

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

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National GSF Centre in End of Life Care
Values and the Culture of Compassion
Stafford Uni Jan 14th 2014**

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



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”

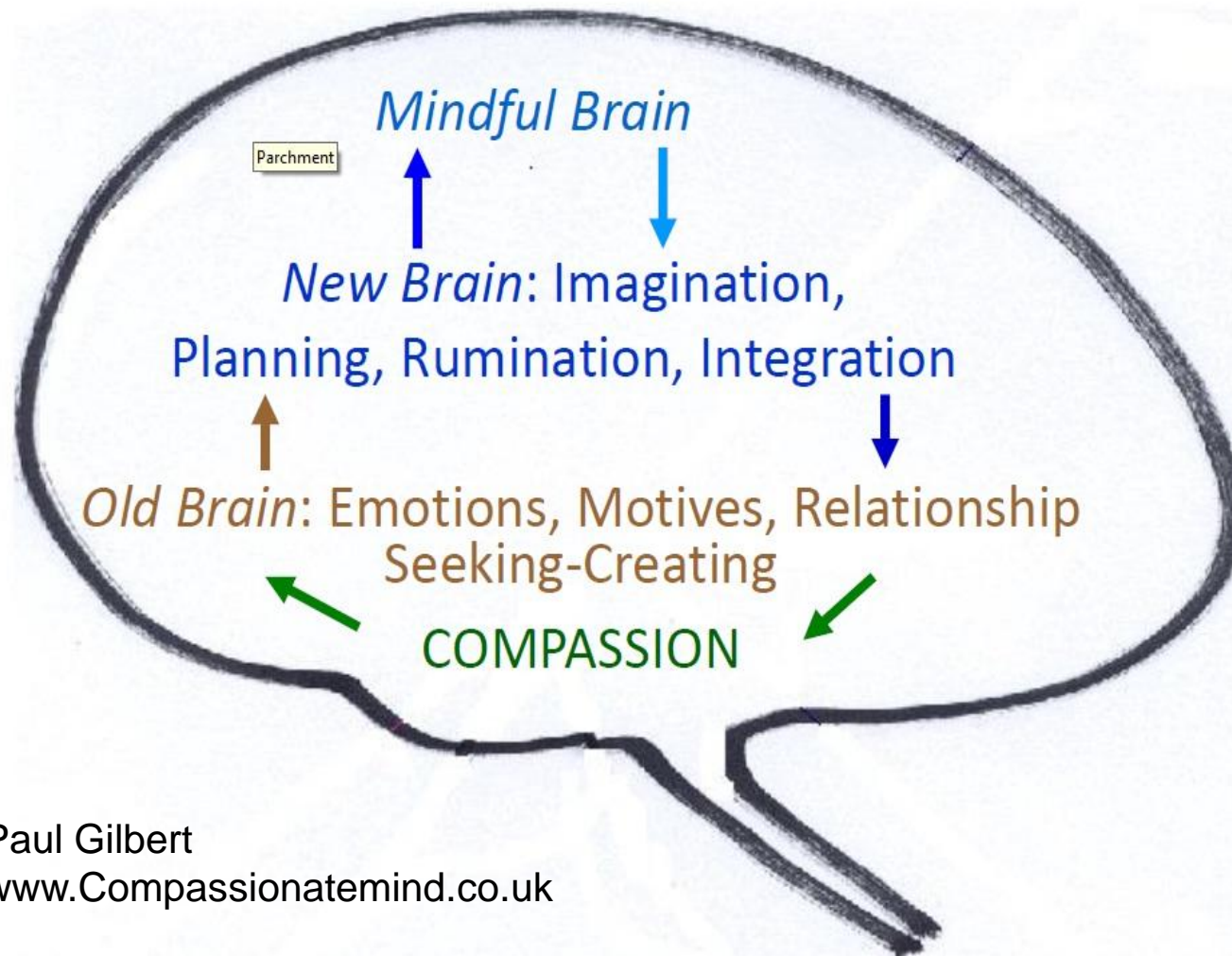


Compassion

- *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 It is no longer we and them- that concept is out of date - we are all part of we.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.



Care for the dyingand the living



GSF- 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

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

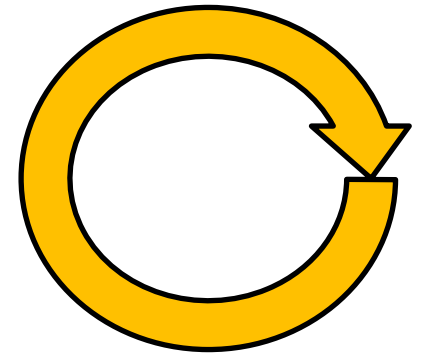
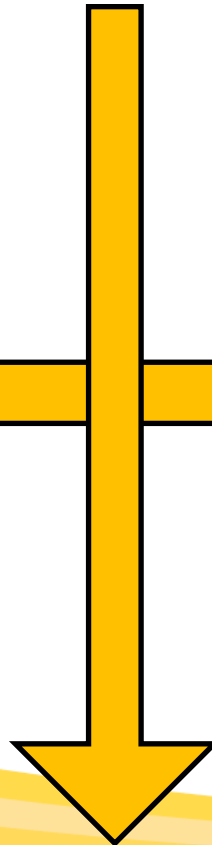
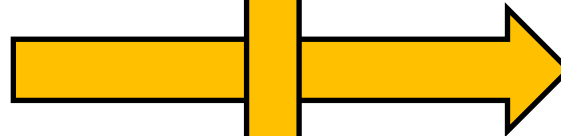
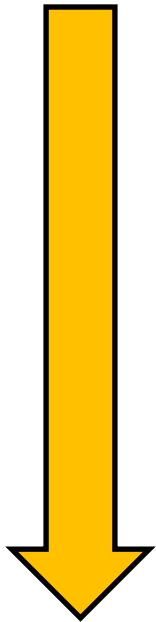


Horizontal
practical care
-doing



Holistic
Whole person
care

Vertical-
-deeper level
- something other
- *being*



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”



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- **Environment**



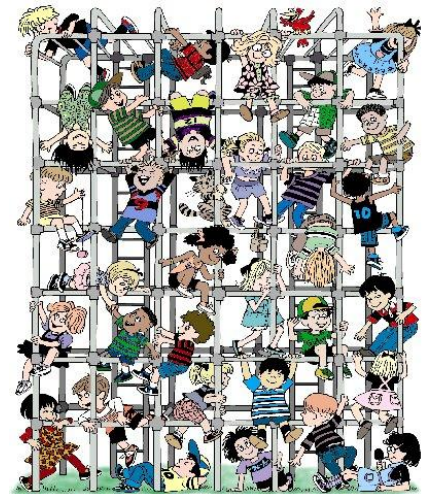
Doing – collective

- 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**

**enabling a 'gold standard' of care
for all people nearing the end of life**

We provide

- Training programmes
- Tools + resources
- Measures
- and support

Leading to

- **Quality improvement**
- **Quality assurance**
- **Quality recognition**

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 hospital s,



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

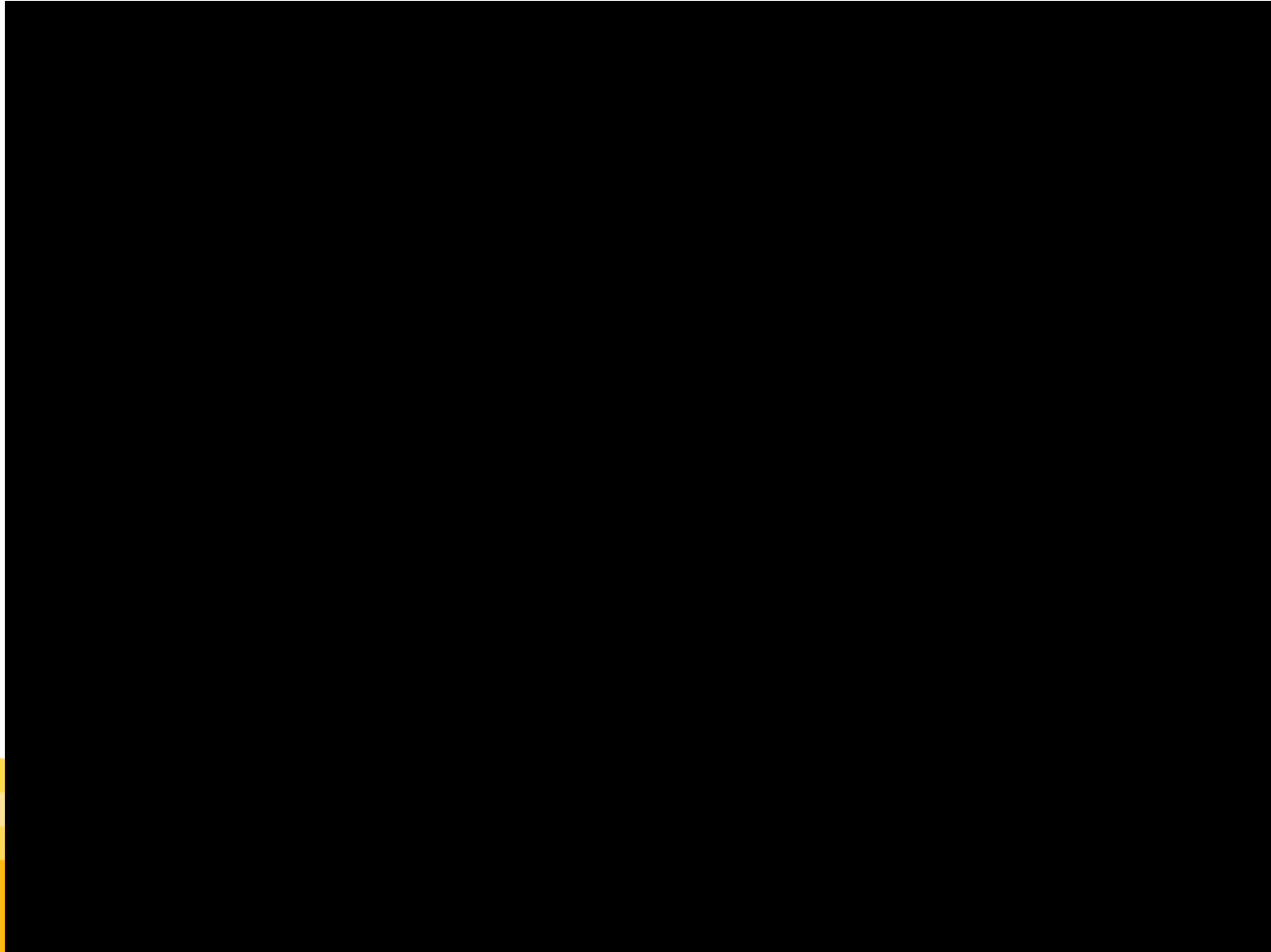
- **Right person** – *identifying the population, communicating this to others*
- **Right care** – *assessing needs, preferences and care required + providing services*
- **Right place** – *reducing hospitalisation enabling more to live and die at home*
- **Right time** – *proactive planning, fewer crises,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



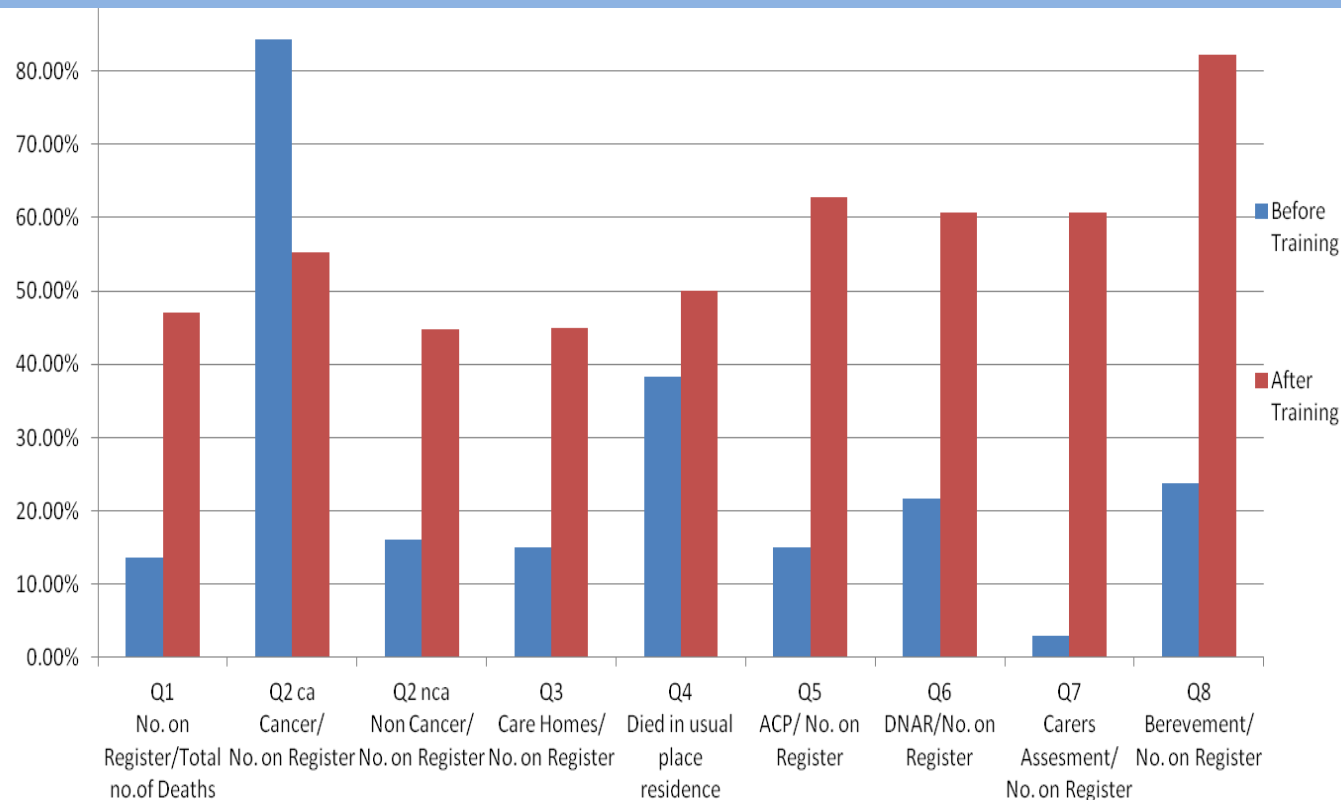
“We look after the **whole population of our elderly patients** much better now- much more proactively”

“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

Key Ratios

Summary of cumulative results from all practices in key practice ratios before and after GSF training





GSF Care Homes Training and Accreditation

the gold standards
framework
in care homes

“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

2007/2008	2008/2009	2009/2010	2010/2011	2011/2011
Percentage of deaths occurring in NHs [numbers of deaths]				
57% n=324 deaths across 19 NHs	67% n=989 deaths across 52 NHs	72% n=1071 deaths across 53 NHs	76% n=1375 deaths across 71 NHs	78% n=1351 deaths across 71 NHs



GSF Acute Hospitals

the gold standards
framework
in acute hospitals

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*

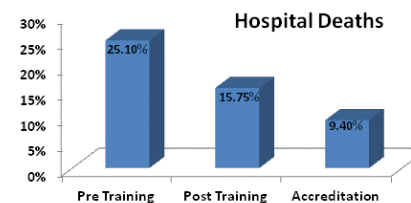
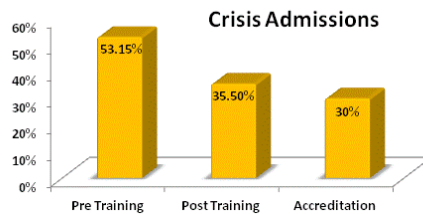
- **Better quality** patient experience of care perceived
- Greater **confidence**, awareness, focus and job satisfaction

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

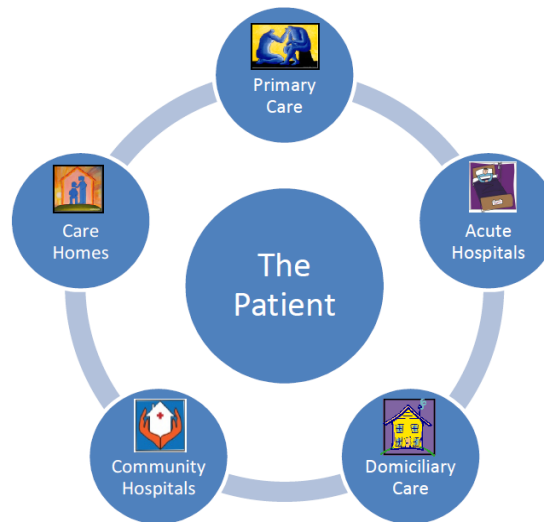
HOME

GSF Primary Care and Domiciliary Care



CARE HOME

GSF Care Homes



HOSPITAL

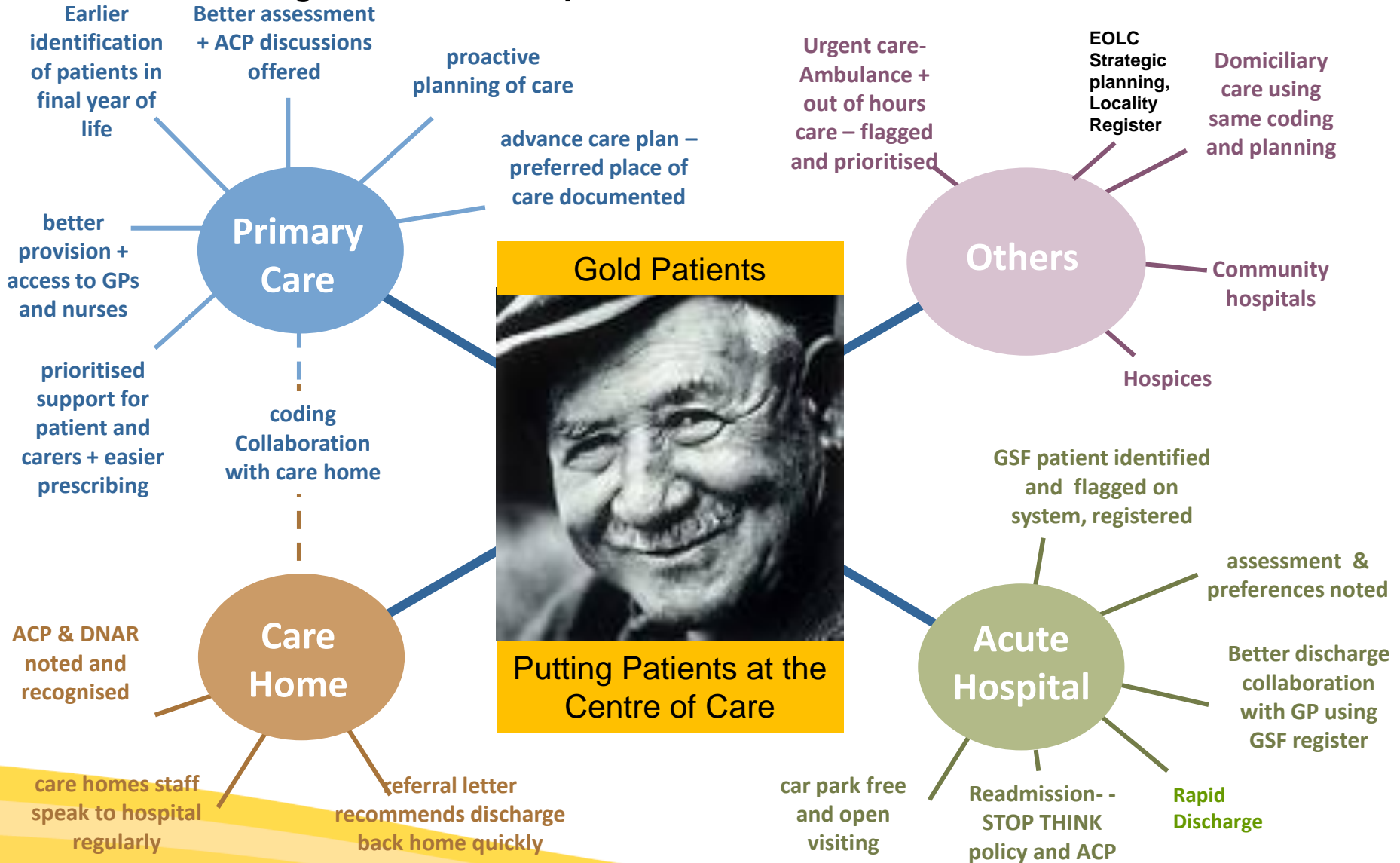
GSF Acute Hospitals



Phase 1 Demonstrator Sites –2013

Vision of Integrated Cross Boundary Care

– *care in alignment with preferences*- **GSF 'Heart of Gold' projects**



What does being a GOLD patient mean to you?



- **G**ood communication
 - **O**n- going 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 atis 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

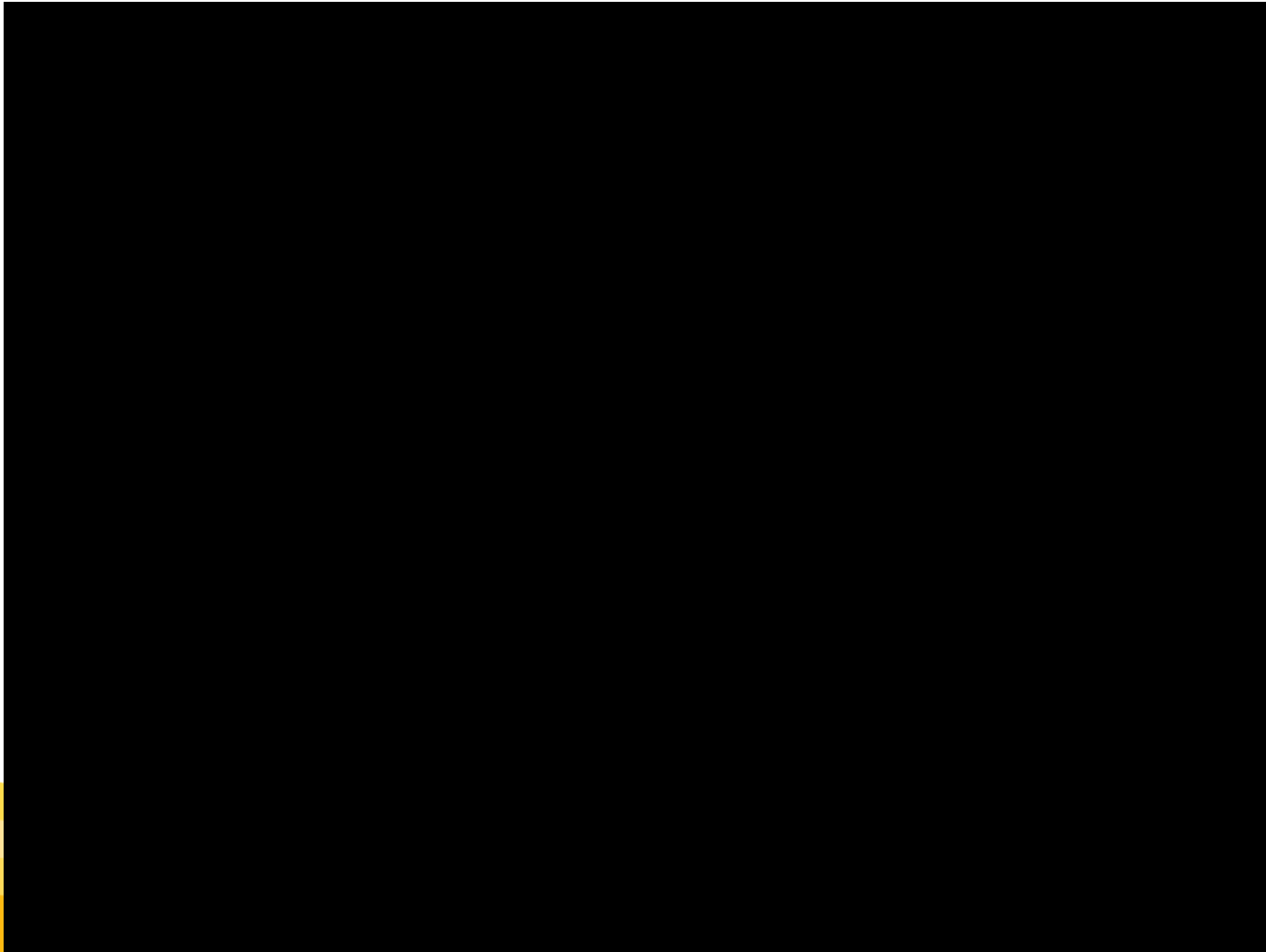
- In 2010 I was diagnosed with cancer of the womb and had a hysterectomy. I was supposed to have radiotherapy, I was afraid of the machine and so only had two treatments.
- Sherdley Court arranged for me to stay in Clatterbridge Hospital during the treatment but I was too afraid to have it done and came 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.



www.goldstandardsframework.org.uk

info@gsfcentre.co.uk



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

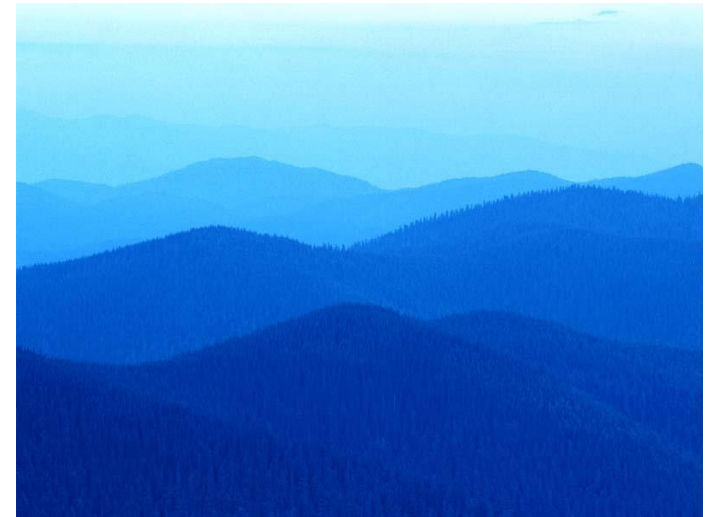
Dying brings life –

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