Context and challenges in health and social care
Our experience from The GSF Centre in End of Life care

Prof Keri Thomas, Maggie Stobbart-Rowlands, Mark Thomas
National GSF Centre in End of Life Care
Values and the Culture of Compassion
Stafford Uni Jan 14th 2014

www.goldstandardsframework.org.uk • info@gsfcentre.co.uk
Context and challenges in health and social care

• Current context
  – of growing medicalisation, aging population and tightening funding
  – Increasing need and demand
  – NHS changes- CCGs etc

• Political and Policy reports
  – Frances report , Neuberger, Berwick
  – Political emphasis – Hunt, Lamb

• Challenges -focus on compassionate care
Values and the Culture of Compassion in End of Life Care

In light of CQC reports 2012, Jeremy Hunt said…

“The unacceptable has become the norm… the quality of care is as important as the quality of treatment…we must ensure everyone is treated in a decent humane way”

How can GSF help as part of the solution…?
Compassion fatigue

It CAN be tough to find the time to listen. But listening makes an enormous difference.

...so then I was 17, and I went to see...
Compassion

Compassion - ‘feeling/ suffering with...’

“The patient I care for – they may not remember my name but they certainly will remember how I made them feel”
Compassion

• Compassion is the keen awareness of the interdependence of all things. --Thomas Merton

• Compassion is the ultimate and most meaningful embodiment of emotional maturity--Arthur Jersild

• Compassion is not a moral commandment but a flow and overflow of the fullest human and divine energies. Matthew Fox

• The world has changed. It is no longer we and them- that concept is out of date - we are all part of we. Our interests are interdependent. --H.H. the Dalai Lama
The Complexity of Compassion

Need compassion for a very tricky brain.

Mindful Brain

New Brain: Imagination, Planning, Rumination, Integration

Old Brain: Emotions, Motives, Relationship Seeking-Creating

COMPASSION

Paul Gilbert
www.Compassionatemind.co.uk
Care for the dying …and the living
GSF- Improving End of Life Care

Head Hands and Heart

Knowing

HEAD
Evidenced-based knowledge, clinical competence
‘what you know’

HANDS
Systems minded care coordination
‘what you do’

HEART
person-centred compassionate care
‘the way you do it’

caring/ being
Compassion in...

Doing – collective

- Doing it right- The right care, for the right person, in the right place, at the right time, every time
- Thinking Ahead- Predicting needs before aware of them
- Compassionate people, organisations, communities and society
Compassion in…

**Being – connected**

- Connected with ourselves, our inner lives, deep connection
- Being connected with others - ‘empathy’ feeling with, team support
- Being - caring + present more than words
- Being human - the space between people
- Environment
How to nurture compassion?

- Recognising the value of the spiritual/inner life
- Mindfulness
- Prayer / Meditation
- Reflective practice
- Valuing kindness
- Recognising conflicting demands
- People- team support
- Space, place
- Time
Horizontal
practical care
-doing

Vertical-
deep level
-something other
-being

Holistic
Whole person care
Resilience

- Latin - Resilio to rebound, leap back
- Concept of
  - rebound/reform
  - plus to grow from the experience
- Enables growth
- ‘Realistic hope’
- ‘Hold the pain until you’ve learnt the lessons’
- Nurturing resilience in our patients… and in ourselves
Improving End of Life Care

Head Hands and Heart

knowing

**HEAD**
Evidenced-based knowledge, clinical competence

‘what you know’

doing

**HANDS**
Systems minded care coordination

‘what you do’

**HEART**
Person-centred compassionate care

‘the way you do it’

caring/ being
‘Heart care’

• Values and making meaning
• Empathy/compassion
• Spiritual care
• Attitude-Person-centred care
• Dignity/respect
• Changing culture
• Quality of care

• Being fully human
Making sense

“Spirituality is about what we do with our pain—
we can either transform it or transmit it.”

Fr Richard Rohr
Centre for Action and Contemplation

Pain can be useful

Your pain is the breaking of the shell around your understanding
The Prophet Kahil Gibran
• Being –
  • Quiet mind - I am here and paying you full attention - are you distracted?
  
  • Open heart –relating to the person - I care deeply
  
  • Connecting – touch, smile, fewer words, not them and us - just we - being human
GSF Accreditation for Care Homes
Standard 19 Spiritual care

Recognition of the inner life of residents and awareness of their spiritual / religious needs and their core values

Evidence

• Examples of awareness of the inner person, and affirmation of their core values
• Recognition of their individual journey of faith or means of understanding
• Recognition of any matters of cultural significance
GSF Spiritual Care Course

- Collaboration with Stafford University
- Distance Learning + Workshop – ‘blended’

- Aims to build confidence in delivering spiritual care to those approaching the end of life,
- and to help develop the inner resources we need to give care with compassion

- Pilot in care homes
GSF Spiritual Care Course

4 modules

1. What is spirituality – inner life and outer compassion, humanity mortality
2. Spiritual assessment + advance care planning
3. Relationships religion and ritual
4. Resilience and hope, living and dying well
Connectedness

“Spirituality is not primarily about saying the right words or even believing the right thing but its about connectedness”
Compassion in…

**Being – connected**

- Connected with ourselves, our inner lives, deep connection
- Being connected with others - ‘empathy’ feeling with, team support
- Being -caring + present more than words
- Being human- the space between people
- Environment

**Doing – collective**

- Doing it right- The right care, for the right person, in the right place, at the right time, every time
- Thinking Ahead- Predicting needs before aware of them
- Compassionate people, organisations, communities and society
Our Experience at The National GSF Centre in End of Life Care

The leading EOLC training centre enabling generalist frontline staff to deliver a ‘gold standard’ of care for all people nearing the end of life

The right care, for the right people, in the right place, at the right time… everytime
We provide
• Training programmes
• Tools + resources
• Measures
• and support

Leading to
• Quality improvement
• Quality assurance
• Quality recognition

enabling a ‘gold standard’ of care for all people nearing the end of life
GSF Training Programmes  

**Quality improvement**

**GSF Primary Care** - 95% Foundation Level (8,500 practices)
1. From 2000 - Foundation GSF mainstreamed (QOF)
2. From 2009 - Next Stage GSF ‘Going for Gold’ training programme
Round 1 GP practices accredited Nov 2012, Round 2 2013

**GSF Care Homes** - 2300 care homes trained
From 2004  Comprehensive training and accreditation programmes
200 / year accredited – recognised quality assurance
Many re-accredited annually – recognised by CQC and commissioners

**GSF Acute Hospitals** – 40 acute hospitals
2008 -Phase 1 pilot 15 hospitals + Improving cross boundary care
2011- Phase 2 9 hospitals, 2012- Phase 3 –8 ,Phase 4 -8
Accreditation in development – some whole hospitals,

**GSF Domiciliary care** – 300 care workers
Phase 1-Manchester, West Mids SHA, Rotherham + others
Phase 2- Train the trainers 6 modular distance learning programme

**GSF Community Hospitals** - 42 community hospitals
Phase 1 - December 2011 - Cornwall & Dorset-14 each
Phase 2 Summer 2013 - Cumbria

**GSF Dementia Care**- 60 candidates
Phase 1 Pilot programme complete 2013 – evaluations underway
Now 8 GSF Regional Centres

Current
1. St Christopher's Hospice
2. South East Coast
3. Dorset
4. Locala, Huddersfield

NEW GSF Regional Centres from 2012/3
1. St Frances Hospice Romford
2. Princess Alice Hospice Esher
3. North London Hospice
4. Worcester
GSF International

- Australia - Tasmania + Adelaide GSF Care Homes Centre,
- Also Canada, New Zealand, Belgium, Portugal, USA, Singapore, Holland, Japan + others

New GSF programmes in

- Integrated cross Boundary Care
- GSF IT Solutions
- Hospice support
- Clinical skills
GSF Accreditation - **Quality Assurance**

**GSF Five Standards**

- **Right person** – identifying the population, communicating this to others
- **Right care** – assessing needs, preferences and care required + providing services
- **Right place** – reducing hospitalisation enabling more to live and die at home
- **Right time** – proactive planning, fewer crises, predicted care in final days of life
- **Every-time** – consistency of practice

**GSF Accreditation for** care homes, primary care, community hospitals, acute hospitals
Quality Recognition

• Experience with Regulator- Care Quality Commission CQC
• CQC changes from April 2014 – especially in hospital where EOLC one of key areas to be inspected
• Aligning with GSF standards
• Helping to drive up standards
Alan Rosenbach CQC
1. First Stage - Foundation Level

Most (95%) GP practices in UK using GSF - QOF Foundation Level - having a register and a meeting

BUT…National Primary Care Snapshot Audit 09/10
Every death Feb March 09 in 502 practices, 4500 pts
- 25% patient deaths on register only
- 25% non-cancer patients on register
- Of those on a register - better coordinated care

2. Next Stage GSF - ‘Going for Gold’
Practice based Distance Learning - move to Accreditation Level
Over 300 practices - first wave accreditation - Nov 12
GSF Accredited GP Practices - case study

“We've changed the culture of how we practice and ..when we look back on the way we practiced before, it seems very old fashioned and unsatisfactory”

Karen Chumley
Essex GP

“We look after the whole population of our elderly patients much better now- much more proactively”
GSF Care Homes
Training and Accreditation

“the biggest, most comprehensive end of life care training programme in the UK”

Training
Over 2300 care homes trained
- About 12 projects / year
- Almost 50% nursing homes

Accreditation
Up to 200 /year accredited
Externally recognised
- Supported by NCA ECCA etc.
- CQC recognition
- Evidence base showing significant reduction in hospitalisation

Vision of national momentum of best practice
# Case Study - Comparison of place of death across SE London nursing homes [2007 to 2012]

Care Home Project Team, St Christopher’s Hospice

<table>
<thead>
<tr>
<th>Year</th>
<th>Percentage</th>
<th>Number of Deaths</th>
<th>Number of NHs</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007/2008</td>
<td>57%</td>
<td>324</td>
<td>19</td>
</tr>
<tr>
<td>2008/2009</td>
<td>67%</td>
<td>989</td>
<td>52</td>
</tr>
<tr>
<td>2009/2010</td>
<td>72%</td>
<td>1071</td>
<td>53</td>
</tr>
<tr>
<td>2010/2011</td>
<td>76%</td>
<td>1375</td>
<td>71</td>
</tr>
<tr>
<td>2011/2011</td>
<td>78%</td>
<td>1351</td>
<td>71</td>
</tr>
</tbody>
</table>
GSFAH Programme

- Pilot 2010-11 Phase 1+2 - 24 hospitals
- Phase 3 - 8 hospitals - several whole hospital
- Phase 4 - 7 hospitals

- Defined Foundation and Enhanced levels
- Developing accreditation process for 2014/15

- Improved communication with primary care and cross boundary care

GSFAH Phase 2 Independent Evaluation

- Decrease length of stay 6 days
- Better communication with GPs
- Better integration with community
- Earlier recognition of decline by staff
- Greater staff confidence
- More patient views sought (ACP)
Improving quality of care and saving costs
The possible ‘win-win’ in EOLC – our GSF Experience

1. Quality of care - *Attitude awareness and approach*
   - Better quality patient experience of care perceived
   - Greater confidence, awareness, focus and job satisfaction

2. Coordination/Collaboration - *structure, processes, and patterns*
   - Better organisation, coordination, communication & cross-boundary care

3. Patient Outcomes – *hospitalisation, ACP alignment*
   - Reduced crises, hospital admissions, length of stay e.g. halve hospital deaths
   - Care delivered in alignment with patient and family preferences
Integrated Cross Boundary Care

HOME

GSF Primary Care and Domiciliary Care

CARE HOME

GSF Care Homes

HOSPITAL

GSF Acute Hospitals

Phase 1 Demonstrator Sites – 2013
Vision of Integrated Cross Boundary Care
– care in alignment with preferences –

GSF ‘Heart of Gold’ projects

**Primary Care**
- Earlier identification of patients in final year of life
- Better provision + access to GPs and nurses
- Prioritised support for patient and carers + easier prescribing

**Gold Patients**
- Advance care plan – preferred place of care documented

**Care Home**
- ACP & DNAR noted and recognised
- Care homes staff speak to hospital regularly
- Referral letter recommends discharge back home quickly

**Others**
- Urgent care - Ambulance + out of hours care – flagged and prioritised
- Assessment & preferences noted

**Acute Hospital**
- GSF patient identified and flagged on system, registered
- Better discharge collaboration with GP using GSF register
- Readmission - STOP THINK policy and ACP
- Rapid Discharge

**Community Hospitals**
- Hospices

**Hospices**
- EOLC Strategic planning, Locality Register
- Domiciliary care using same coding and planning

**Putting Patients at the Centre of Care**

- Proactive planning of care
- Better assessment + ACP discussions offered

**The Gold Standards Framework**

- Better discharge collaboration with GP using GSF register
- Car park free and open
- Visiting

**EOLC**
- Strategic planning, Locality Register
What does being a GOLD patient mean to you?

- **G**ood communication
- **O**ngoing assessment of needs
- **L**iving well
- **D**ying with dignity in the place of choice

- Helps everyone communicate better
- Improved team-working and collaboration with colleagues in different settings
- Better listening to preferences e.g. Preferred place of care discussed and noted
- Advance care planning discussion offered
- Resuscitation (DNACPR) discussed and noted
- GP records on their register – quicker access and response
- OOH’s information sent by GP, so quicker response
- Helps keep at home + out of hospital where possible
- Better support for carers and family
- GSF Alert Flag on hospital system (PAS) if readmitted
- Quicker access to medication at home / hospital
- Open visiting / free parking
LETTER - Steve....... received the best imaginable care

- Sadly, in the 12 months since he broke his hip, he spent the majority of time in hospital. We encountered very variable care. Occasionally excellent, often average and sometimes clearly sub-standard. Undoubtedly, this variation was based entirely on people and never on environment.

- In these days of targets, numbers and measurable criteria in healthcare, one of the least quantifiable aspects of care is that of human input. When human beings care, the quality of care becomes excellent. What we have seen as exceptional at ....is this quality in all of the staff, all of the time.

- It is difficult to express how much comfort his family had from knowing that he was in such professional and caring hands in the last stages of his life.

- Thank you all for his exceptional care.
Teresa’s story

• In 2010 I was diagnosed with cancer of the womb and had a hysterectomy. I was supposed to have radiotherapy, I was afraid of the machine and so only had two treatments.

• Sherdley Court arranged for me to stay in Clatterbridge Hospital during the treatment but I was too afraid to have it done and came back to Sherdley Court.

• Sherdley Court is doing the Gold Standards Framework and this has helped staff understand how to help me plan my end of life care and make sure that I am as comfortable, pain free and surrounded by my friends and people who know me best.

• I have an advance care plan in which I have recorded my wishes to be cared for at Sherdley Court when I become very ill and also my wishes for my funeral.

• I love living at Sherdley Court, I have all my friends here with the residents and the staff. I know that I’m in the best place to be well cared for by people who love me and know me well.
Quotes

• “GSF has made my work simpler, drawn me closer to residents and relatives and given me the confidence in discussing end of life care” care home GSF Lead Nurse

• “GSF has been life changing for us, improving all aspects of care, not just towards the end of life” Care home manager
‘a gold standard of care’
Baroness Julia Neuberger
The sun setting is no less beautiful than the sun rising.
Changing the culture of care

Valuing compassion
Making space
We live in the context of our dying

Paradoxes reveal a hidden truth
Death teaches us about life
Dying teaches us about living
Our weakness is our strength
Pain can be our teacher

Dying brings life –
  life in all its fullness
Bigger picture – priorities
Meaning and making sense
Forgiveness and thankfulness
End of Life care
Companions on the Journey

We are not meant to walk this path alone
There is a fundamental need within our souls
To have companions on the journey as we move
Along this shared chronology of time

If we can be that good companion, that trusted friend
We will receive far more than ever we will give
The stark horizon throws our lives in sharp relief
And we will see our empty fears as nothing more than ghosts
The Emperor’s clothes will vanish from our sight
We are most human and yet still most divine

And we will hear within the inner whisper of our soul
That this is the reason we have come
Thank you and
Goodbye