WELCOME!

Improving End of Life Care for people with dementia

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Why is this important?

- Death is a certainty
- Dementia is a life-limiting condition
- Prognosis about 4 years from diagnosis so ‘End of Life’ Care starts from diagnosis
- Better care helps people live better

- It could be you ....
Frailty and dementia

- Frailty as a ‘long term condition’
- Dementia recognised as biggest cause of death for women

A New Tipping Point

“Just because we can… doesn’t mean to say we should “
Inequity- with diagnoses
Rapid, erratic and slow dying trajectories- After Lynn

Rapid eg Cancer

Erratic eg Organ Failure

GP has about 20 deaths / year

Sudden death / Other

Slow eg Dementia, frailty
Inequity - Choice - preferred and actual place of death

Most people die in hospital though evidence confirms that most would prefer to die at home.
Experiences from the National GSF Centre in End of Life Care

The leading EOLC training centre enabling generalist frontline staff

GSF Quality Hallmark awards are recognised by CQC and commissioners as a kite-mark for quality
Bill – 82 year old with dementia

Current

• In care home
• Behaviour changing condition worsening
• Poor quality of life
• Ad hoc visits - no future plan discussed
• Staff and family struggling to cope
• No advance care planning, no life closure discussion
• Crisis - worsens at weekend - calls 999 paramedics admit to hospital - A&E - 8 hour wait on trolley - dies on ward alone
• Family given little support in grief - staff feel let family down
• No reflection by teams - no improvement
• Expensive for NHS - inappropriate use of hospital

Ideal

Using GSF Care Homes

• Identify and code stage
• Assessment of clinical and personal needs
• Advanced care planning
• Planning - regular support + coordination within primary care
• Handover form out of hours
• Crisis – discussion with family + GP
• Admission averted
• High quality care provided
• Dies in care home
• Bereavement care for family
• Audit (ADA), reflection
• Continuous Quality Improvement

• Better outcome for patient, family, staff
• Most cost effective + best use of NHS
GSF Training Programmes in EOLC

**GSF Primary Care**
Thousands trained bronze
Bronze - Silver - Gold – 350 trained – 10 accredited

**GSF Care Homes**
2500 care homes trained
Bronze, Silver, Gold – NEW ways of distance learning

**GSF Acute Hospitals**
44
5 some whole hospitals, first wards for accreditation

**GSF Community Hospitals**
41 community hospitals
Cornwall, Dorset, Cumbria – first 12 accredited

**GSF Domiciliary care**
almost 2000 care workers
5 regions, 60 trainers,

**GSF Integrated Cross Boundary Care**
Demonstrator sites - Airedale, Dorset, Nottingham - New sites 2015

**GSF Dementia Care**
4 module course available on VLZ.

**GSF Hospice Support**
May 2014 – launch 5 hospices
Day care, hospice at home

**GSF Clinical Skills**
2015 – re-launched Spring

**GSF Spiritual Care**
2015 – Spring
VLZ and workshops roadshow
GSF enables Quality Improvement, Quality assurance, Quality recognition

1. Spread

GSF Quality Improvement provides full package of support for all settings

2. Depth

Quality assurance and Quality recognition
Evaluation measures and accreditation

3. Joined-up

Integrated Cross boundary care
GSF can be a common language
Measures - Impact + integrity using GSF
Improving quality, coordination and outcomes

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 - *decreased hospitalisation, dying in preferred place*
   - Reduced crises, **hospital admissions**, length of stay e.g. halve hospital deaths
   - Care delivered in alignment with patient and family preferences
An introduction to the GSF Care Homes and Dementia Care Training Programmes

Maggie Stobart Rowlands
GSF Lead Nurse and Programme Manager, GSF Centre
The National GSF Centre in End of Life Care

GSF Care Homes programme & GSF Dementia care at End of Life

The right care, for the right people, in the right place, at the right time… everytime
1. 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

- Challenges - focus on compassionate care
Compassion

Doing – collective
• The right care, for the right person, in the right place, at the right time, every time
• Compassionate people, organisations, communities and society

Being – connected
• Being caring + present
• Being connected-
  – less us and them
  – feeling with
• Being compassionate
• Human- more than words
Improving End of Life Care with GSF

Head Hands and Heart

**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’
The Five GSF Gold Standards

Standard 1: **Right people**
- identifying the right patients

Standard 2: **Right care**
- assessing their needs - clinical and personal

Standard 3: **Right place**
- planning coordinated cross boundary care

Standard 4: **Right time**
- Proactively planning care including in final days

Standard 5: **Every-time**
- Embedding consistency of good practice, extending further and integrating cross boundary care
• Steve.......received the best imaginable care at .......
• 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 qua3lity 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.
Decreased hospital admissions and deaths with GSFCH Training programme as measured by ADA phases 4-6

Halving hospital deaths

Potential Cost Savings – estimated £30-40k/ care home/ year - £1-2 m / PCT area
Why does dementia matter in end of life care?

• Increasing ageing population = higher risk of dementia
• Age is also a big risk factor for most cancers.
• By 2030 - 63,000,0000 people worldwide will have dementia (2)
• By 2030 – 70% of all cancers will occur in elderly people (1)
Why does dementia matter in end of life care?

• \( \frac{1}{4} \) of Acute hospital beds are occupied by people with dementia
• \( \frac{1}{3} \)rd of people in acute hospital beds are in the last year of life
• On average \( \frac{3}{4} \) of care home residents have some degree of cognitive impairment
GSF Dementia training programme

Key Aims

1) Improve person centred care & reduce carer stress

2) Improved assessment of symptoms including pain & distress

3) Improvement in Advance care planning & best interests (MCA)

4) Increase in people dying in their usual place of residence by reducing inappropriate hospital admissions and deaths
**The GSF Dementia Training programme**  
*(4 x 1 1/2 hr sessions – distance learning)*

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<tr>
<th>Sessions</th>
<th>Key topic</th>
<th>Comparative Evaluation</th>
<th>Outcome</th>
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| 1. Identify *Right person* | **Awareness** - of impact, dignity, carers | Confidence survey  
Case studies | Greater knowledge skills and confidence |
| 3. Assess – personal *Right care* | **Advance Care Planning** - needs and preferences recorded | Case studies | Increased numbers offered ACP |
| 4. Plan- care *Right place, right time* | **Reduce hospitalisation** - the right to die in the preferred place of residence | Supportive Care Analysis  
Case studies | Decreased hospitalisation ↓crisis ↓hospital deaths |
GSF End of Life care for people with dementia

“The GSF dementia training has been very educational and interesting for me. I hope that in the future others will have the same opportunity.”

“We have gained knowledge and confidence in the correct use of pain charts which we use as evidence of need to educate the GPs as to the need for good pain relief.”

“the course has changed the whole ethos & atmosphere of the home”

‘Very educational and interesting’

‘Brilliant course’
• For further information

www.goldstandardsframework.org.uk

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