Improving Community Palliative Care in the UK using the Gold Standards Framework

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Greetings from England!
Plan

1. **Why** is improving community palliative care important+ context in UK?
2. **What** is the Gold Standards Framework?
3. **How** is it spread, used and measured?
4. **What next** - GSF developments
5. **What if**- Future vision -
   End of Life Care Strategic planning

www.goldstandardsframework.nhs.uk

1. **Why.** We are all involved ... get it right for when we might need it ourselves!

   The sun setting is no less beautiful than the sun rising.
Actual and predicted births and deaths in UK 1901 - 2051
http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/facts/UK/index20.aspx?ComponentId=7041&SourcePageId=14975

Why is this important?

Key Issues

1. **Increasing urgency**
   with demographic changes- baby boomers hit old age

2. **Care for ALL patients**
   1% population die/ year- 3 /4 people die of non-cancer -
   most die in hospitals- only 4% people die in hospices

3. **Current Lottery**
   Quality is variable and unreliable .

4. **Choice and equity**
   Half don’t die where they choose- control/ self
   determination- inherent inequities-inconsistencies

5. **Cost effectiveness and better patient outcomes**
   Too many crises, overuse of hospitals, unreliability and poor outcomes
Key Issues

6. **All are involved - Enabling Generalists - infiltrate all care**
   End of life care involves us all - need to come from other standpoints - 'palliative care approach'

7. **Home care is vital - most common location of pts - pivotal to other areas - 20% people die at home in UK**

8. **Care homes (RACF)**
   Improved coordination, decrease hospital overuse - 20% people die in care homes

9. **Better strategic planning for End of life care**
   First English National Strategy in End of Life Care

10. **More are catching the vision - Political imperative**
    "It's an idea whose time has come"

Palliative Care is at the next stage-
Dame Cicely Saunders
WHO 2004 'Palliative Care - The Solid Facts'

The next stage........
"The time has now come for the next stage........ the introduction of palliative care into mainstream medicine ......to give relief but also choice to each individual and family."
The Big Challenge
of the demographic time-bomb

How are we going to be able to care well for all people nearing the end of their lives in the future?

A different approach...the 1% Rule.

1% population die each year ~600,000/yr/England

Every GP has about 20 patients who are in the last year of life...

....how can we make the best of this last year?

"It's all about how you live"
Three ways of dying
Rapid, erratic and slow dying trajectories - After Lynn

- Rapid eg Cancer
- Erratic eg Organ Failure
- Slow eg Dementia, frailty

Sudden death / Other

GP has about 20 deaths / year

Choice - preferred and actual place of death

- Preference for place of death
- Where people with cancer die
- Where people die - all causes
Outcomes and Cost

OUTCOMES
• NOW- about 50% not dying where they choose
• Many die poorly
• Weighted towards cancer patients- more die of HF+COPD

COST
• Overspending on hospitals and unwanted treatments
• 30% rise in costs if stay same

CONCLUSION
• With better planning and prevention of crises more could be expected to die at home/where they choose
• Focus on community care and reduction of hospital admissions

NHS Policy Context of Palliative and End of Life Care Developments

• NHS Ca Plan +palliative care investment £50m
• NICE Guidance -2003
• Cancer Services Collaborative support for GSF and the Liverpool Care Pathway (LCP) 03
• NHS End of Life Care Programme (EoLC) 05
• The first National EOLC Strategy in England due Autumn 07
• Changing landscape of NHS
Clarification of 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 3 types of pt (cancer, organ failure, frail elderly, dementia pts)
  - ‘Ante-mortal’ care like ante-natal or early life care

- **Supportive Care**
  - Helping the patient and family cope better with their illness
  - Not disease or time specific, ‘less end stage’

- **Palliative care**
  - Holistic care (physical psychological, social, spiritual)
  - Specialist and generalist palliative care
  - Some regard as overlapping or following curative treatment

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

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Enabling more dying people to remain at home
Thorpe’s Paradoxes

Thorpe BMJ 1993:307.915-8

**First Paradox**
Most dying people would prefer to remain at home but most of them die in institutions.

**Second Paradox**
Most of the final year of life is spent at home but most people are admitted to hospital to die.

*Reasons for admission*
- **carer breakdown**
- **symptom control**
How well do GPs deliver palliative care: systematic review  

GPs’ contribution pts appreciate
• being listened to, 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
The reality....Mr B
79 yr old cancer/ HF pt + co-morbidities

- Increasing crisis admissions to hospital
- Deteriorating- symptoms worsening
- Ad hoc visits -no future plan discussed/ACP
- Wife struggling to cope unsupported
- No life closure discussions,DS1500, respite etc
- Worsens at weekend - calls 999-Paramedics attend
- A&E- 8 hour wait on trolley
- Admitted to hospital-dies on ward- alone
- Wife given little support in grief
- No reflection by teams
- ? Inappropriate use of hospital

Fail on .....  
1. Pt Outcomes  
2. Cost effectiveness

"Why are we leaving it to luck?"

“What will we need when we have to live with a fatal disease?
We need reliability, a care system we can count on- doing the RIGHT thing at RIGHT time
This is too important to be left to luck.” Joanne Lynn

We must develop something 
that reduces the element of luck

“Be the change you want to see”
2. What is 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

Background to GSF

- Developed from primary care for primary care
- Palliative care really matters to GPs and DNss
- ‘7th c’ based on LCP for dying

- GSF Support Programme -7 years – supporting 200 facilitators across UK- 11 phases of programme

- GSF Care Homes developed 3 years ago-now Ph4
GSF is about...

- Get behind peoples motivation
- Optimising care provided
- Enabling and affirming Generalists’ home care
- Pre-planning care
- Adaptable framework using well used tools and resources to kick-start
- An ethos that this is important, we do it well but we can do it better

Head Hands and Heart

HEAD
- knowledge
- clinical competence
- ‘what to do’

HANDS
- process/organisation
- systems
- ‘how to do it’

HEART
- compassion/care
- human dimension-‘why’
- experience of care
1 The Gold Standard

One gold standard of care to aspire to, for all people nearing the end of their lives, whatever their diagnosis stage or setting.

GSF 1, 3, 5, 7

GSF 3 Steps: ......then provide

1. Identify
2. Assess
3. Plan
+ communicate
5 Goals of GSF

Patients are enabled to live well and die well in the place and in the manner of their choosing

1) Symptoms controlled
2) Preferred place of care
3) Safe + secure with fewer crises
4) Carers feel supported, involved, empowered, and satisfied.
5) Staff confidence, teamwork, satisfaction, co-working with specialists and communication better.

7 Key tasks

C1 Communication
SC Register, PHCT Meetings, PHR /care plan
Advanced care planning (ACP) eg PPC

C2 Coordination
Identified coordinator for GSF, keyworker for patient

C3 Control of Symptoms
Assessment tools, body chart, SPC, ACP

C4 Continuity Out of Hours
Handover form + OOH protocol

C5 Continued Learning
Learning about conditions on patients seen, SEA / reflective practice

C6 Carer Support
Practical, emotional, bereavement, National Carer’s Strategy

C7 Care in dying phase
Protocol LCP / ICP
Hope for the best but prepare for the worst!

GSF Supported Spread Cascade

National team

SHA, Ca Network

GSF Project group

Facilitators

Co-ordinators
GSF- 7 yr Support + training
Programme + Evaluation

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<th>Programme</th>
<th>National Policy Support for GSF</th>
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<td>PHASE 1</td>
<td>• Royal College of GPs</td>
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<td>• National Council for Palliative Care</td>
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**GSF Spread UK wide**
- most GP practices using GSF basic level 1

Overall- almost 65% practices using GSF in UK, covering almost 3/4 of the population (largely unpaid)

England - over 4000 practices registered with GSF Programme (50%)  
Scotland-GSFS project-750 practices-(75%)  
Mainstreaming through GP contract (QOF)  
Estimated 85-90% say using GSF Level 1

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**Why use GSF ?**

1. Spread- extensively used  
2. Evidence base of effectiveness  
3. Policy support  
4. Experience of GSF  
5. Available
3. How to do GSF?

1. Agree to undertake GSF programme + Register
2. Work with local facilitator (trained and resourced)
3. Receive materials, guidance, DVDs
4. Measure- baseline and follow up measures (ADA)
5. Set up register and meeting (level1)
6. Deepen levels so becomes mainstream (levels 2-4)
7. Extend to other areas - optimising home care becomes part of EOLC Strategy
8. Become an accredited/ beacon practice- TBC

Step by step developments

Accreditation
Embed
Audit, Protocol
C6,7
C 3,4,5
C1,2
Supportive Care register templates

How does it work?

- Raising awareness
- Practical change in processes - 'system redesign'
- Enables with tools and resources
- Increases confidence of staff
- Raises baseline- increases consistency and reliability - fewer 'slipping through the net'
- Improves communication and documentation
- Pre-planning of care underpins it
- Needs based care- right care at right time
- Encourages ownership and creativity
Three Work Streams of GSF

- Primary care
- Care Homes
- EOLC Support

a. The Gold Standards Framework in Community Palliative Care

The Aim for Primary Care teams:
to develop a practice-based system to improve the organisation and quality of care of patients in the last year of life in the community.

So generalist better dovetail skills with specialists
b. The Gold Standards Framework in Care Homes Programme – (RACF)

“The biggest palliative care initiative in care homes so far”

- Based on GSF Primary Care
- New fully adapted model for care homes since 03
- Phased 3 stage programme 1-2 yrs
- Over 400 nursing homes so far
- Quality assurance- accreditation process developing

The Gold Standards Framework in Care Homes Programme

Goals
1. To improve the quality of end of life care
2. To improve collaboration with primary care and palliative care specialists
3. To reduce numbers of hospital admissions and increase home deaths
GSFCH Care Homes Programme

- Structured programme over 1-2 years
  - 3 stages - Preparation, training, consolidation
  - 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%

- See Briefing Paper and DVD

c. End of Life Care Support

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<td>GSF Children</td>
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<td>1. Use of GSF by Primary Care Team</td>
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SO WHAT!

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
Comments from GPs
"its important stuff"

• “It puts me back in touch with the reason I came into medicine!”

• “The investment is relatively small but the pay back is great-we need this work. It is readily achievable for GPs, whereas many things are difficult or irrelevant. It is important stuff!”

• “we work better as a team -this is having a real impact in a quiet way on our patient care Macmillan nurses come in and we are working better with them now.”

• “Overall care feels better, more holistic, more patient centred. … Patients really need us at this time We are enjoying this aspect of our care more than we did.-we can make a real difference here.”

Research studies related to GSF

• Phase 1 Thomas K Noble Pall Med 2007 21:49-53
• Phase 2 King N Thomas K Pall Med 2005;19:619-27
• Phase 3-6 Warwick Uni- GSF evaluation in primary care 2000 practices- Dale etc paper in press
• Editorial Munday Dale BMJ 2007 334(7598)809-810
• Phase 7-11 Birmingham Uni- evaluation in primary care Phase 7-10(05-07) Shaw et al in press
• Others Manchester Uni 05 Todd, Edinburgh Uni- GSFS Qualiatiative study of impact on patients

• GSF in Care Homes Ph2 study EJPC Clifford et al Birmingham
• ADA- Walsall PCT study Birmingham Uni Clifford et al
• Cost effectiveness ADA- Walsall PCT
• Paediatrics -use of GSF - Bham Uni
• Local GSF audits- + case histories
What if ....Mr B

Current

- Increasing crisis admissions to hospital
- Symptoms worsening
- Ad hoc visits - no future plan discussed
- Wife struggling to cope unsupported
- No life closure discussions, DS1500, respite etc
- Worsens at weekend - calls 999, Paramedics attend
- A&E - 8 hour wait on trolley
- Admitted to hospital - dies on ward - alone
- Wife given little support in grief
- No reflection by teams
- ? Inappropriate use of hospital

Ideal

- Identification and Planning PIG
- Regular support + Collaboration with primary care - GSF
- Support at home - H@H / Homecare team
- Self/ Carer support - GSF + expert pt
- Advanced care planning ACP
- Handover form and crisis prevention
- Crisis Admission averted LTC
- Hi quality routine inpatient care SCP
- Dies at home/ hospital ICP/LCP
- Bereavement care + SEA by team GSF
- Better outcome for patient, family
- Most cost effective + best use of NHS

Gold Patients!

- Patients know they are on the 'gold' register
- Implies best care
- Encouraging if heard no more can be done for them
But...... reality check

- Variably implemented - inconsistency
- Takes some time and energy
- Sustaining innovations
- Working as a team
- Patient expectations
- Meetings + paperwork
- Hard to measure patient outcomes


**Tools**
- Prognostic Indicator Guidance
- Advanced Care Planning
- After Death Analysis
- Needs / Support Matrix
- Patient leaflets
- OOH 'Just in Case' boxes

**Areas**
- International spread
- End of life strategic planning
- Extension to other areas - hospitals in-reach, children
- GP contract-QOF, LES + levels of adoption
- Accreditation
- Admission Avoidance + commissioning
**GPs paid to do GSF Level 1 GP Contract**

**Mainstreaming GSF Level 1 Quality Outcomes Framework (QOF)**
- 3 points for palliative care register - includes non-cancer
- 3 points for Multi Disciplinary Team meeting

**GSF Team wrote guidance for GMS**
- Prognostic Indicators Guidance, Brief QOF Guidance flyer, Full QOF guidance paper with Read codes and templates

Work on QOF revision 08

**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 1 year

2. **Patient preference** for comfort care/need

3. **Clinical indicators** for each disease area
   - eg Ca metastases, NY Stage
   - FEV1, Karnowski, etc
Identification and prediction of likely need

Prognostic coding ABCD
- A - years
- B - months
- C - weeks
- D - days- (LDP)

Reframe-
'hope for the best, prepare for the worst'

Needs Support Matrix

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<tr>
<th>Pt needs</th>
<th>Support from hospital/SPC</th>
<th>Support from GP</th>
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<tr>
<td>Years</td>
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Advance Care Planning

Advanced Statement
- Formulate 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 and may also need Advanced Directive and DNAR

Advanced Decisions
- Formalizes what patients do not wish to happen to them
- Legally binding document
- Related to capacity of decision making, Mental Capacity Act, Living Will etc.

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
Other areas

Patient Information

Out-of-Hours drug boxes

In-reach to hospital

GSF Children

Online After Death Analysis (ADA) Audit Tool

- Diagnosis + Cause of death
- Place of death
- Length of Stay in Care Home
- Hospital stay in last 6 months
- Crisis Events in last 6 months
- Crisis admissions in last 6 months
- Advanced care plan
- PRN drugs listed
- Last days pathway
- Written information to family
- Quality of Care
- Comments
**International GSF partnerships**

*Being used in / enquiries / visits from:

- Canada
- USA
- Australia
- Sweden
- Belgium
- Portugal
- Malta
- Cuba
- New Zealand
- + others

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**How to best use GSF programme in Australia??**

1. **Plan pilot** - national / local area - appoint local facilitators
   - National support - reduce barriers for GPs + ? incentivise

2. **Work with us** - agreement for adapted GSF programme with Central Team - Receive training, materials, guidance, DVDs - Use accreditation process

3. **Try it** - baseline and follow-up measures (e.g. ADA) - follow step by step - deepen levels - adapt as needed so best Aussie fit

4. **Spread + mainstream** to other areas - use in RACF? - becomes part of EOLC Strategy
5. What if.....
We could reduce the element of luck!

We could ensure good care
for all people at the end of life
in all settings, with any diagnosis,
as standard practice
and not as a matter of good luck?

A gold standard for all.....

Supportive Care Framework
for all patients nearing the end of life

Diagnosis

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<td>Home/ Hospice/Care Home/ Hospital</td>
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Death
NHS End of Life care strategy- a daunting prospect!

GSF is part of the jigsaw

GSF is part of the jigsaw to enabling reliable high quality proactive end of life care for all.

©Michele Angelo Petrone
Take Home messages

1. Think big and work together. The challenge of end of life care is too big to do alone - need optimal working of generalists and collaboration with specialists.

2. Focus on generalists and community palliative care. Palliative care provided by GPs is important and can be excellent.

3. GSF - can use system to optimise care eg GSF - has been piloted, spread and mainstreamed in the UK - can make a real difference. Keen to partner others.

4. Catch the vision! This can be a building block to meet the challenge of End of life care in future.

This is it!
Companions on the Journey

“You matter because you are you.

You matter to the last moment of your life.

And we will do all we can not only to help you die peacefully, but to help you live until you die”

Dame Cicely Saunders

Thank you Australia!

www.goldstandardsframework.nhs.uk
keri.thomas@btinternet.com