



End of Life Care Programme

the gold standards framework

Improving the reliability of home care for patients nearing the end of life



Dr Keri Thomas and Helen Meehan from the GSF Central Team, Birmingham UK

A framework to deliver a 'gold standard of care' for all people with advanced disease, nearing the end of their lives

The Beginnings of GSF

- Developed from primary care for primary care
- A multi-disciplinary reference group led by GP with a Special Interest, Dr Keri Thomas
- Piloted in 12 practices in Phase 1, 78 in Phase 2
- A GSF Support Programme developed with national funding (CSC, Macmillan, now the NHS End of Life Care Programme)
- Endorsed by RCGP, NICE, the National Council for Palliative care, the House of Commons Health Select Committee and the White Paper 'Our health our care our say'
- Now mainstreamed through the GP contract QOF palliative care points

Example of Patient Journey - without GSF

- Mr B's Experience
- GP and DN have ad hoc arrangements - no plan discussed or anticipated
- Problems with symptom control - high anxiety
- Crisis call e.g. out of hours - no plan or drugs available
- Admitted to hospital (bed blocks)
- Dies in hospital - 'over intervention / medicalised'
- Carer given minimal support in grief
- No reflection / improvements by team / PCT
- Inappropriate costly use of hospital bed



Example of Patient Journey - with GSF

- Mrs W's Experience
- On SC Register-discussed at PHCT meeting
- DS1500 and info given to pt+carer (home pack)
- Regular support, visits phone calls-proactive
- Assessment of symptoms-referral to SPC - customised care to pt and carer needs
- Carer assessed incl psychosocial needs
- Preferred place of care noted and organised
- Handover form issued - drugs issued for home
- End of Life pathway / LCP / protocol used
- Pt dies in preferred place - bereavement support Staff reflect-SEA, audit gaps improve care, learn



New Developments

- GSF in Care Homes**
A phased programme involving about 100 care homes aiming to:
 1. Improve end of life care
 2. Reduce un-needed hospital admissions
 3. Improve collaboration with GPs and DNs
 4. Develop guidance for future use
- Prognostic Indicator Guidance for non-cancer patients**
Key indicators that patient may be in the last year of life and in need of supportive care - see website for Guidance paper and how to use it
- End of Life Strategic planning**
GSF as part of a supportive care framework for patients nearing the end of life, from diagnosis of advanced and to death
- Advanced Care Plans**
Suggested plans to discuss with patients to seek their views and preferences
- After Death Analysis**
A self check tool to improve care
- Education** -Tools for Generalists eg DVDs
- GSF children** a pilot for care of children with life threatening illness
- GSF In-reach to hospitals**

"The majority of GSF participants felt that the framework had strengthened their provision of community palliative care. In particular, communication within primary health care teams and co-ordination ... were better in the GSF practices ... Practitioners felt there was more consistency of care, with a reduced likelihood that individual patients would 'slip through the net'".
King N, Thomas K et al Palliative Medicine 2005; 19: 619-627

Too often home care for patients in the final year of life is inconsistent and unreliable. Using the GSF helps improve quality, organisation and consistency of care and prevents patients 'slipping through the net'. This programme for community palliative care, begun in primary care in England, is now being used nationally and internationally, and is being adapted for other areas such as care homes, for children, etc.
It is part of the means to improve the reliability of home care for all patients nearing the end of their lives. GSF is now part of the NHS End of Life Care Programme, and links also with Birmingham's Supportive Care Pathway in hospitals.

What is GSF? GSF Summary - 1, 3, 5, 7

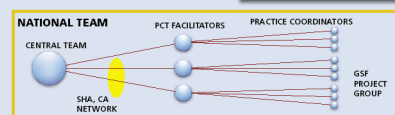
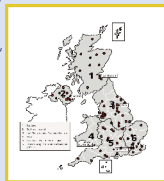
- 1 AIM
One Gold Standard Of Care For All Patients nearing the end of life, whatever the diagnosis, stage or setting
- 3 PROCESSES
1. Identify palliative care patients
 2. Assess problems, concerns, needs, preferences
 3. Plan advance care planning
- + communicate at each stage
- 5 GOALS
To enable patients to end their lives well
- 1 As symptom controlled as possible
 - 2 Living & dying where they choose
 - 3 With security & support, better informed, less fear fewer crises
 - 4 Carers well-informed, supported, enabled & empowered
 - 5 Staff confidence, team working, communication improved
- 7 KEY TASKS - 7 CS
- C1 COMMUNICATION
 - C2 CO-ORDINATION
 - C3 CONTROL OF SYMPTOMS
 - C4 CONTINUITY OUT OF HOURS
 - C5 CONTINUED LEARNING
 - C6 CARER SUPPORT
 - C7 CARE IN DYING PHASE
- with enabling tools, ideas & resources to support each task

Why Use GSF?

- GSF is a tried and tested framework to improve the quality & organisation of care for patients in the last year of life in the community
- It helps GPs & DNs provide better care at home & helps reduce un-needed hospital admissions
- It is being used by about a third of GP practices in the UK
- It is being mainstreamed within the NHS in the new GP contract QOF, central DH funding & support & it is recommended by NICE, RCGP, NCPCC etc.
- It is part of the way we can provide excellence in end of life care for everyone - something we are all going to need at some time!

Spread of Use of GSF

Phased programme of support 12 phases from 2001-2007
Supported by GSF Central Team with resources, toolkit, website, training, workshops, targeted support, evaluation etc.
Now almost 3000 practices using GSF covering every Strategic Health Authority, Cancer Network and two thirds of the PCTs. Now each SHA receives national funding as part of the NHS End of Life Care Programme.

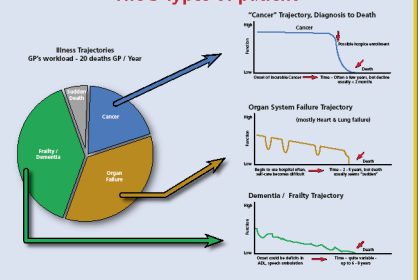


"The care of all dying patients should be raised to the level of the best"
NHS Cancer Plan 2000

"Better care for the dying should become a touchstone for success in modernising the NHS"
Sir Nigel Crisp
Chief Executive of the NHS

"The college is pleased to support the Gold Standards Framework, which is having a huge impact on the quality of care at the end of patients' lives. The values expressed in this framework are central to the college ethos of Knowledge with Compassion"
Dr Graham Archard
Vice Chairman Royal College of General Practitioners, March 2005

The 3 Types of patient



"GPs say we're really busy but will make time for this - something about putting people back in touch with the reasons they came into healthcare"
GP, Dorset

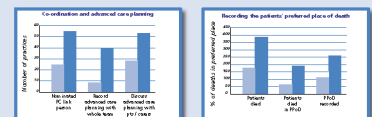
"The Gold Standards Framework is the only thing in Palliative Care over recent years that has really made a difference"
District Nurse, Scotland

"That's what it (GSF) is all about - giving the dying person what they want. There's no argument in that"
Bereaved Carer

From research evidence GSF can be seen as a means to change three areas:

1. Awareness of and attitudes towards dying patients
2. Patterns of working - systems, team-working & communication
3. Patient outcomes - tangible developments eg more home deaths, asking preferences, information etc

Phase 3/6 - 2003/4 Macmillan GSF Evaluation Warwick University



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Pan-Birmingham Palliative Care Network

GSF Text Book: 'Caring for the Dying at Home: Companions on the Journey' Thomas K, Radcliffe 03