Outlining the Gold Standards Framework for Outstanding End of Life Care.

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Plan

1. **Context** of population based EOLC

2. **Our experience at GSF Centre** in EOLC, using systematic evidence based approach to optimising care

3. **Measurement, benchmarking + examples** of standards achieved by front-runners and cross boundary care sites

4. **Enhancing commissioning** and next steps
1. Context of population based EOLC

Things are changing with our ageing population, increasing multi-morbidities, complexity + costs

From pyramid to coffin
Changing age structure of the Australian population, 1925-2045

Frailty and multi-morbidity are the biggest killers

Increasing Multi-morbidities

Over-use of hospitals

In Last Year of Life
- 1% general population
- 30% hospital patients
- 80% care homes residents

Expenditures
Life span

Gray area under the curve equals 100% of all health care expenditures over a life span
Plan ahead, plan big
Think ahead, be proactive, face mortality

GMC Definition of ‘End of Life’
www.gmc-uk.org/static/documents/content/End_of_life.pdf

Final year(s) of life

Population based EOLC
‘nearing the end of life, final stage of life, LYL, rest of life care’
Priorities for Care of the Dying Person

Care in the Final Days of Life

- Recognise
  - The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions reviewed accordingly.

- Communicate
  - Sensitive communication takes place between staff and the dying person, and those identified as important to them.

- Support
  - The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

- Involve
  - The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

Plan & do

As an individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, as estimated and delivered with compassion.

CQC in hospitals assesses care in the
- Final year
- Final days
- After death

GSF Hospital Accreditation process approved by CQC as the only EOLC information source in hospitals

Earlier planning prevents crises in final days - GSF can help

A - Blue "All" from Diagnosis Stable Year plus prognosis
B - Green 'Benefits' - DS1500 Unstable/Advanced disease Monthly prognosis
C - Yellow 'Continuing Care' Deteriorating Weeks prognosis
D - Red 'Days' Final days of life Days prognosis
Purple 'After Care'
Inequity - Different ways of dying
Rapid, erratic and slow dying trajectories - After Lynn

- **Rapid** e.g. Cancer
  - GP has about 20 deaths/year

- **Erratic** e.g. Organ Failure

- **Slow** e.g. Dementia, frailty

Sudden death / Other
Enabling generalists in end of life care

1) Specialists

2) Generalists - GSF

3) Lay People - general public

Hospice and Specialist Palliative Care
Workforce 5,500

Enabling Generalists
- Primary Care
- Care Homes
- Hospital
- Domiciliary Care
Workforce -2.5 m

- Public Awareness
- Community Care
- Carers Support etc
- Population 60m

End of Life care is everybody’s business
‘A new Tipping Point of potential over-medicalisation’

“Just because we can…doesn’t mean to say we should”

A new paradigm – time for a proactive approach.
Population-based care – Muir Grey

After a certain level of investment, health gain may start to decline

www.rightcare.nhs.uk
Population-based End of Life care Approach

1. Whole population focus
   - Populations - 1% population, 30% hospitals, 80% care homes
   - Based on need, not condition/setting (most multi-morbidity)
   - Equitable - consistent – reliable - inclusive *Rolls Royce/bicycle*

2. Everyone's involved – enabling all step by step

3. Be proactive
   - *Identify* early where possible

4. Tailored to individual - person-centred care
   - Right person, Right care, Right place, Right time, Everytime

5. Measure appropriately
   - Proxy Outcome Measures - 4 Levels of Influence

6. Value based - triple value healthcare
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Our Experience at The GSF Centre
The Leading Training Provider in End of Life Care

Aspiring to gold standard care for all people nearing the end of life

1. Spread
10 GSF training programmes - support for all settings - 12 GSF Regional Centres

2. Depth
Quality assurance
6 Accreditation Quality Hallmark Awards

3. Joined-up
Integrated Cross boundary care
GSF can be a common vocabulary - working with partners eg GMC, RCGP, BGS

GSF Integrated Framework

Primary Care
Acute Hospitals
Community Hospitals
Domiciliary Care
The Patient

Care Homes
What do we hope to achieve with GSF?

1. Better quality of care experienced by all people nearing the end of life

2. Better communication, + coordination, systems, teamwork

3. Better outcomes – for people - living well and dying well where they choose

+ health systems - better use of limited resources, reducing over- hospitalisation.
Spread to all settings - GSF Training Programmes

**GSF Primary Care**
- All GPs doing bronze
- Hundreds - Silver - Gold – 14 accredited

**GSF Care Homes**
- 3000 trained – 25% N homes
- Bronze, Silver, Gold – NEW ways of distance learning

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

**GSF Community Hospitals**
- 53 community hospitals
- Cornwall, Dorset, Cumbria – first 14 accredited

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

**GSF Hospice Support**
- Day care, hospice at home

**GSF Prisons**
- New programme adapted for needs of prisons

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

**GSF Clinical Skills**
- Supporting background clinical skills of staff in care homes

**GSF Spiritual Care/Compassion**
- Deeper ‘heart 'care, inner life + compassion . VLZ and workshops

**GSF Integrated Cross Boundary Care Sites**
- Airedale, Dorset, Nottingham, BHR, Morecombe Bay
- Jersey, Southport, + others
Improving systems
GSF 3 Steps Summary

**identify**
patients who may be in the last year of life and identify their needs-based code/ stage

**assess**
current and future, clinical and personal needs

**plan**
Living well and dying well

GSF Prognostic Indicator Guidance identifying patients with advanced progressive decline/ disease who may be in the final year of life – 1%, 30%, 80%

*Every appropriate person should be offered ACP discussions*, mainly Advance Statements, by their usual/chosen care provider, which then becomes an action plan for quality of care.

Proactively planned (fewer crises) and preferred place
Reducing crises and hospital admissions.
Living and dying well in preferred place of care
Identify the right population

GSF Prognostic Indicator Guidance identifying patients with advanced progressive decline/disease who may be in the final year of life

- 1% of the general population
- 30% hospital population
- 80% care homes population

Three triggers:

1. **The surprise question**
   ‘Would you be surprised if this person was to die within the next year?’

2. **General Indicators**
   for decline + comfort care/need

3. **Clinical indicators**
   Suggested that all patients on register are offered an ACP discussion
30% of hospital patients are in the last year of life
Clarke et al

A prospective observational study of prevalence and outcomes of patients with Gold Standard Framework criteria in a tertiary regional Australian Hospital
Sharyn Milnes, Neil R Orford, Laura Berkeley, Nigel Lambert, Nicholas Simpson, Tania Elderkin, Charlie Corke, Michael Bailey

ABSTRACT
Objectives Report the use of an objective tool, UK Gold Standards Framework (GSF) criteria, to describe the prevalence, recognition and outcomes of patients with palliative care needs in an Australian acute health setting. The rationale for this is to enable hospital doctors to identify patients who should have a patient-centred discussion about goals of care in hospital.
Design Prospective, observational, cohort study.
Participants Adult in-patients during two separate 24-hour periods.
Main outcome measures Prevalence of in-patients with GSF criteria, documentation of treatment limitations, hospital and 1 year survival, admission and discharge destination and multivariate regression analysis of factors associated with the presence of hospital treatment limitations and 1 year survival.
Results Of 626 in-patients reviewed, 171 (27.1%) had at least one GSF criterion with GSF clinical criteria were independently associated with increased risk of death at 3 years. Patients returning home to live reduced from 69% (pseudomission) to 37% after discharge.
Conclusions The use of an objective clinical tool identifies a high prevalence of patients with palliative care needs in the acute tertiary Australian hospital setting, with a high 1 year mortality and poor return to independence in this population. The low rate of documentation of discussions about treatment limitations in this population suggests palliative care needs are not recognised and discussed in the majority of patients.
Trial registration number 11/121.
INTRODUCTION
The combination of an ageing population with complex health needs has led to a large proportion of patients that experience decline and eventual death in the...
Advance Statement to include

- What is important to you?
- What do you want to happen?
- What do you not want to happen?
- Who would speak for you?
GSF Summary Statement on ACP

‘Every appropriate person should be offered ACP discussions’ (mainly Advance Statements) by their usual healthcare provider which then becomes an action plan against which quality of care is measured’.
Plan Living Well and Dying Well

- **Living well**
  - Enabling more to live well at home + reducing hospitalisation

- **Dying Well**
  - More dying at home or where they choose

**GSF Hospitals**
Reduced Length of stay - average 3 days

<table>
<thead>
<tr>
<th></th>
<th>Hospital 4</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>28.0</td>
<td>18.5</td>
</tr>
<tr>
<td>Follow up</td>
<td>13.0</td>
<td>15.6</td>
</tr>
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</table>

**GSF Care Homes**
Reducing crisis and hospital deaths in care homes residents

<table>
<thead>
<tr>
<th></th>
<th>Pre Training</th>
<th>Post Training</th>
<th>Accreditation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crisis Admissions</td>
<td>54.15%</td>
<td>45.56%</td>
<td>30%</td>
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<table>
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<tbody>
<tr>
<td>Hospital Deaths</td>
<td>25.10%</td>
<td>15.75%</td>
<td>9.40%</td>
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</table>
Culture change—better listening to patients and relatives.

“I think the biggest change has been the culture change……..making sure that patients receive the care they want, where they want it, when and how they want it and the satisfaction they and we get from that. ….GSF is the framework that allows us to make that happen.”

Dr Kumar Consultant Geriatrician Stroke Ward Royal Lancaster Infirmary

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”

Dr Karen Chumley Essex GP
Plan

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Key Outcome ratios

ADA

Organisational Questionnaire

Staff Survey

Measurement tools

- Right Person
- Right Care
- Right Place
- Right Time
- Every time

Portfolios
Assessment Visit
GSF Primary Care - Accredited Practices

GSF Primary Care Programmes
• Bronze - 98% GP practices
• Silver
• Gold + Accreditation

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

Key Outcomes Ratios
Summary of cumulative results from 10 accredited practices before and after GSF training

Identifying 50%
GSF Care Homes
Training and Accreditation
“the biggest, most comprehensive end of life care training programme in the UK”

Training
Almost 3000 care homes trained
- About 250 trained per year

Accreditation
Up to 200 per year accredited
Many third time accredited
Externally recognised as kite-mark
- CQC recognition
- Evidence - reduction in hospitalisation

Vision of national momentum of best practice

Place of Death

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Home</th>
<th>Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st time accredited</td>
<td>20%</td>
<td>10%</td>
</tr>
<tr>
<td>2nd time accredited</td>
<td>30%</td>
<td>20%</td>
</tr>
<tr>
<td>3rd time accredited</td>
<td>40%</td>
<td>30%</td>
</tr>
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Hospital deaths reducing
GSF Hospitals

**GSF Acute Hospital**
- Over 80 acute hospital wards
- 8 accredited wards with BGS
- Several whole hospital
- CQC approved information source

**GSF Community hospitals**
- 15 hospitals accredited

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**Identifying over 30%**

- All Offered ACP

- Proportion offered advance care planning in the first 8 GSF accredited wards

- Q4 % of patients offered initial ACP1
- Q5 % of patients who have a further discussion ACP2
- Q6 % of patients that have the full ACP3
Accredited Community hospitals

Identifying patients early
- 31% to 66% patients identified

Advance Care Planning
- Offered to over 90% patients

Offering ACP discussions

Identifying over 30%

Snapshot at Accreditation of the four wards. All patients offered at least initial advance care planning discussions - some full ACP completion.
## Attainment of GSF Accredited teams in different settings

<table>
<thead>
<tr>
<th>Settings</th>
<th>Identify</th>
<th>Assess</th>
<th>Plan Living well</th>
<th>Plan Dying well</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aims of GSF accredited organisations</strong></td>
<td>Early recognition of patients- aim 1% primary care 30% hospital 80% care homes</td>
<td>Advance Care Planning discussion offered to every person</td>
<td>Decreased hospitalisation + improved carers support</td>
<td>Dying where they choose using personalised care plan in final days</td>
</tr>
<tr>
<td><strong>GP practices (Rounds 1-4)</strong></td>
<td>70% patients identified (range 35-90%)</td>
<td>75% offered ACP discussion (range 40-100%)</td>
<td><strong>Halving</strong> hospital deaths, 70%</td>
<td>63% die where they choose using 5Ps care final days plan</td>
</tr>
<tr>
<td><strong>Acute Hospitals</strong></td>
<td>35% identified early (range 20-58%)</td>
<td>92% offered ACP discussion (range 85-100%)</td>
<td><strong>Halving</strong> hospital deaths, 70%</td>
<td>63% die where they choose using 5Ps care final days plan</td>
</tr>
<tr>
<td><strong>Community Hospitals</strong></td>
<td>45% identified</td>
<td>98% offered</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Care Homes accredited</strong></td>
<td>100% identified, 81% identified in dying stages</td>
<td>100% offered 95% uptake</td>
<td><strong>Halving</strong> hospital deaths+ admissions 97% carer support</td>
<td>84% dying where choose, 90% using 5Ps care plan</td>
</tr>
</tbody>
</table>

**It is possible** -
- Identifying more patients
- Offering most ACPs,
- Reducing hospital deaths,
- More dying where choose
- Use 5Ps care in final days
Connect... Integrated Cross Boundary Care

GSF becomes part of a common vocabulary across different settings

HOME
GSF Primary Care and Domiciliary Care

CARE HOME
GSF Care Homes

HOSPITAL
GSF Acute Hospitals
Percent of Lancashire North CCG deaths at home and in hospital
2009 to August 2013

Source: Primary Care Mortality Database, Public Health, Lancashire County Council
*Provisional data, does not include patients outside LCC boundary
GSF Cross Boundary Care Sites- ‘Gold Patients’

GSF Cross Boundary Care Sites- Morecambe Bay, Airedale, BHR, Southport, etc

- GSF registered ‘Gold patients’ identified in different settings, on EpaCCS
- Given Gold card, information sheet, ‘special’ treatment, added benefits eg ‘Gold Line’ to coordinate their care

Airedale Gold Line DIUPR figures
1st April to 31st March, 2011/12-2014/15
Source National EoL Intelligence Network
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Connect with all levels ....

1. Individual- person, family, workforce, staff
2. Organisation- team, practices, care home, ward
3. Population served- Community /STP /CCG/LA
4. National- regulation, quality, standards + policy
**Vision of Integrated Cross Boundary Care**

**Gold patients and GSF ‘Heart of Gold’ projects**

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

**Primary Care**
- Better assessment + ACP discussions offered
- Proactive planning of care
- Advance care plan – preferred place of care documented

**Gold Patients**
- Putting Patients at the Centre of Care
- Urgent care: Ambulance + out of hours care – flagged and prioritised

**Others**
- GSF patient identified and flagged on system, registered
- Assessment & preferences noted

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

**Acute Hospital**
- Car park free and open
- Rapid Discharge
- Readmission - STOP THINK policy and ACP

**Hospices**
- Community hospitals
- GSF patient identified and flagged on system, registered

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

**The Gold Standards Framework**
Connect dying with living ....
Living well, ageing well, dying well
ACP at all stages in all settings

ACP

Living well
at any age
Life planning

Ageing well
with long-term conditions, frailty or decline
ACP/CSP

Dying well
Last stage of life - final years, months, weeks, days
ACP- AS for all, ADRT for some

Life planning
ACP for all eg decade birthdays, pensions, retirement, events

Ageing well ACP
or Care and Support Planning for people with Long Term conditions

Advance Care Planning
for all nearing the end of life (final year)
In every setting
NB The GSF Centre is seeking new recruits

We are expanding and recruiting, do contact us if interested in joining us as

- Clinical Associate
- Nurse trainer social care
- Senior managerial position (MD)
- Part of reference group - public and clinical

- [Info@gsfcentre.co.uk](mailto:Info@gsfcentre.co.uk)
- or Jo Carwardine on 01743 291895
Improving end of life care

Gold Standards Framework
Right person, right care, right place, right time, every-time

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