Harm Reduction using a Treatment Escalation / Limitation Plan
The Hospital ACP in NHS Lanarkshire

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Case study

- 64 year-old lady admitted with metastatic pancreatic cancer causing ascites. It is drained and percutaneous catheter is removed after 24 hours.

- Day 3: Sweaty and pale. Pulse 130, b.p. 70/50. NEWS was 5. Hospital Emergency Care Team was called.
Case study

- The Team decided that acute deterioration was probably due to sepsis, secondary to infected drain site.

- The Sepsis-6 protocol was initiated, including i.v. antibiotics and the insertion of a urinary catheter.

- The patient died 48 hours later.
What are the challenges that the HECT nurse faces?

What can / should be done?

What harms may have occurred?
Case study

- 64 year-old lady admitted with metastatic pancreatic cancer causing ascites. It is drained and percutaneous catheter is removed after 24 hours.
- Day 3: Sweaty and pale. Pulse 130, b.p. 70/50. NEWS was 5. Hospital Emergency Care Team was called.
- The Team decided that acute deterioration was probably due to sepsis, secondary to infected drain site.
- The Sepsis-6 protocol was initiated, including i.v. antibiotics and the insertion of a urinary catheter.
- The patient died 48 hours later.

The case illustrates:
- The pre-eminence of the curative medical model
- Prognostic uncertainty
- Lack of anticipatory care and crisis management planning
- Discontinuity of care
Moral distress

“\textit{I knew the patient was dying, but I could not find anything in the notes that said that escalation of treatment should be limited. I felt very unhappy about it, but the situation was urgent. I did what I had to do.}”

HECT nurse, WGH
Changes in risk-benefit ratio with advancing irreversible disease

- Satisfactory response to intervention
- Partial response
- Very limited response
- No response: futile
Changes in risk-benefit ratio with advancing irreversible disease

- Satisfactory response to intervention
- Partial response
- Very limited response
- No response: futile

RISK / BENEFIT RATIO
Non-beneficial (futile) treatments at the end-of-life: a systematic review

- 38 studies comprising 1.2m. subjects
- On average 33-38% of patients received non-beneficial treatments in the last year of life
  - Renal dialysis
  - Radiotherapy
  - Chemotherapy (last 6 weeks of life)
  - Blood transfusions
  - Cardiorespiratory support in ICU
  - I.V. antibiotics

Why non-beneficial (futile) treatments?
Why non-beneficial (futile) treatments?

- Survival instincts: personal ... or projected
- The death taboo
- Scientific materialism
- The pre-eminence of the curative “fix it” medical model: trained to treat
- The public appetite for “last chance medicines”
- The blame culture: death is someone’s fault
- Discontinuity of care: unfamiliarity, protocol driven interventions
Medical harms: a broader definition

**COMMISSION**
- OVER TREATMENT
  - Futile
  - Wasteful

**OMISSION**
- UNDER TREATMENT
  - Palliative Needs
  - Holistic Needs
Discontinuity of care in crisis management

- What is urgent is dealt with in isolation: the context of an acute event is often neglected.
- Limited treatment aims: to achieve recovery from the acute event.
- Default interventions are protocol-driven and may be indiscriminate.
- Risk versus benefit ratio is skewed: the risks of NOT intervening motivate inappropriate decision making by out-of-hours staff.
- Contributes to avoidable HARMS.
Harms associated with DNACPR

- Misunderstandings:
  - that success rate for CPR is high (in fact it’s only 18% overall)
  - DNACPR perceived to be a surrogate for withholding other treatments

- Discussions about DNACPR in isolation or out of context are difficult and distressing to patients, relatives and clinicians.

- CPR is about one intervention only; many others are much more relevant.
Hospital Anticipatory Care Plan

TREATMENT ESCALATION / LIMITATION PLAN, SUITABLE FOR PATIENTS WITH FRAILTY AND/OR MULTIPLE CO-MORBIDITIES

Other forms are available on FirstPort (At Point of Admission, Advanced Malignancy, Cardiology, COTE, Dementia, ICU, Liver Disease, Orthopaedics, Renal and Respiratory).

The Hospital ACP is indicated when one or more of the following applies:

- The patient is unstable with the possibility of deterioration.
- He/she has severe frailty and is completely dependent for ADLs / has progressive/terminal organ failure / multiple co-morbidities / advanced cancer.
- He/she has specific wishes regarding medical interventions.
- Treatment limitation in the event of a crisis / deterioration would be in the patient’s best interests and would avoid harm.

- Discussion with the patient and their family, welfare attorney or important others regarding this Plan is strongly advised. DNACPR discussions in isolation are potentially unhelpful. If a discussion is not possible, the HACP should be completed if it is in the patient’s best interests to do so, and it would be potentially harmful not to do so.
- Consideration should be given to the issue of mental capacity. The provisions of the AWI Act (Scotland) 2000 apply.
- An HACP should be completed prior to making an ICU or Palliative Care referral.
- Information in an existing ACP / KIS / Palliative Care Summary should be used.

An HACP must be used concurrently when a DNACPR order is being put in place

GOALS OF CARE It is often helpful to write down the treatment aims in your own words:

Immediately reversible problems should be addressed. Management should always include symptom control if the patient is in pain, nauseated, breathless or distressed.

TREATMENT ESCALATION / LIMITATION PREFERENCES

FOR FULL ESCALATION, INCLUDING CPR

<table>
<thead>
<tr>
<th></th>
<th>DO NOT ATTEMPT CPR</th>
<th>ESCALATE / LIMIT TREATMENTS using options below</th>
</tr>
</thead>
<tbody>
<tr>
<td>ROUTINE BLOOD TESTS</td>
<td>YES / NO</td>
<td>NIL BY MOUTH (if yes, document reason in Hospital Notes)</td>
</tr>
<tr>
<td>ABG ANALYSIS</td>
<td>YES / NO</td>
<td>PROCEDURES / INVESTIGATIONS (state)</td>
</tr>
<tr>
<td>IV ACCESS</td>
<td>YES / NO</td>
<td>PROCEDURES / INVESTIGATIONS (state)</td>
</tr>
<tr>
<td>IV FLUIDS (with time limit if appropriate)</td>
<td>YES / NO</td>
<td>PROCEDURES / INVESTIGATIONS (state)</td>
</tr>
<tr>
<td>SUBCUT. FLUIDS</td>
<td>YES / NO</td>
<td>PROCEDURES / INVESTIGATIONS (state)</td>
</tr>
<tr>
<td>IV A/BIOTICS (with time limit if appropriate)</td>
<td>YES / NO</td>
<td>PROCEDURES / INVESTIGATIONS (state)</td>
</tr>
<tr>
<td>ORAL ANTIBIOTICS</td>
<td>YES / NO</td>
<td>PROCEDURES / INVESTIGATIONS (state)</td>
</tr>
<tr>
<td>COMFORT FEED</td>
<td>YES / NO</td>
<td>PROCEDURES / INVESTIGATIONS (state)</td>
</tr>
<tr>
<td>BLOOD TRANFUSION</td>
<td>YES / NO</td>
<td>PROCEDURES / INVESTIGATIONS (state)</td>
</tr>
</tbody>
</table>
Is a TOOL designed:

a) to MINIMISE HARM due to overtreatment or undertreatment

b) to provide CONTINUITY OF CARE and GOOD COMMUNICATION especially out of hours.

c) to provide information about, as well as appropriate limitations to interventions which are likely to be FUTILE AND/OR BURDENSOME AND CONTRARY TO THE PATIENT’S WISHES. Interventions in these categories are UNETHICAL.

- To be guided by discussions with patient and family or POA.
- Does not provide for the withdrawal of any treatment.
- To be reviewed and modified as the clinical situation evolves.
Developing and implementing the TELP

<table>
<thead>
<tr>
<th>Ownership of the TELP pro forma</th>
<th>Responses in NHS Lanarkshire</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Input from, and adaptation for, each of the major clinical areas (n=12) e.g. A and E, Psychogeriatrics, Community Hospitals Test of change methodology prior to introduction of 2016 version. Further feedback for 2018 version</td>
</tr>
<tr>
<td>Safeguarding</td>
<td>Each <em>pro forma</em> sets out reminders of medico-legal, ethical and patient-centred aspects of TELP delivery</td>
</tr>
<tr>
<td><strong>Responses in NHS Lanarkshire</strong></td>
<td></td>
</tr>
<tr>
<td>-------------------------------</td>
<td></td>
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<tr>
<td><strong>Culture change</strong></td>
<td>Individual coaching for medical / surgical consultants (n=169) and SCNs (n=45) on the topics of treatment overuse, cognitive biases favouring non-beneficial interventions, prognostic conversations</td>
</tr>
</tbody>
</table>
| **Education** | Learn Pro module  
Customised TELP / HACP training video  
Routine training to HECT teams, FY1s (at induction) |
| **Other** | Incorporation into Structured Response to Deteriorating Patient *pro forma*  
Incorporation into Morbidity and Mortality review documentation |
TELP / HACP - video

https://vimeo.com/204400091/
Password NHS2017
Consultant coaching
NHS Lanarkshire 2016-7 (n=169)

Structured coaching exercise comprising ..... 

- Case study: extract from Ombudsman Report – illustrating discontinuity of care, poor communication, conflicted goals of care at EOL
- Abstract of academic paper on non-beneficial treatments
- Futility: reflection on personal cognitive biases
- Prognostic conversations – “what does the future hold?”
- Introduction to HACP
Futility in medical decision-making

Cognitive bias

- aversion to death and dying, “doom and gloom”
- intolerance of uncertainty, ambiguity
- personality traits … “I like to be a positive person”
- personal experiences … “last chance medicine”
- risk aversion (memorable failures, audits, criticisms and conflict)
- information bias
- time pressure
- moral self-justification for doing everything ... “last chance medicine”
The TELP study: methods

- Determination of “expected death” made for each case using Gold Standards Framework Prognostic Indicator Guidance (n=247, 85.5%)
- Identification of Non-Beneficial Treatments and Clinical Harms using Structured Judgement Review Method

289 case records available

300 consecutive deaths

- TELP & DNACPR: n = 155 (53%)
- DNACPR only: n = 113 (40%)
- Neither: n = 21 (7%)
The Structured Judgement Review Method
(Royal College of Physicians, London)

<table>
<thead>
<tr>
<th>Category</th>
<th>Description of ‘problem’</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Assessment, investigation or diagnosis</td>
</tr>
<tr>
<td>2</td>
<td>Medication / IV fluids / electrolytes / oxygen</td>
</tr>
<tr>
<td>3</td>
<td>Treatment and management plan</td>
</tr>
<tr>
<td>4</td>
<td>Palliative or end-of-life care</td>
</tr>
<tr>
<td>5</td>
<td>Operation/invasive procedure</td>
</tr>
<tr>
<td>6</td>
<td>Clinical monitoring</td>
</tr>
<tr>
<td>7</td>
<td>Resuscitation following a cardiac or respiratory arrest</td>
</tr>
<tr>
<td>8</td>
<td>Any other type not fitting into the categories above</td>
</tr>
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The Structured Judgement Review Method (example)

1A. Problem in assessment, investigation or diagnosis
(e.g. arterial blood gas sampling or CT scans that did not change management):
Yes (1) No (2) 1A

1B. Was the problem associated with non-beneficial intervention / treatment?
Yes (1) No (2) Possibly (3) 1B

1C. Did the problem lead to harm?
Yes (1) No (2) Possibly (3) 1C

Comments
## Incident Rate Ratios: all patients (n=289)

<table>
<thead>
<tr>
<th></th>
<th>HACP + DNACPR N=155</th>
<th>DNACPR only N=113</th>
<th>p</th>
<th>Neither HACP nor DNACPR N=21</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>‘Problems’</strong></td>
<td>1.00</td>
<td>2.05 (1.62 – 2.58)</td>
<td>&lt;0.001</td>
<td>1.78 (1.19 – 2.68)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Non-beneficial interventions</td>
<td>1.00</td>
<td>1.98 (1.48 – 2.64)</td>
<td>&lt;0.001</td>
<td>1.44 (0.83 – 2.50)</td>
<td>0.198</td>
</tr>
<tr>
<td><strong>Harms</strong></td>
<td>1.00</td>
<td>2.77 (1.96 – 3.92)</td>
<td>&lt;0.001</td>
<td>2.61 (1.50 – 4.55)</td>
<td>&lt;0.001</td>
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Lightbody et al. BMJ Open, 2018
Clinical ‘problems’, NBIs and harms
Lightbody et al. BMJ Open, 2018

Rate per 1000 patient days

P<0.001 for all within group comparisons
<table>
<thead>
<tr>
<th>Description of clinical ‘problem’ as per Structured Judgment Review</th>
<th>All patients N=289</th>
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<th>Neither TELP nor DNACPR N=21</th>
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<tr>
<td>1</td>
<td>Assessment, investigation or diagnosis</td>
<td>12.5</td>
<td>6.7</td>
<td>25.2</td>
</tr>
<tr>
<td>2</td>
<td>Medication / IV fluids / electrolytes / oxygen</td>
<td>19.5</td>
<td>12.6</td>
<td>33.9</td>
</tr>
<tr>
<td>3</td>
<td>Treatment and management plan</td>
<td>21.3</td>
<td>11.5</td>
<td>40.0</td>
</tr>
<tr>
<td>4</td>
<td>Palliative or end-of-life care</td>
<td>15.8</td>
<td>7.8</td>
<td>33.9</td>
</tr>
<tr>
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<td>Operation/invasive procedure</td>
<td>2.8</td>
<td>1.1</td>
<td>4.4</td>
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Rate of events per 1000 patient days
The real cost of NBIs and harms

- Patient and family harm / distress
- Hospital costs
- Moral distress among staff

The total cost of a “Bad Death”
Thank you