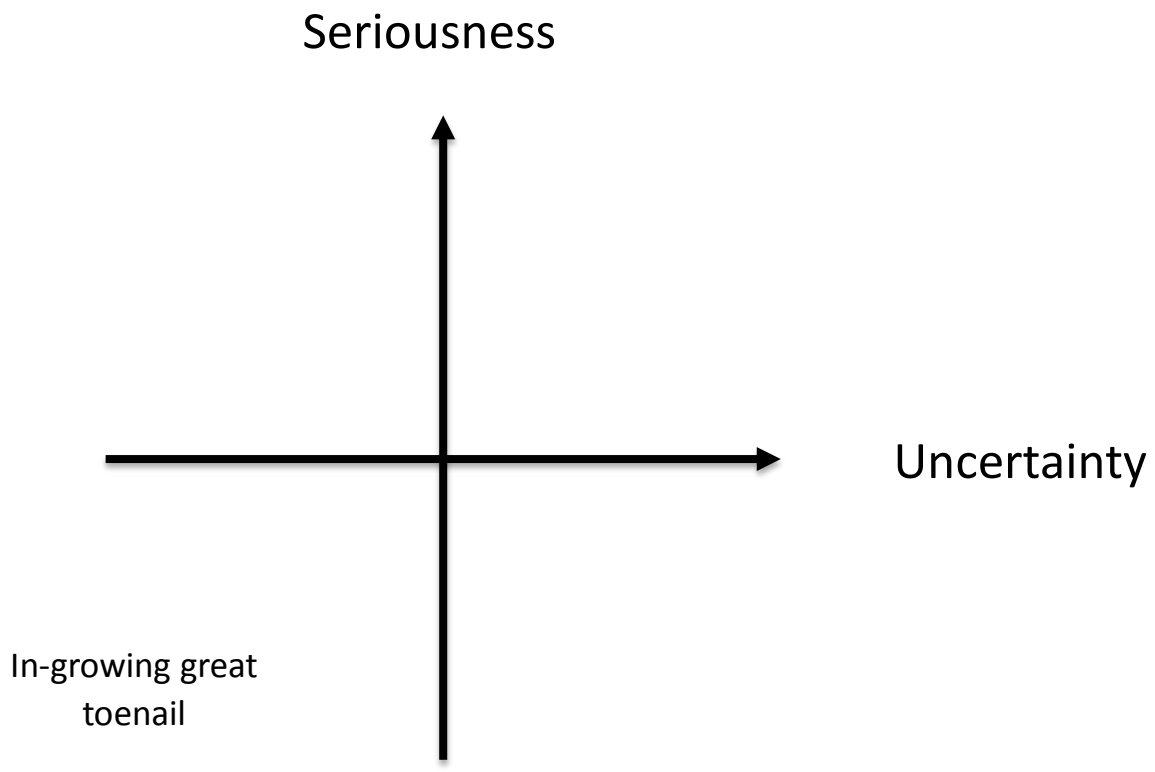
Trajectory

- The Index of Concern



Trajectory

- The Index of Concern



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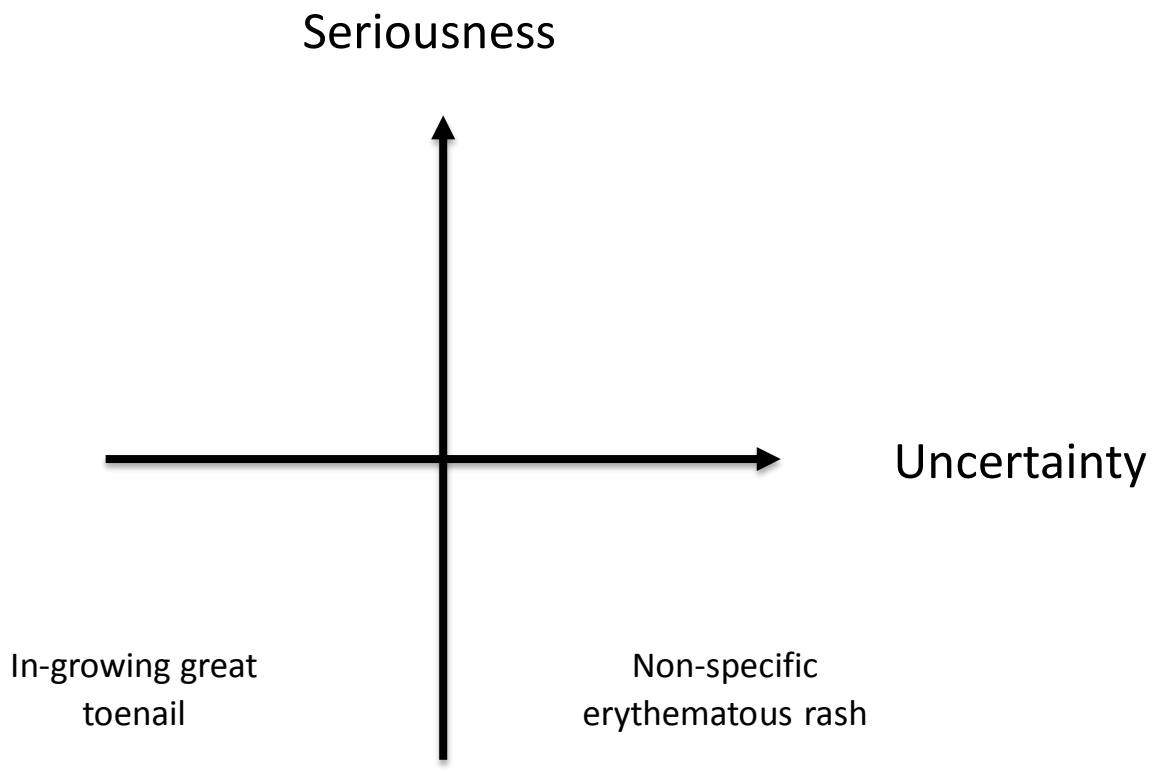

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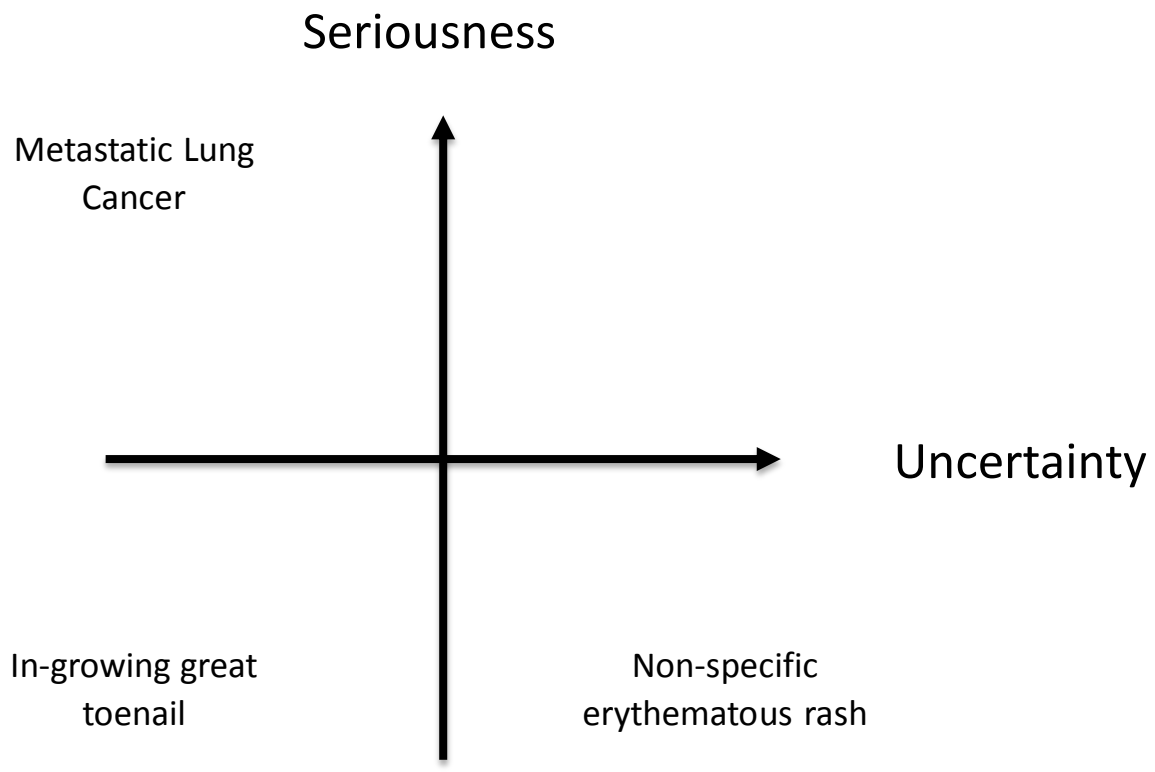

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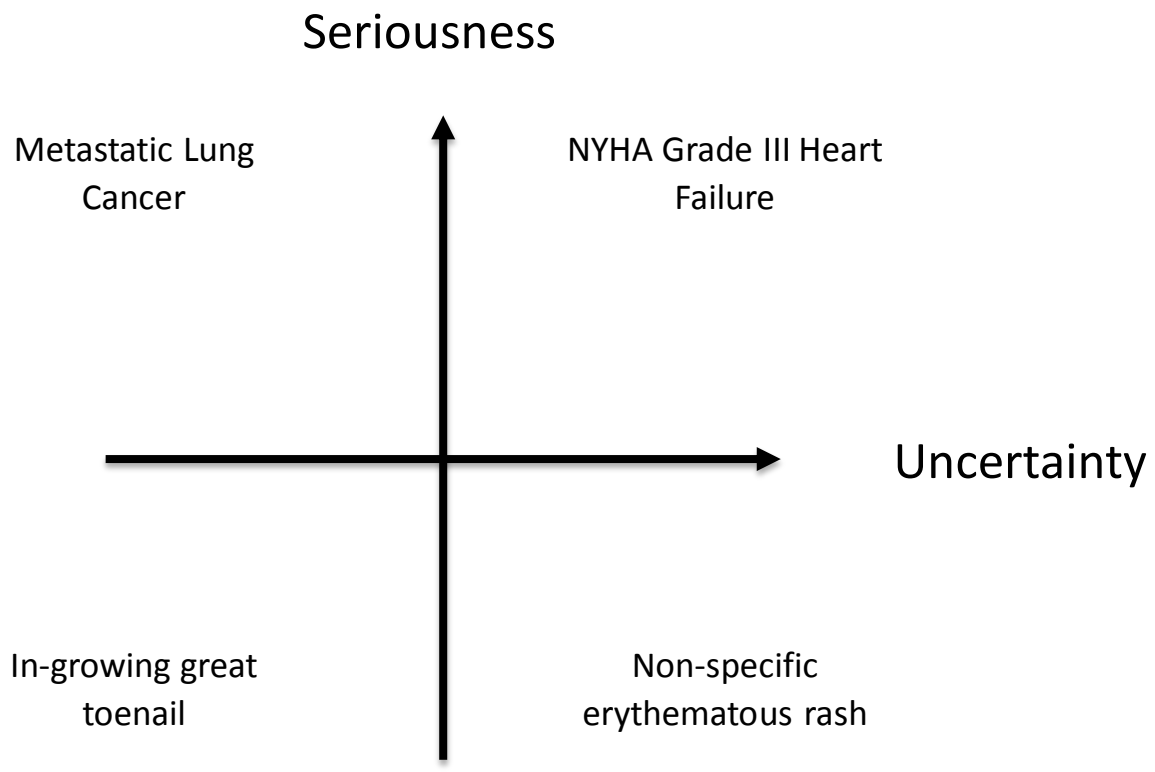


How do we decide?

- 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?
- Would you be surprised…?

Who we are talking about

- Whoever YOU feel should be included!
- Consider:
  - What primary disease(s) do they suffer from
  - Personal trajectory
  - Would you be surprised…?
  - Palliative care register
  - 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 website (www.spict.org.uk) for information and updates.

SPICT™, April 2017

Advance Care Plan – ‘definition’

- A process of discussion between an individual, their care providers, and often those close to them, about future care

NHS End of Life Care Programme, 2007

Anticipatory Care Plan – ‘definition’

- A plan that anticipates significant changes in a patient (or their care needs) and describes action, which could be taken, to manage the anticipated problem in the best way. It is used by healthcare professionals to record decisions agreed with patients about their anticipated care needs and wishes
- These discussions should include family / carers /representatives whenever possible

Anticipatory Care Planning – actual

- What we do naturally
- Extension (relatively simple)
- Formalisation
- Verb rather than noun!

The 10 Cs 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

C 1 – Consider dying as a possibility

- Done…!

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 / ePCS)
  - Advance decision to refuse treatment

C 5 – Communication

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

Who needs to know?

- Patient / family / loved ones / significant others
- ‘Professionals’
  - e.g. Partners, Nurses, OOH, SAS, Pharmacy, Acute, Specialists, Social Workers, Social Carers, Reception staff, Minister, Priest, Faith leader…

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!

What needs to be known by ‘Professionals’?

- 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 the same?)
- An ‘Advance Statement’

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; non-admission
- Who they would wish consulted

What needs to be known by ‘Professionals’?

- 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 the same?)
- An ‘Advance Statement’
- All the other ‘professional’ views!

How can we make communication better?

- Gathering
  - Using our vast communication skills!
  - My Thinking Ahead & Making Plans (MTA&MP)

How can we make communication better?

- My Thinking Ahead & Making Plans
  - 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

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 6 – Current needs

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

C 8 – Care Planning (Anticipatory)

- Plan A
  - Active treatment aimed at recovery
- Plan B
  - Active treatment aimed at a good and dignified death

- What are the similarities and differences between Plan A & Plan B?

C 8 – Care Planning (Anticipatory)

- Similarities and differences
  - Similarities
    - Almost everything!
  - Differences
    - Aim
    - Enormity – seriousness of dying/death
    - Time cost
    - Ceilings of treatment / intervention
    - Anything else?

C 7 – Ceilings of treatment / intervention

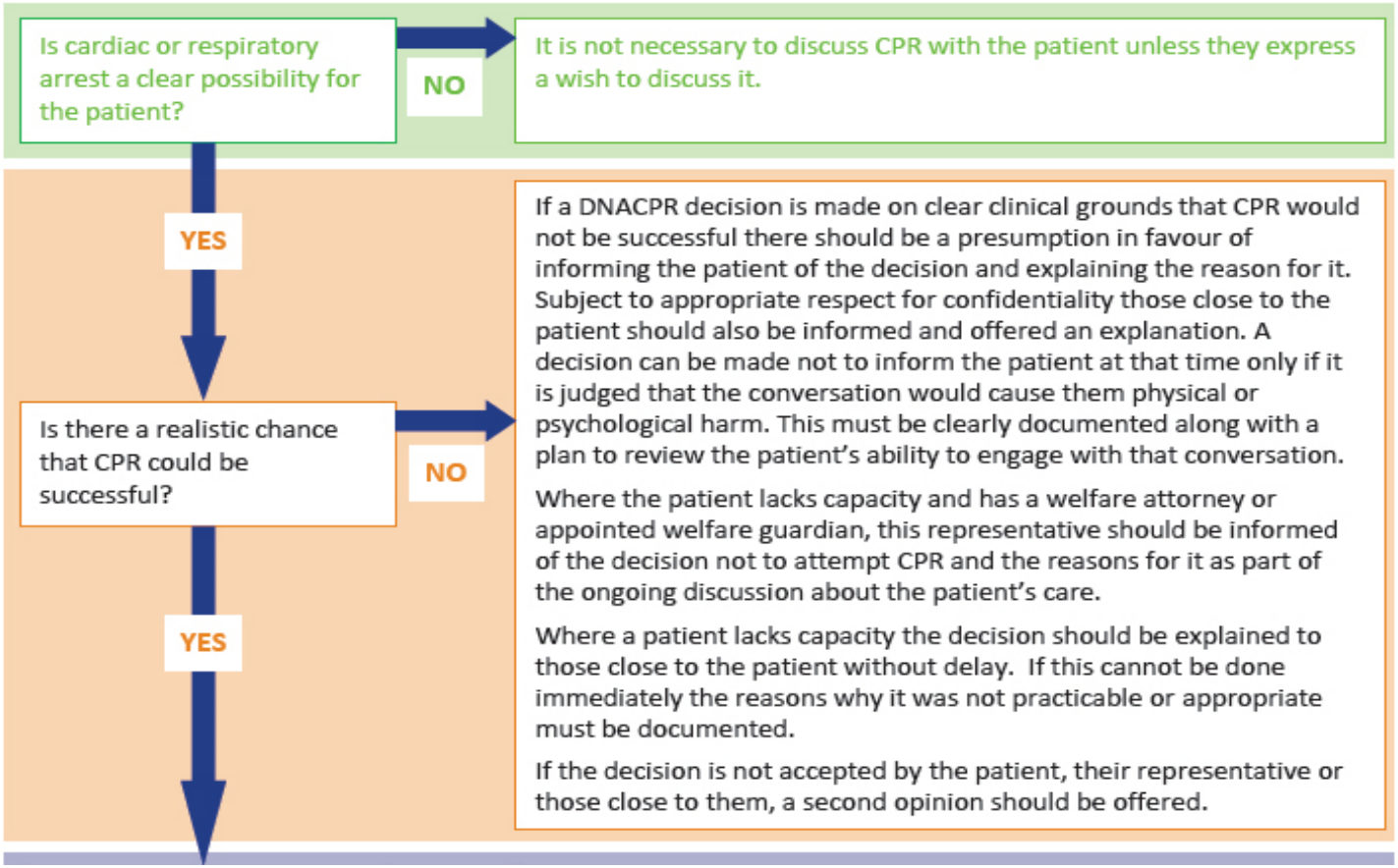
- Some ceilings
  - Transplant(!!)
  - Dialysis; ventilation; cardiac devices(!)
  - CPR

DNACPR – Framework

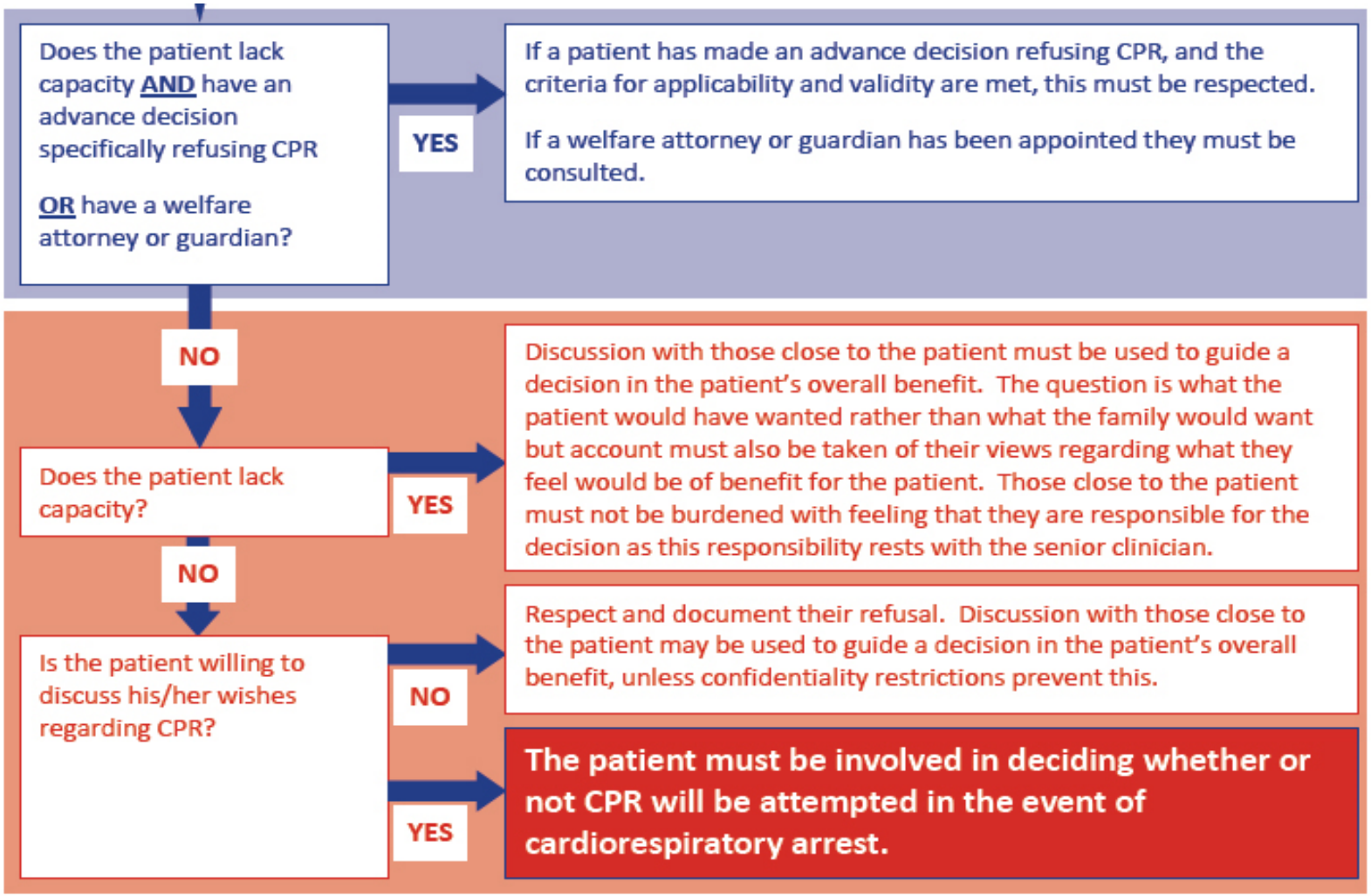
NHS Scotland DNACPR Policy 2016

Decision-making framework

NHS SCOTLAND



DNACPR – Framework



Adapted from Decisions Relating to Cardiopulmonary Resuscitation - guidance from the BMA, RC(UK) and the RCN 2016

Discussing 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!**

Practicalities of DNACPR

- Completing the DNACPR form
- Where should form be kept
- When to update form
  - Possible to not need to do this
- Patient transfer
  - Original form
- Communication
  - Patient
  - Family / loved ones
  - OOH Services
  - Scottish Ambulance Service
  - Others?

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 <u>discussed</u>
- If success not anticipated – patient needs to be <u>informed</u> 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!

C 7 – Ceilings of treatment / intervention

- Some ceilings
  - Transplant(!!)
  - Dialysis; ventilation; cardiac devices(!)
  - CPR
  - Surgery
  - Chemotherapy / Radiotherapy
  - <u>Antibiotics I/V</u>
  - <u>Admission or transfer</u>
  - Nutritional support
  - Hydration / S/C fluids
  - Blood tests (arterial, venous, capillary)
  - Antibiotics oral
  - Routine positional change

C 8 – Care Planning

- 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

C 8 – Care Planning

- Prescribing issues
  - What is essential?
  - What is not needed?
  - What to do with those in between?
  - Route of administration (S/C?)
  - What might be needed (Just in Case)?

Just in Case

- Anticipatory prescribing
- ‘Upstream’ of Last Stages of Life
- Avoid delays in treatment
- Pre-empt shift from Oral to SC
- Increases overall proactive approach (not just Rx)

Just in Case – medication

- Pain / Breathlessness
  - e.g. Diamorphine 1-2mg SC / 1 hourly as required
- Nausea / Vomiting
  - e.g. Levomepromazine 2.5-5mg SC / 8 hourly as required
- Restlessness / Agitation
  - e.g. Midazolam 2mg SC / 1 hourly as required
  - Lorazepam 500 microgms SL as required
- Respiratory secretions
  - e.g. Hyoscine Butylbromide 20mg SC / 1 hourly as required

C 8 – Care Planning

- 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
  - (DNACPR)
  - KIS
  - DNVoED

DN Verification of Expected Death

- Competence – training of Registered Nurses
- Consider possibility of expected death
  - Anticipatory care planning
  - Care in the Last Stages of Life
- GP completes form
- Communicate
  - In hours team
  - OOH services
  - Patient / family

C 8 – Care Planning

- 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 Last Stages of Life / Death
  - The prodromal phase

C 8 – Care Planning

- Prodromal phase
  - Plan A: Active treatment aimed at improvement / recovery
  - Plan B: Active treatment aimed at a good and dignified death
  - Acknowledge the uncertainty
  - Gradual / sudden shift 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 considerations
  - Probable / what is likely to happen
  - Possible / what might happen
  - 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

ACP Process

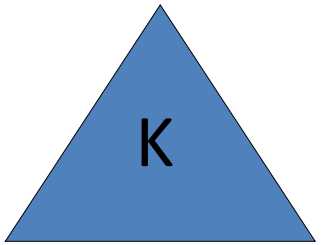
- When should this be done?
- Who should do it?
- How can it be shared?

ACP Process

- When should this be done?
  - At any time in life that seems appropriate
  - Continuously
- Who should do it?
  - By anyone with an appropriate relationship!
- How can it be shared?
  - KIS / (ePCS)
  - All other means of communication!

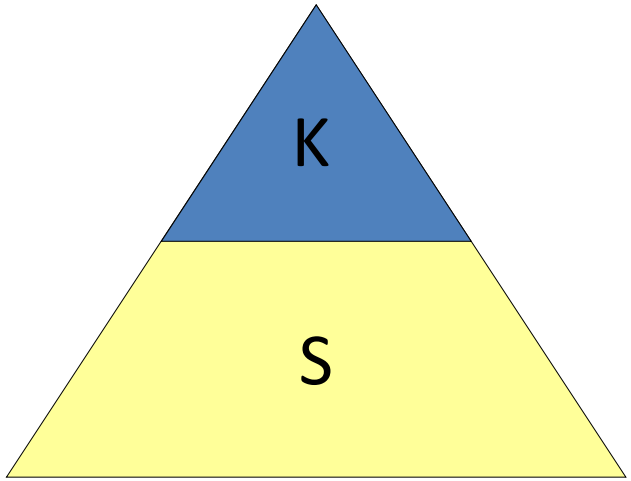
What does the GP bring to P&EoLC?

- Knowledge



What does the GP bring to P&EoLC?

- Skills



What does the GP bring to P&EoLC?

- Treating role
  - Diagnostician
  - Treatment planner
  - Decision maker
  - Decision ratifier

What does the GP bring to P&EoLC?

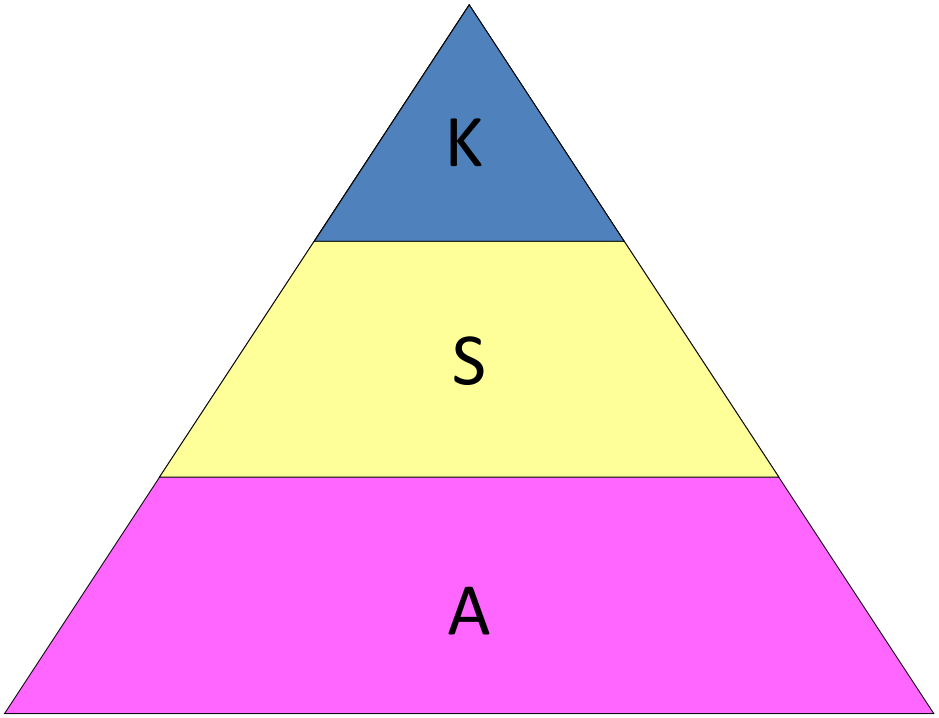
- Treating role
- Pre-morbid awareness
  - Narrative & biography

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

Sir William Osler

What does the GP bring to P&EoLC?

- Attitudes



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

What does the GP bring to P&EoLC?

- Treating role
- Pre-morbid awareness
- Healing role
  - Show that we care
    - Polite and courteous
    - Show interest
    - Make it personal
    - Give time (even when there is very little available)
    - Add ‘little touches’
    - Unbidden acts of human kindness

What does the GP bring to P&EoLC?

- Treating role
- Pre-morbid awareness
- Healing role
  - Show that we care
  - Explaining & normalizing
  - Affirming & validating
  - Understanding

‘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
  - Show that we care
  - Explaining & normalizing
  - Affirming & validating
  - Understanding
  - Enabling & empowering
  - Witnessing

‘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

…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

‘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

www.palliativecareggc.org.uk
Professional >> Education >> Local Education Providers >> GP evening meetings

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