



Palliative Care Research: leading internationally and making a difference in Scotland

Scottish Cross Party Group, June, 2011

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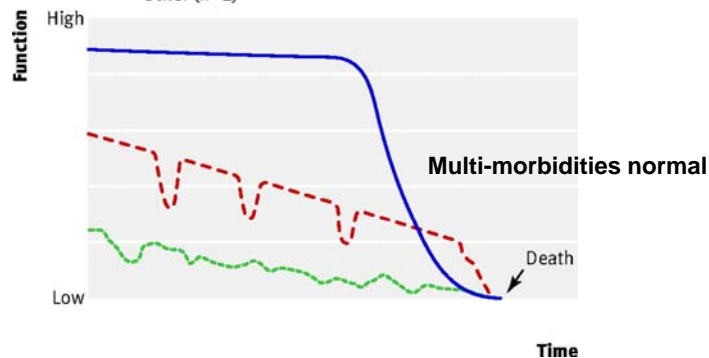


International Primary Palliative Care Research Group

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)



Murray, S. A et al. BMJ 2008;336:958-959

BMJ

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dimensions of need

physical

psychological

social

spiritual

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

More PhDs

- Barbara Kimbell - liver failure
- Elizabeth Sullnow - Health promoting palliative care (HPPC)
- Sally Paul - HPPC: schools and hospices
- Elizabeth Mukwanjaga- illness trajectories in Africa
- Julies Watson - dementia

Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies. Grant E, Brown J, Leng M, Bettega N, Murray SA
BMC Palliative Care 2011, 10:8doi:10.1186



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.

Palliat Med. 2010, doi: 10.1177/0269216310373162



- 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



Palliative care DES

- Well accepted by practices – helped them do what they wanted
- Patients and carers appreciated it
- Difficulty in identifying people as palliative –some doctors reticent
- Not using guidance e.g. PIG

Palliative care DES evaluation

- 29% of people on register before they die
 - 68% with cancer were on register at death
 - 20% with organ failure
 - 20% with frailty
- If on register, 25% chance of dying in hospital
- If not on register, 53% chance hosp death



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

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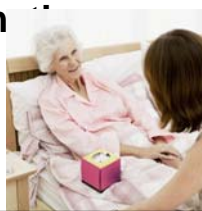
Acknowledgements

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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**



Recommendations

- All patients with any progressive advanced illness should have an ePCS completed in case they need care out-of-hours
- But currently completion of a ePCS only occurs after the patient is placed on the practice “palliative care register”, which is a complex consideration for primary care teams
- Out-of-hours staff should be made routinely and reliably aware of an ePCS where it exists and access these as a matter of course
- Training in ePCS completion and updating should be available for all GPs and community nurses
- Should GPs remain resistant to early identification of all palliative patients, consideration could be given to renaming the register to “supportive care register”

SPIC: supportive and palliative care indicator tool

Supportive & palliative care indicators tool		
1. Ask		
Does this patient have an advanced long term condition and/or a new diagnosis of a progressive life limiting illness?		Yes
Would you be surprised if this patient died in the next 6-12 months?		No
2. Look for one or more general clinical indicators		
Performance status poor (limited self care; in bed or chair over 50% of the day) or deteriorating.		
Patient has continued to lose weight (>10%) over the past 6 months.		
Patient has had two or more unplanned admissions in the past 6 months.		
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		
Heart disease	Respiratory disease	Cancer
NYHA Class IV heart failure, severe valve disease or extensive coronary artery disease.	Severe airways obstruction (FEV ₁ <30%) or restrictive deficit (vital capacity < 60%, TLCO <40%).	Performance status deteriorating due to metastatic cancer and/ or co-morbidities.
	Meets criteria for long term oxygen therapy (PaO ₂ < 7.3).	Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment.
Breathless or chest pain at rest or on minimal exertion.	Breathless at rest or on minimal exertion between exacerbations.	
Persistent symptoms despite optimal tolerated therapy.	Persistent symptoms despite optimal tolerated therapy.	Neurological disease



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	
Heart disease	Respiratory disease
NYHA Class III/IV heart failure, severe valve disease or extensive coronary artery disease.	Severe airways obstruction (FEV1 < 30%) or restrictive deficit (vital capacity < 60%, transfer factor < 40%).
Breathless or chest pain at rest or on minimal exertion.	Meets criteria for long term oxygen therapy (PaO2 < 7.3 kPa).
Persistent symptoms despite optimal tolerated therapy.	Breathless at rest or on minimal exertion between exacerbations.
Systolic blood pressure < 100mmHg and/or pulse > 100.	Persistent severe symptoms despite optimal tolerated therapy.
Renal impairment (eGFR < 30 ml/min).	Symptomatic right heart failure.
Cardiac cachexia.	Low body mass index (< 21).
Two or more acute episodes needing intravenous therapy in past 6 months.	More emergency admissions (> 3) for infective exacerbations or respiratory failure in past year.
Kidney disease	Liver disease
Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min).	Advanced cirrhosis with one or more complications:
Conservative kidney management due to multi-morbidity.	• intractable ascites
Deteriorating on renal replacement therapy with persistent symptoms and/or increasing dependency.	• hepatic encephalopathy
Not starting dialysis following failure of a renal transplant.	• hepatorenal syndrome
New life limiting condition or kidney failure as a complication of another condition or treatment.	• bacterial peritonitis
	• recurrent variceal bleeds
	Serum albumin < 25g/l and prothrombin time raised or INR prolonged (INR > 2).
	Hepatocellular carcinoma.
	Not fit for liver transplant.
	Cancer
	Performance status deteriorating due to metastatic cancer and/or co-morbidities.
	Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment.
	Neurological disease
	Progressive deterioration in physical and/or cognitive function despite optimal therapy.
	Symptoms which are complex and difficult to control.
	Speech problems with increasing difficulty communicating and/or progressive dysphagia.
	Recurrent aspiration pneumonia; breathless or respiratory failure.
	Dementia
	Unable to dress, walk or eat without assistance; unable to communicate meaningfully.
	Worsening eating problems (dysphagia or dementia related) - now needing pureed/ soft diet or supplements.
	Recurrent febrile episodes or infections; aspiration pneumonia.
	Urinary and faecal incontinence.
4. Assess patient & family for supportive & palliative care needs. Review treatment/	

CT 16/01/12, December 2013



Co-ordination at the end of life

- DOH funded
- Edinburgh, Kings, Warwick
- £480,000
- People who are probably in last year of life but get no specialist palliative care – cancer, organ failure, frail
- Lack of follow-up and continuity, lack of a palliative care approach

Service redesign: 4 main types of possible end of life developments to consider

	Inside	Outside
Sustaining innovation		
Disruptive innovation		

Dying for change. Leadbeater C, 2010, DEMOS