The Gold Standards Framework for end-of-life care in the community

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Our group’s vision

Is for better Palliative Care
- in the community
- beyond cancer.
- including spiritual aspect.
## Dying in developed countries: a century of Change

<table>
<thead>
<tr>
<th></th>
<th>1900</th>
<th>2000</th>
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</thead>
<tbody>
<tr>
<td><strong>Age at death</strong></td>
<td>46 years</td>
<td>82 years</td>
</tr>
<tr>
<td><strong>Top Causes</strong></td>
<td>Infection</td>
<td>Cancer</td>
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<tr>
<td></td>
<td>Accident</td>
<td>Organ system failure</td>
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<tr>
<td></td>
<td>Childbirth</td>
<td>Frail / Dementia</td>
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</tbody>
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GP has 20 deaths per list of 2000 patients per year

Acute

Organ failure

Cancer

Dementia, frailty and decline
Actual and predicted births and deaths in UK 1901 - 2051

http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/facts/UK/index20.aspx?ComponentId=7041&SourcePageId=14975
Choice—preferred and actual place of death

Preference for place of death

Where people with cancer die

Where people die—all causes

- Other
- Nursing home
- Hospital
- Hospice
- Home
How well do GPs deliver palliative care: systematic review

Patients appreciate GPs’ contribution
• As they listen, allowing ventilation of feelings
• Being accessible
• Basic symptom control

GPs deliver sound and effective pall care
• Best with specialist support
• Increasing exposure/formalised engagement
5 Key factors in enabling home death

Factors influencing death at home in terminally ill patients with cancer: systematic review.

Gomes, B and Higginson, I J. BMJ 2006: 515-518

1. Intense sustained reliable home care
   • Primary care working optimally,
   • Supportive care in the home
2. Self care - public education
3. Support for families and carers
4. Advance Care planning - risk assessment
5. Training practitioners
Caring for the dying in the community.

Acknowledgments to Dr Keri Thomas
National Clinical Lead for the GSF Centre
RCGP End of Life Care Clinical Champion
Senior Clin. Lecturer University of Birmingham

www.goldstandardsframework.nhs.uk
The Gold Standards Framework

A framework to deliver a ‘gold standard of care’ for all people approaching the end of their lives

A systematic approach to optimising the care delivered by generalist healthcare professionals
The Framework

• System developed by primary care for primary care

• Common sense approach

• Formalises the best standards of care into normal practice

• Builds on the good work that many are doing already
GSF - Why?

- **Patients** - improve quality of life in last year, in preferred place of care, with fewer crises
- **Carers** - feel supported, informed, involved, acknowledged, empowered
- **Staff** - increase in confidence, teamwork, communication, job satisfaction
A positive approach: allowing health promotion in the face of death

How can we make the best of the final months and years?

“Its all about living well until you die!”
The Key Tasks or 7 Cs

- Communication
- Co-ordination
- Control of symptoms
- Continuity out of hours
- Continued learning
- Carer support
- Care in the last days/week
C1 - Communication

• Palliative care register

• Regular primary care team meetings
  - Identify patients/carers
  - Assess and anticipate need
  - Plan care
  - Share information with team
C2 - Co-ordination

- Identify co-ordinator/lead nurse/lead GP
- Maintain “palliative care” register
- Organise multidisciplinary team meetings
C3 - Control of Symptoms

- Assessment tools
- Plan and review treatment
- Physical, psychological, social, practical and spiritual
C4 - Continuity

- Send handover form to out-of-hours provider
- Information to patients, carers, use of home pack
- Continuity with practice team
- Dovetailing with specialist palliative care services
C5 - Continued Learning

• Learn as you go

• Audit/review meetings

• Significant Event Analysis sessions

• Team identifies own learning needs
C6 - Carer Support

• Identify carers (carer register)

• Practical information

• Emotional and bereavement support
C7 - Care of the Dying

• Protocol checklist for care of the dying

• Anticipatory care

• Care Pathway eg Liverpool Care Pathway
3 steps of GSF

• **Identify** palliative care patients and use a register

• **Assess** physical, psychosocial and spiritual needs of patients (and carers)

• **Plan** ahead and share appropriate information across teams
Organ failure trajectory
Frailty trajectory
GSF “Prognostic” Indicator Guidance- identifying pts with advanced disease in need of palliative/ supportive care/for register

Three triggers

1. **Surprise question**- would you be surprised if the pt was to die within a year?

2. **Critical/events**- hospital admission, admission to care home?

3. **Clinical indicators** for each disease area eg Ca metastases, NY Stage FEV1, Karnowski, etc
Extract from the Prognostic Indicator Guidance, GSF

2. Organ Failure Patients

2.1 Heart Disease
- CHF NYHA stage IV - shortness of breath at rest
- Patient thought to be in the last year of life - the 'surprise' question
- Repeated hospital admissions with symptoms of heart failure

2.2 Chronic Obstructive Pulmonary Disease
- Disease assessed to be severe e.g. (FEV1 <30%predicted)
- Recurrent hospital admission exacerbations
- Long Term Oxygen Therapy Criteria
- MRC grade 4/5 - shortness of breath

2.3 Renal Disease
- Patients with stage 5 kidney disease who are not seeking or are discontinuing dialysis or renal transplant.
Appropriate care near the end of life: from disease modifying to active palliation.

Assess: possible questions


- Holistic assessment
- What’s the most important issue in your life right now?
- What helps you keep going?
- What is your greatest problem?
- You usually seem quite cheerful, but do you ever feel down?
- If things got worse, where would you like to be cared for?
Advance Care planning

- Advance Care Planning
  - Advance statement of Preferences
    - Formalize what patients and their family do wish to happen to them
    - Can be useful to clinicians in planning of patient’s individual care
    - Not legally binding
  - Advance Decisions to Refuse Treatment
    - Formalizes what patients do not wish to happen to them
    - Legally binding document
    - Related to capacity of decision making, Mental Capacity Act,
Why do it?

- Better planning
- Better provision of care and services to meet needs and preferences
- Preferred place of care/death - Home death rates
- Prevent inappropriate admissions/resuscitations
- Begin realistic dialogue
- Catalyst for deeper discussions
- Enhanced Communication
- Control - self determination
- Empowerment
- Dispel fear
- Hope

- What elements of care are important to you and what would you like to happen?
- If your condition deteriorates, where would you like to be cared for (first and second choices)?
- Do you have a view on resuscitation if your heart suddenly stops?
- This can engender hope rather than dissipate it.
GSF - Advance Care Planning

GSF template includes:

- **Thinking ahead** - open questions
  - what matters to pt/ carer
  - what to do and what not to do

- **Proxy** - who else involved (LPOA)

- **Who to call in a crisis**

- **Preferred place of care & death, options**

- **Other requests** eg organ donation / special instructions

- **+ DNAR / Allow Natural Death**
C7 Care of the dying pathway
http://www.mcpcil.org.uk/liverpool_care_pathway

- Initiate specific document
- All possible reversible causes have been considered
- Multi-disciplinary team confirmed patient is dying
- Non-essential meds stopped
- Write up prn Sub-cut med
- Communicate with relatives..................
GSF 3 Steps

1. Identify
2. Assess
3. Plan
1. GSF Primary care Spread most GP practices using GSF basic level 1

- **90%** practices GSF Level 1 (register and planning meeting)
  Mainstreaming through GP contract

- **60%+** practices using GSF in UK, covering almost 3/4 of the population (2 surveys)

- **15%** Estimated using GSF Level 4
Evaluation of GSF

Successes with using GSF

1. **Attitude awareness and approach** –
   - Better quality of care perceived
   - Greater confidence and job satisfaction
   - Immeasurable benefits- communication, teamwork, roles respected esp DNs
   - Focus + proactive approach,

2. **Patterns of working, structure/ processes**
   - Better organisation + consistency of standards, even under stress
   - Fewer slipping through the net- raising the baseline
   - Better communication within and between teams, co-working with specialists
   - Better recording, tracking of pts and organisation of care

3. **Patient Outcomes**
   - Reduced crises/ hospital admissions /length of stay
   - Some doubled home death rate- more pts dying in preferred place
   - More recorded Advance care planning discussions
Online After Death Analysis (ADA) Audit Tool

ADA measures patient outcomes eg place of death, preferences, use of services etc

1. Comparative - before and after
2. Benchmarking
Gold Patients!

- Patients know they are on the ‘gold’ register
- Implies best care
- Encouraging if heard no more can be done for them
GSF Care Homes Programme

- Over **600** nursing homes so far in UK

- Structured programme
  - 3 stages: Preparation, training, consolidation over 18 months
  - 4 gears, 4 workshops + homework
  - Facilitator training and support

- Fully resourced+ Locally facilitated

- Quality assurance- Accreditation process

- **Evaluation**—Improved quality of care,
  Decreased hospital admissions by **12%** ,
  Decreased hospital deaths by **8%**
Identification of need in Care Homes patients - GSFCH

Prognostic coding ABCD

A - All residents on admission - years
B - Benefits (DS1500) - months
C - Continuing care funding - weeks
D - Last days of life pathway - days
Overall conclusions

Clifford C. Badger F.
University of Birmingham

1. The GSFCH programme makes a positive difference to the quality of end of life care in Care Homes

2. Evidence of reduction of crisis admissions to hospital - changing place of death.

3. The ADA tool is a simple effective measurement tool for end of life care - ongoing benchmarking potential.
Using GSF can enable...

• Improved attitude, processes + outcomes
• Increase numbers dying where prefer
• Increase home death rate
• Decrease hospital death rate
• Improve collaboration + teamwork
• Improved knowledge + confidence of staff
• Contribute to better end of life care
This is about life before death

“Our aim is that every person should be able to live well and die well in the place and in the manner of their choosing”
Death is multi-dimensional

*His old friends won’t even take a cup of tea with me now*

*I’ve got cancer*” Mrs LR.

**Figure 1:** Physical, social, psychological and spiritual wellbeing in the last year of life

- Wellbeing
- Lung Cancer
- Distress
- Diagnosis
- Recurrence
- Return home
- Terminal Stage
- Trajectories
  - Physical
  - Social

**Figure 1**: Physical, social, psychological and spiritual wellbeing in the last year of life.

Wellbeing vs Lung Cancer trajectories:
- Physical
- Social
- Psychological
- Spiritual

Distress:
- Diagnosis
- Recurrence
- Terminal Stage
- Death

Return home
Murray SA, Grant E, Grant A, Kendall M. Dying from cancer in developed and developing countries; lessons from two countries. BMJ 2003: 326;368-71
Kenya

- Pain
- Peace

- We can learn about public awareness and community support

Scotland

- Little pain
- Angst

- We can go to help establish and train in pain control
Dr Fiona Godlee, BMJ Editor said:

- Care for non-malignant disease will now be prioritised by the BMJ publishing group over the coming years, by commissioning and inviting work in the BMJ Group's 24 specialist journals, in BMJ Clinical Evidence, Best Treatments, and BMJ learning."
Develop, evaluate and publish
Better end-of-life care
• in the community
• beyond cancer - PCFA
• including spiritual aspect
Shifting Terms

- **End of Life care**
  - 'Care that helps all those with advanced progressive incurable illness to live as well as possible until they die'
  - Pts living with the condition they may die from - weeks/months/years
  - All illnesses

- **Supportive Care**
  - Helping the patient and family cope better with their illness
  - not disease or time specific,'

- **Palliative care**
  - holistic care (physical psychological, social, spiritual )
  - specialist and generalist palliative care
  - Can overlap with curative treatment

- **Terminal care/ Final days**
  - Diagnosing dying-care in last hours and days of life