OBJECTIVES

• To be aware of the three commonest trajectories of decline in the UK
• To understand the challenges faced in delivering effective Palliative Care to each group
• To be able to recall and apply the general indicators seen in the last years of life
DEFINITION: END OF LIFE CARE

• Patients are considered to be approaching the end of their life when they are likely to die within the next 12 months this includes:
  • Imminent death (hours to days)
  • Advanced progressive incurable conditions
  • General fragility and co-existing conditions that mean they are expected to die within 12months
  • Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
  • Life threatening acute conditions caused by sudden catastrophic events

GMC ‘Treatment and care towards the end of life: good practice in decision making’ 2010

WHY DO WE TRY TO IDENTIFY PATIENTS APPROACHING THE END OF THEIR LIFE?

• Improve the quality of the patients life
• Provide the opportunity to undertake better and earlier advanced care planning with the patient
• Allow better co ordination of care between clinical teams
• Reduce or prevent crisis admissions to hospital
• Allow special rules to be applied in relation to social care funding (DS1500 at <6months and fast track for CHC <3months)
WHAT ARE PREDICTORS OF ALL END OF LIFE CONDITIONS

- Decrease in functional performance status (e.g. in bed or chair 50% daytime)
- Increase in need for care and support
- Co-morbidity
- Deteriorating condition
- Progressive weight loss (>10% in 6 months)
- Repeated crisis/ admissions
- Sentinel Event (serious fall, bereavement, transfer to nursing home)
- Would I be surprised if....

WHAT ARE YOUR PATIENTS DYING FROM?

Average GP’s workload - Average 20 Deaths/ GP/Year (approximate proportions)
THE THREE MAIN TRAJECTORIES OF ILLNESS


CASE STUDY

• 52 year old lady
• June 2016 diagnosed with cervical cancer treated with radical radiotherapy
• November 2016 admitted to RBH with drowsiness and jerkiness – found to be in ARF secondary to both ureters being obstructed eGFR 9
• Dec 2016 admitted to hospice for symptom control (vomiting, nausea and pain) and end of life care
TRAJECTORY OF ILLNESS IN CANCER

• Rapid change in condition usually clear indicator that patient is approaching end of life
• Often linked to progression of disease burden (e.g. metastasis)
• Prognosis often commented on and clear information given by specialist teams (e.g. asking for patients to be added to GSF)
• Information on prognosis for individual cancer groups readily available (e.g. 1 year and 5 year survival data)
• Less time living with poor function and disability

SPECIFIC PROGNOSTIC INDICATORS: CANCER

• Metastatic Disease
• Clear predictable link to loss of function ‘if patients are spending more than 50% of their waking time in bed/lying down prognosis is likely to be <3months’
CHALLENGES

• Difficulty to patients and families in adapting to rapid changes (social, psychological, grief reactions)
• May develop worsening symptoms which require medical input and rapid adjustments in medications (one indication for hospice referral/admission)
• Unrealistic expectations from patient and/or family (that decline will reverse or that another treatment will become available)
• Not all cancer diagnosis will fit into this category e.g. slower decline in prostate cancer prolonged

CASE STUDY: ORGAN FAILURE

• 64 year old man
• Jan 2014 diagnosed with Motor Neurone Disease
• April 2015 Dysarthric speech, Strong neck muscles, weak limbs between 2 and 3+/5 working as project manager using appropriate adaptions at work
• May 2015 Seen for first time at hospice for introduction to services and day hospice
• October 2015 PEG inserted at Wythenshawe under respiratory support
• November 2015 (Neurology f/u) unable to stand (started using hoist for transfers), mild drooling, worsening limb weakness (no power to left arm and minimal to right) speech more dysarthric and difficult to understand
• May 2016 admitted to Wythenshawe started NIV deterioration (LRTI) transferred to hospice for possible EOL care
• June 2016 admitted to hospice on NIV intermittently at night unable to discharge as no nursing home bed available
• Oct-Dec 2016 increasing NIV until on 24/7, two episodes of mucous plugging causing cyanosis
TRAJECTORY OF ILLNESS IN ORGAN FAILURE

• Acute exacerbations
• Usually step down in function after exacerbations
• Loss of function needing increasing support
• Prognosis varies depending on cause but may be over many years
• Can be difficult to know whether you are seeing a patient at the end of their life or at a ‘trough’ in their acute exacerbation (e.g. patient A’s family were told he was likely at end of life 7 months prior to death)
• Patients may also die rapidly during an acute exacerbation

PROGNOSTIC INDICATORS: CHRONIC ILLNESS COPD

• COPD:
  • Two of
    • Known severe disease e.g. FEV1<30% predicted
    • at least 3 admissions to hospital in the last 12 months
    • fulfils long term oxygen criteria
    • SOB on <100yds flat or confined to house
    • Signs/symptoms of right heart failure
    • more than 6 weeks steroids over previous 6 weeks
  • other complications such as NIV resistant factors
PROGNOSTIC INDICATORS: HEART DISEASE

• At least two of
  • CHF Stage 3 or 4 (shortness of breath at rest or on minimal exertion)
  • Patient thought to be in last year of life by specialist care team
  • Repeated hospital admissions
  • Difficulty physical or psychological symptoms despite optimal tolerated therapy

PROGNOSTIC INDICATORS: RENAL DISEASE

• Stage 4 or 5 disease with two of the following
  • Patient thought to be in last year of life by care team
  • Those who choose no dialysis option or not to continue dialysis
  • Patients with difficult physical or psychological symptoms despite optimal tolerated renal replacement therapy
  • Symptomatic renal failure
PROGNOSTIC INDICATOR: GENERAL NEUROLOGICAL DISEASE

• Progressive deterioration in physical and/or cognitive function
• Symptoms which are complex and difficult to control
• Swallowing problems leading to recurrent aspiration pneumonia
• Speech problems and

PROGNOSTIC INDICATOR: GENERAL NEUROLOGICAL DISEASE

• For MND
  • Low vital capacity <70% predicted
  • Communication problems
  • Dyskinesia, mobility problems, falls
• For Parkinsons
  • Drug treatment less effective or increasingly complex regime
  • Needing assistance with ADL
  • Dyskinesias, mobility problems and falls
  • Psychiatric problems
• For Multiple Sclerosis
  • Significant complex symptoms and medical complications
  • Dysphagia and poor nutritional state
  • Communication difficulties
CHALLENGES

• Identifying last year of life may be difficult particularly in context of an acute exacerbation
• Loss of function may need high levels of care input however where there is slow decline patients may not fit into the ‘special rules’ and may not initially meet CHC requirements leaving patients and caregivers struggling
• Depending on illness disease may have a number of medical teams involved (e.g. SRHT for MND, Wythenshawe for NIV and Bolton for Palliative and GP care for this patient)
• Balance of benefit vs drawback for intervention may be changing and complex (for example whether to go to hospital for acute exacerbations of COPD, whether to start NIV in MND) and even with advanced care planning decisions may change at the time of an exacerbation
• Patients may struggle to accept that their condition has moved from active treatment to best supportive care (for example ESHF and COPD patient refusing to have ICD turned off)

TRAJECTORY OF ILLNESS IN FRAILTY / DEMENTIA

• Slow decline
• Poor and slowly declining functional ability
• Require long term full care packages or nursing / residential home care
PROGNOSTIC INDICATORS IN FRAILITY

- Fraility (multiple co morbidities with significant impairment in day to day living)
  - deteriorating functional score
  - three of the following symptoms
    - weakness
    - slow walking speed
    - significant weight loss
    - exhaustion
    - low physical activity
    - depression

PROGNOSTIC INDICATORS: STROKE

- Persistent vegetative or minimal consciousness state or dense paralysis
- Medical complications
- Lack of improvement within 3 months onset
- Cognitive impairment/ Post stroke demenitia
PROGNOSTIC INDICATORS: DEMENTIA

• Unable to walk without assistance
• Urinary and faecal incontinence
• No consistently meaningful conversation
• Unable to do ADL
• Plus
  • Weight loss
  • UTI
  • Stage 3/4 pressure sores
  • Recurrent fever
  • Reduced oral intake

CHALLENGES

• Timing of advance care planning (may need to be discussed much earlier in dementia to allow patients opportunity to make their own choices)
• Finding joy and meaning in life for the patient and the carers
• Keeping skin intact
• Avoiding life prolonging interventions which do not relieve symptoms but prolong suffering
REFERENCES

• http://caretobedifferent.co.uk/continuing-care-fast-track-assessments-how-to-get-a-quick-decision/


• Thomas K. (1997) ABC of Palliative care Chapter 16 Community Palliative Care