Good Life, Good Death, Good Grief

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www.chs.ed.ac.uk/gp/research/ppcrg.php
Last phase of life care

- What are the problems in this area?
- So why is this most important?
- What is our aim?
- What we are doing?
- How you might chose to succeed
5 key problems for end of life services

1. All illnesses
2. Earlier than later
3. All cultures
4. All settings
5. All dimensions
Profile of People who die

Europe 1900
Age at death 46

Top 3 causes
➢ Infectious diseases
➢ Accident
➢ Childbirth

• Disability before death
➢ Not much

Europe 2000
Age at death 78

Top 3 groupings
■ Cancer
■ Organ failure
■ Frailty/ dementia

Disability before death
➢ Months - many years
1. Primary care can deliver palliative care for all in need.

- **Organ failure**
  - Function: High to Low over Months or years

- **Cancer**
  - Function: High to Low over Weeks, months, years

- **Acute**
  - Function: High to Low over Many years

- **Dementia, frailty and decline**

GP has 20 deaths per list of 2000 patients per year.
Organ failure trajectory
Frailty trajectory
Challenge for specialist palliative care is how to get involved with generalists in a redesign process to care according to needs.

Number of deaths in each trajectory, out of the average 20 deaths each year per UK general practice list of 2000 patients:
- Cancer (n=5)
- Organ failure (n=6)
- Physical and cognitive frailty (n=7)
- Other (n=2)

Multi-morbidities normal

2 Integrating curative and palliative care earlier rather than later.

3. Meeting all dimensions of need

physical | psychological
---|---
social | spiritual

Grant E, Murray SA, Sheikh A. Spiritual dimensions of dying in different cultures. *BMJ* 2010;341:4859.
Spiritual needs

- Everyone has them if faced with a serious illness
- Accepted definition used internationally relates to meaning and purpose of life
- People may or may not use religious vocabulary
- Such needs may cause distress and increase medical demand

Murray SA, Kendall M, Worth A, Boyd K, Benton TF, Clausen H. 
Dying is a 4-D activity

What’s happening with respect to other dimensions of need?

Method: meta-synthesis

• Thematically analysed in-depth serial interviews as case studies longitudinally and then cross-sectionally from a number of studies.

• Identified the presence and characteristics of social, psychological and spiritual needs
Murray SA, Kendall M, Grant E, Boyd K, Barclay S, Sheikh A. Patterns of social psychological and spiritual decline towards the end of life. *J Pain Sympt Man 2007; 34: 393-402*

*His old friends won't even take a cup of tea with me now I've got cancer*” Mrs LR.
"living with uncertainty"

"It was like a black hole"

"It's much worse the second time round"

"You don't know what is going to happen to you, fear is the worst thing"

"great nurses and departments they are so caring"

Dyspnoea crises were multi-dimensional
Fluctuations of physical, social, psychological and spiritual wellbeing in **family carers** of patients with lung cancer

**Trajectories**

- Physical
- Social
- Psychological
- Spiritual

Wellbeing

Distress

Diagnosis  Return home  Recurrence  Terminal stage  Death

Awareness of these trajectories

- We can explain the likely course of the illness
- Patient and carers can understand what the future might hold
- We can plan timely 4-D care when needs expected, provide continuity through them
- Avoid futile physical treatment and expenditure

“The physician who can foretell the course of the illness is the most highly esteemed”. Hippocrates

Murray SA, Chinn DJ, Sheikh A  Access to psychological and psychiatric services needs to be improved for the dying  JRSM 2006;99(12):601
Potential of palliative care in all settings especially primary care

- Over 50% would prefer to die at home
- But in UK 20% of people die at home
May 2008

*BMJ* poll: What area in medicine should be prioritised to make the most clinical difference to most people?

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**Care for all at the end of life**

Scott A Murray and Aziz Sheikh

• Improve quality of life and death for people with progressive life-threatening illnesses
“Living and Dying Well”

National Action Plan for Palliative and End of Life Care in Scotland

Elizabeth Ireland

All Scottish Health Boards and Hospices are having to report
5 key problems for end of life services

1. All illnesses
2. Earlier than later
3. All cultures
4. All settings
5. All dimensions
Structure of changes

Short term working groups

Investment in services- 3 parts
• Identify more people for end of life care
• Needs assessment
• Communication with out-of-hours care

• Promoting a public awareness
2 Integrating curative and palliative care earlier rather than later.

Caring for people with organ failure: 3 stages

Stage 1  Physically well

Stage 2  Active supportive and palliative care

Stage 3  Terminal care

Sentinel events

Gold standards Framework

Care Plan

Liverpool Care Pathway

Death

When is a patient “palliative”? 

- Would you be surprised if Mrs A were to die within the next 12 months?
- Study in cardiology ward revealed that this question identifies 60 -70% of admissions
- Avoid “prognostic paralysis* ”

### Supportive & Palliative Care Indicators Tool

<table>
<thead>
<tr>
<th>1. Ask</th>
<th>Yes</th>
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<tbody>
<tr>
<td>Does this patient have an advanced long term condition and/or a new diagnosis of a progressive life limiting illness?</td>
<td>Yes</td>
</tr>
<tr>
<td>Would you be surprised if this patient died in the next 6-12 months?</td>
<td>No</td>
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<table>
<thead>
<tr>
<th>2. Look for One or More General Clinical Indicators</th>
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<tbody>
<tr>
<td>Performance status poor (limited self care; in bed or chair over 50% of the day) or deteriorating.</td>
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<tr>
<td>Patient has continued to lose weight (&gt;10%) over the past 6 months.</td>
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<tr>
<td>Patient has had two or more unplanned admissions in the past 6 months.</td>
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<tr>
<td>Patient is in a nursing care home or NHS continuing care unit; or needs more care at home.</td>
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<tr>
<th>3. Now Look for Two or More Disease Related Indicators</th>
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<tbody>
<tr>
<td><strong>Heart Disease</strong></td>
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<tr>
<td>NYHA Class IV heart failure, severe valve disease or extensive coronary artery disease.</td>
<td>Meets criteria for long term oxygen therapy (PaO₂ &lt; 7.3).</td>
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<td></td>
<td>Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment.</td>
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<tr>
<td><strong>Respiratory Disease</strong></td>
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<td>Severe airways obstruction (FEV₁&lt;30%) or restrictive deficit (vital capacity &lt; 60%, TLCO &lt;40%).</td>
<td>Persistent symptoms despite optimal tolerated therapy.</td>
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<tr>
<td></td>
<td>Neurological disease</td>
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<tr>
<td>Breathless or chest pain at rest or on minimal exertion.</td>
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<tr>
<td>Breathless at rest or on minimal exertion between exacerbations.</td>
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<tr>
<td>Persistent symptoms despite optimal tolerated therapy.</td>
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Community based: care frameworks

Steps:

1. Identify
2. Assess
3. Plan
Advance care planning interventions

• What’s the most important issue in your life right now?
• If things got worse, where would you like to be cared for?

Mr JR 79 yrs

- Emphysema
- Bilateral basal bronchiectasis
- Ischaemic heart disease
- Vascular dementia
- Panic attacks
- Frequent admissions
Why no further admissions?

- Identified for supportive/palliative care
- Decided he would rather stay at home when ill
- DNAR form signed and left at home
- Placed on practice “supportive & palliative care register”
- Classified as a “gold patient”
- Regular contact to provide ongoing support
- Sadly finally admitted to die
Midlothian Care Homes project
Hockley J, Watson J, Oxenham D & Murray SA. The integrated implementation of two end of life care tools in nursing care homes in the UK: an in-depth evaluation.


- Routine advance care planning from admission to care homes
- Increase in DNAR status documented from 8 to 71% in patients who died
- Reduction of nearly 50% (from 15% to 8%) of unnecessary admissions
- Interviewed bereaved relatives reported better care

Lothian Health Board
Introducing an electronic Palliative Care Summary: patient, carer and professional perspectives

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² Primary Palliative Care Group, Centre for Population Health Sciences, University of Edinburgh,

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Dr Peter Kiehlmann for commissioning and facilitating the study;
Electronic Palliative Care Summary

• Allows family physicians & Nurses to record in one place diagnosis, treatment, patients understanding & wishes,
• Anticipatory Care Plans, review dates
• Transmitted to out-of hours services and A&E units daily
• Continuity of information
Health promoting palliative care
National Health Service England

• “Dying matters”

Promoting general discussion about death and dying
Vision Scotland

• A society which deals with dying, and bereavement in a healthy and constructive way
• Death is seen as part of life
• The public and health and social care workers have awareness of the many ways in which communities and individuals can support each other
Aims

• Raise public awareness of ways of dealing with death, dying and bereavement

• Promote community involvement in death, dying and bereavement
Who We Are

• Good Life, Good Death, Good Grief is an alliance of organisations and individuals
• Hosted and resourced by the Scottish Partnership for Palliative Care
• Membership is free and open to all who support our aims
• A broad-based stakeholder group advises and shapes the work of Good Life, Good Death, Good Grief
Key Messages

• Being more open about death is a good thing
• Death is normal
• Thinking about death when you’re healthy means there is less to think about if you get sick
• We can all help each other with death, dying and bereavement
• Coming terms with your own mortality can help you to live life to the full
• There are things individuals and communities can actively do to help friends through difficult times relating to death, dying and bereavement

http://www.goodlifedeadthgrief.org.uk/
Cheers!
Service redesign: 4 main types of possible end of life developments to consider

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<th>Inside</th>
<th>Outside</th>
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<td>Sustaining innovation</td>
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<td>Disruptive innovation</td>
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Dying for change. Leadbeater C, 2010, DEMOS

Scott A Murray, May 2011