ANTICIPATORY CARE PLANNING

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Problems

• The ‘sudden’ deterioration
• What does the patient know / think / want?
• What do the family know / think / want?
• Lack of medication
• Blue light ‘999’ at end of life
• Who knows what?
• The weekend catastrophe
• The ‘bad’ death…
• …and then 4 hours to confirm it happened!
Anticipatory Care Planning (ACP)

• What is it?
• Why is it (possibly) more important in palliative care?
• Who is it for?
• What are the components of ACP?
• ACP process
  • When should this be done?
  • Who should do it?
  • How should it be done?
• The Palliative Care DES
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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!
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Who is ACP for?

- Patients with supportive / palliative care needs
  - Consider dying as a diagnosis
  - What major disease / diseases do they suffer from?
Numbers and Trajectories

GP has 20 deaths per list of 2000 patients per year

- **Organ failure**: Months or years
- **Cancer**: Weeks to years
- **Dementia, frailty and decline**: Many years

6
5
2
7

Acute
Who is ACP for?

- Patients with supportive / palliative care needs
  - Consider dying as a diagnosis
  - What major disease / diseases do they suffer from?
  - Would you be surprised…?
  - How are they at this moment?
  - How rapidly are they changing?
- Tools
  - SPICT / GSFS Prognostication Indicators
  - Palliative Performance Scale V2 (PPSV2)
  - Supportive & Palliative Action Register
# Identifying patients for supportive and palliative care

## Supportive & Palliative Care Indicators Tool

### 1. Ask
Would it be a surprise if this patient died in the next 6-12 months?  
No

### 2. Look for two or more general clinical indicators
- Performance status poor (limited self care; in bed or chair over 50% of the day) or deteriorating.
- Progressive weight loss (>10%) over the past 6 months.
- Two or more unplanned admissions in the past 6 months.
- A new diagnosis of a progressive, life limiting illness.
- Two or more advanced or complex conditions (multi-morbidity).
- Patient is in a nursing care home or NHS continuing care unit; or needs more care at home.

### 3. Now look for two or more disease related indicators

<table>
<thead>
<tr>
<th>Heart disease</th>
<th>Respiratory disease</th>
<th>Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>NYHA Class III/IV heart failure, severe valve disease or extensive coronary artery disease.</td>
<td>Severe airflow obstruction (FEV1 &lt; 30%) or restrictive deficit (vital capacity &lt; 60%, transfer factor &lt; 40%).</td>
<td>Performance status deteriorating due to metastatic cancer and/or co-morbidities.</td>
</tr>
<tr>
<td>Breathless or chest pain at rest or on minimal exertion.</td>
<td>Meets criteria for long term oxygen therapy (PaO2 &lt; 7.3 kPa).</td>
<td>Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment.</td>
</tr>
<tr>
<td>Persistent symptoms despite optimal tolerated therapy.</td>
<td>Breathless at rest or on minimal exertion between exacerbations.</td>
<td>Neurological disease</td>
</tr>
<tr>
<td>Systolic blood pressure &lt; 100 mmHg and/or pulse &gt; 100.</td>
<td>Persistent severe symptoms despite optimal tolerated therapy.</td>
<td>Progressive deterioration in physical and/or cognitive function despite optimal therapy.</td>
</tr>
<tr>
<td>Renal impairment (eGFR &lt; 30 ml/min).</td>
<td>Symptomatic right heart failure.</td>
<td>Symptoms which are complex and difficult to control.</td>
</tr>
<tr>
<td>Cardiac cachexia.</td>
<td>Low body mass index (&lt; 21).</td>
<td>Speech problems with increasing difficulty communicating and/or progressive dysphagia.</td>
</tr>
<tr>
<td>Two or more acute episodes needing intravenous therapy in past 6 months.</td>
<td>More emergency admissions (&gt; 3) for infective exacerbations or respiratory failure in past year,</td>
<td>Recurrent aspiration pneumonia; breathless or respiratory failure.</td>
</tr>
</tbody>
</table>

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<tr>
<th>Kidney disease</th>
<th>Liver disease</th>
<th>Dementia</th>
</tr>
</thead>
</table>
| Stage 4 or 5 chronic kidney disease (eGFR < 30 ml/min). | Advanced cirrhosis with one or more complications:  
- intractable ascites  
- hepatic encephalopathy  
- hepatorenal syndrome  
- bacterial peritonitis  
- recurrent variceal bleed  
Serum albumin < 25 g/L and prothrombin time raised or INR prolonged (INR > 2). | Unable to dress, walk or eat without assistance; unable to communicate meaningfully. |
| Conservative kidney management due to multi-morbidity. | Hepatocellular carcinoma. | Worsening eating problems (dysphagia or dementia related) - now needing pureed/soft diet or supplements. |
| Deteriorating on renal replacement therapy with persistent symptoms and/or increasing dependency. | Not fit for liver transplant. | Recurrent febrile episodes or infections; aspiration pneumonia; Urinary and faecal incontinence. |
| Not starting dialysis following failure of a renal transplant. | New life limiting condition or kidney failure as a complication of another condition or treatment. | |
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<table>
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<tr>
<th>PPS Level</th>
<th>Ambulation</th>
<th>Activity &amp; Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Full</td>
<td>Normal activity &amp; work No evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>90%</td>
<td>Full</td>
<td>Normal activity &amp; work Some evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>80%</td>
<td>Full</td>
<td>Normal activity with Effort Some evidence of disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>70%</td>
<td>Reduced</td>
<td>Unable Normal Job/Work Significant disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>60%</td>
<td>Reduced</td>
<td>Unable hobby/house work Significant disease</td>
<td>Occasional assistance necessary</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>50%</td>
<td>Mainly Sit/Lie</td>
<td>Unable to do any work Extensive disease</td>
<td>Considerable assistance required</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>40%</td>
<td>Mainly in Bed</td>
<td>Unable to do most activity Extensive disease</td>
<td>Mainly assistance</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>30%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity Extensive disease</td>
<td>Total Care</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>20%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity Extensive disease</td>
<td>Total Care</td>
<td>Minimal to sips</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>10%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity Extensive disease</td>
<td>Total Care</td>
<td>Mouth care only</td>
<td>Drowsy or Coma +/- Confusion</td>
</tr>
<tr>
<td>0%</td>
<td>Death</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Supportive & Palliative Action Register (SPAR)

- Care homes (nursing & non-nursing)
  - Assess all residents
  - Colour code related to changing need
    - Green – little change
    - Amber – changing quite quickly
    - Red – changing very quickly & last few days
Who is ACP for?

- Patients with supportive / palliative care needs
  - Whoever YOU feel should be included!
    - Diagnoses
    - Rate of decline
    - ‘Surprise’ question
    - Tools (GSF PIG, SPICT, PPSv2, SPAR)
- Palliative care register
- GSFS register
- Chronic disease registers?
- Care Home patients??
- Housebound patients??
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Advance Care Planning

Legal
- Welfare Power of Attorney
- Continuing Power of Attorney
- Guardianship

Personal
- Advance Statement
  - 1 Statement of values
  - 2 Preferences & priorities
  - 3 Advance decision to refuse treatment
  - 4 Who else to consult
- My Thinking Ahead & Making Plans

Medical
- Potential Problems
- Lanarkshire Home Care Pack
- DNA CPR
  - SPAR
  - GSFS
  - Just in Case
  - Liverpool Care Pathway
  - DN Verification of Death

Anticipatory Care Plan
- preferred priorities of care
Legal

• Capacity
  • Welfare Power of Attorney
  • Continuing Power of Attorney
  • Guardianship

• Consent
  • To record
  • To transfer

• Advance decision to refuse treatment
Medical

• Consideration of potential problems
  • What is likely to happen to THIS patient
  • What might happen to THIS patient

• Just in Case
  • Proactive prescribing

• DNACPR
• DN Verification of Expected Death
• Liverpool Care Pathway for the Dying
• Bereavement
Structures

- Gold Standards Framework
- Supportive & Palliative Action Register
- Palliative Care DES?
- ePCS (electronic Palliative Care Summary)
- Just in Case (anticipatory prescribing)
- National DNA CPR policy
- LCP (Liverpool Care Pathway)
- DN VOED (District Nurse Verification of Expected Death)
Gold Standards Framework (Scotland)

The 8 Cs

- C1 - Communication
- C2 - Coordination
- C3 - Control of Symptoms
- C4 - Continuity
- C5 - Continued Learning
- C6 - Carer Support
- C7 - Care of the Dying
- C8 - Cancer Register
Supportive & Palliative Action Register (SPAR)

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  - Assess all residents
  - Colour code related to changing need
    - Green – little change
    - Amber – changing quite quickly
    - Red – changing very quickly & last few days
  - Specific actions
  - Structured review
ePCS – functions

- Information transfer
  - ‘In Hours’ GP > OOH
  - Primary Care > A&E / Acute Receiving Units
  - Primary Care > SAS
- Prompts for proactive care
- All data stored in one place
- Structure for lists / meetings / etc
- Anticipatory Care Plan
  - Practical
  - Contractual?
ePCS – data set

- Consent & ePCS review date
- Current situation
  - Diagnoses
  - Key personnel involved
  - Carer details
  - Current treatment
    - Repeat
    - Last 30 day acute
- Patient / Carer understanding
  - Diagnosis
  - Prognosis
ePCS – data set

• Anticipatory Care Plan
  • Patient wishes
  • Preferred Place of Care
  • Resuscitation status
  • ‘Just in Case’ prescribing
  • Liverpool Care Pathway
  • Advice for OOH GP e.g.
    • Contact own GP
    • Death expected
Just in Case

- Anticipatory prescribing
- ‘Upstream’ of LCP
- 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 as required

- **Nausea / Vomiting**
  - e.g. Levomepromazine 6mg SC

- **Restlessness / Agitation**
  - e.g. Midazolam 2mg SC as required
  - Lorazepam 500 microgms SL as required

- **Respiratory secretions**
  - e.g. Hyoscine Butylbromide 20mg SC as required
DNA CPR - practicalities

• Decision making
  • Is CPR realistically likely to succeed?
    • Population that we are considering
    • Facilities available
    • People available

• Communication
  • Patients home
    • Patient
    • Family / loved ones
    • OOH Services
    • Scottish Ambulance Service
DNACPR – key points

- The decision to offer CPR is a medical one
- Nothing to do with ‘quality of life’
- If CPR is likely to be futile do not offer it
- If success not anticipated – inform patient
- If success anticipated - discussion needed
- Relatives should not be asked to ‘decide’ unless legally empowered to do so
- Communicate sensitively!
DN verification of expected death

- Competence - training of Registered Nurses
- Consider possibility of expected death
  - Anticipatory care planning
  - LCP
- GP completes form
- Communicate
  - In hours team
  - OOH services
  - Patient / family
Liverpool Care Pathway

• Who is it for?
  • Team decision / 2 of 4 criteria / nil reversible

• Initial Assessment & Goals
  • Medication
  • Awareness of situation

• Care Pathway

• Death

• Audit / Review / Reflection
Patient / Personal

• Preferred priorities of care
  • Place of care
  • Aggressiveness of treatment
  • Admission
  • Place of death
  • Who is to be involved
Patient / Personal

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

- Process
  - Gathering
    - Sensitive consultations & discussion
    - My Thinking Ahead & Making Plans
  - Recording
My thinking ahead and making plans

• What is important to me just now
• Planning ahead
• Looking after me well
• My concerns
• Other important things
• Things I want to know more about
• Keeping track (who helped me)
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  - How should it be done?
Process

• When should this be done?
  • At any time in life that it seems appropriate
  • Continuously
• Who should do it?
  • By anyone with an appropriate relationship!
• How should it be done?
  • My Thinking Ahead & Making Plans
  • Very carefully!!!
  • Write it down
  • Transfer it (ePCS)
  • Communicate
The ACP Checklist

• Capacity
  • Power of Attorney / Possible future problems?

• Have we considered
  • What is likely & what might happen to this patient?
  • Where the patient would like to be cared for?
  • CPR / DNACPR?
  • OOH information transfer (ePCS)

• Have we considered the possible need for
  • Anticipatory prescribing (Just in Case)
  • RN Verification of Expected Death
  • The Liverpool Care Pathway for the Dying

• The patient / carer view
  • My Thinking Ahead & Making Plans…
Palliative Care DES

• Decide who should be on it (see ACP / ePCS)

• EMIS
  • Add data via ePCS template
  • Then
    • Obtain consent
    • Add palliative review date
  • Then
    • Add to Palliative Care Register

• INPS / VISION
  • Do it ALL at once!
Palliative Care DES (2011–12)

- Patient cohort – patients on palliative care register
  - ACP & transfer to OOH medical service within 2 weeks
  - Payment based on percentage achieved
  - Capped c6.5/1000 patients
  - Payment (token!) for using LCP
Palliative Care DES (2012–13)

• Patient cohort – patients on palliative care register
• Level 1
  • ACP & transfer to OOH medical service within 2 weeks
    • Diagnoses
    • Consent
    • Review date
  • Payment per patient (£56)
  • Not capped
  • No payment for using LCP
Palliative Care DES (2012-13)

- Level 2
  - Significant Event Analysis
    - 1 per 1000/list
    - Malignant / non-malignant
    - Not on PC register
    - No ePCS
    - No DNACPR
    - Preferred place of care / death – met / not met
    - LCP used / not used

- Payment
  - £250 administration
  - £23/SEA (max 1/1000/list)