



the gold standards framework in community palliative care



A GOOD DEATH FOR ALL

The aim is that every person should be able to live well and die well in the place and in the manner of their choosing.

THE BEGINNINGS OF GSF

A GP with a special interest in palliative care (Dr Keri Thomas) supported by a team of generalist and specialist clinicians, felt that even though GPs and District Nurses were trying hard to deliver excellent care, too often primary care was failing its patients at the end of their lives. They wanted to develop a means to ensure the standards of palliative care delivered by primary care teams was consistently good - a 'gold standard' of care every time. To do this, they mapped out the patient pathways and the barriers to good care occurring every time, and the suggested means to effect best practice. This grass roots development - from the bedside not the boardroom - was first piloted by 12 practices in West Yorkshire then adopted across the UK, in a phased programme of supported spread. It is hoped to be mainstreamed as part of standard practice within primary care.

GSF IN PRACTICE

MR B'S EXPERIENCE

Reactive Patient Journey - Without GSF

- 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



MRS W'S EXPERIENCE

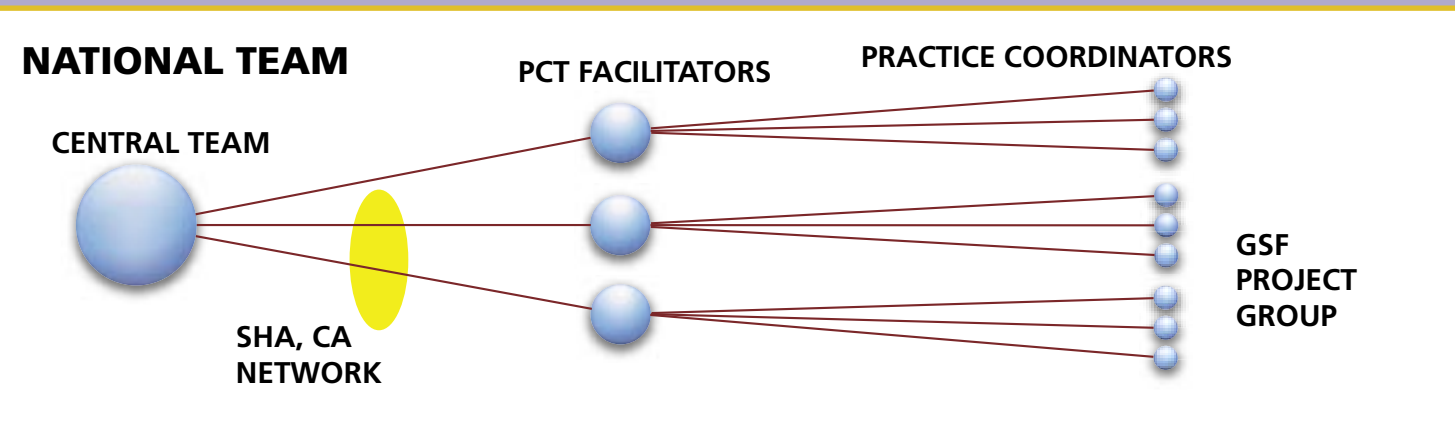
Proactive Patient Journey - With GSF

- 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



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 over 2000 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.



Lessons learnt about key generic processes in successful dissemination

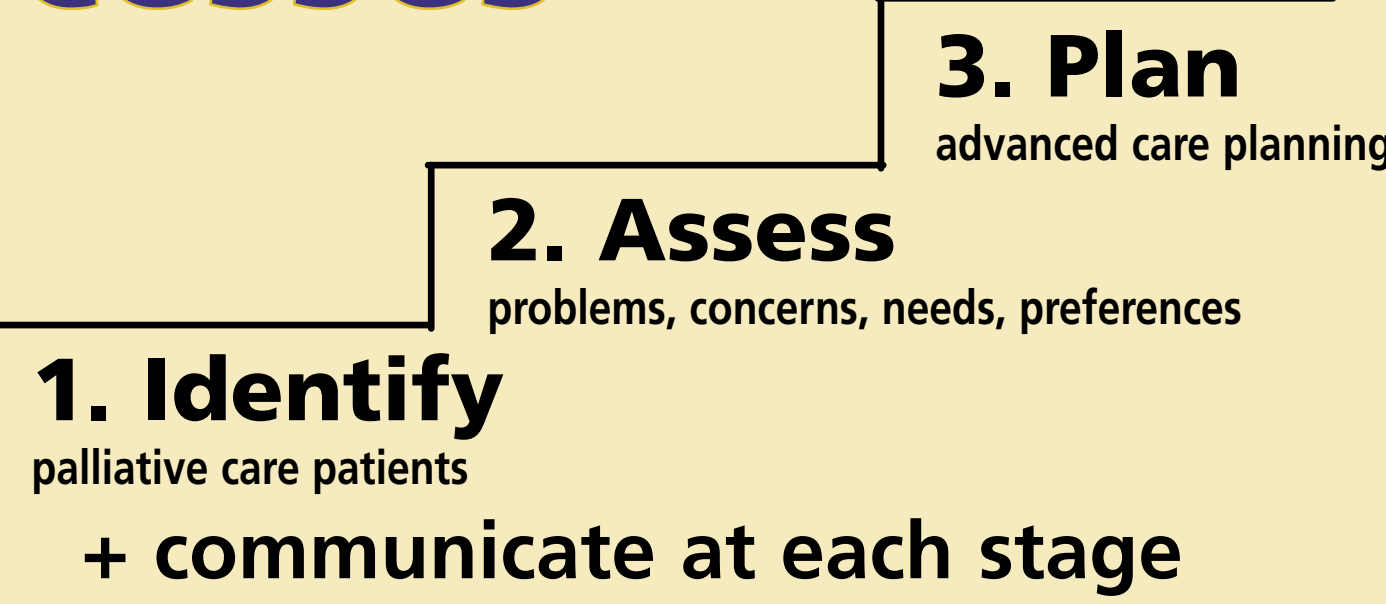
- Aspire to the best and tap into ideals and visions of others
- Use what we know to enable people to do what they already want to do
- Listen hard to patients, carers and staff needs
- Develop systems not dependent on luck
- Enable support, be practical, develop ownership, adopt and adapt
- Strengthen relationships and partnerships
- Develop a spread cascade ie enable your facilitators
- Develop a national momentum, celebrate success and mainstream in policy
- Measure what is important, do not make important what can be measured eg nos. dying where they choose, nos recording preferred place of care, no. of crisis admissions, estimation of quality of care and communication, etc.

An example of innovation, development and national adoption of a programme to improve end of life care for all patients. The GSF is now adopted by almost a fifth of all practices in the UK, covering about 16 million patients. It is supported by the NHS End of Life Care Programme, NHS Cancer Services Collaborative, NICE Guidance in Supportive and Palliative Care, House of Commons Health Select Committee for Palliative Care, Macmillan Cancer Relief, the Royal College of General Practitioners and the National Council for Palliative care.

GSF Summary- 1,3,5,7

1 Aim *One Gold Standard of care for ALL patients nearing the end of their life, whatever the diagnosis, stage or setting.*

3 Processes



5 Goals to enable patients to end their lives well

1. As symptom controlled as possible
2. Living and dying where they choose
3. With security and support, better informed, less fear fewer crises
4. Carers well-informed, supported, enabled and empowered
5. Staff confidence, team working, communication improved

7 Key tasks - 7 C's

- 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 and resources to support each task

Development

Adapted GSF to be used in

1. In other settings eg Care Homes
2. For all types of patient-
 - a. cancer
 - b. organ failure (heart failure, COPD, Neurological disease and renal failure mainly)
3. Educational initiatives
4. Advanced Care Planning and Advanced Directives
5. An end of Life care pathway for all patients from diagnosis to death, to enable better quality care, fewer hospital admissions and more dying where they choose

Contact Details for GSF Support Programme

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WEBSITES

www.goldstandardsframework.nhs.uk
www.modern.nhs.uk/cancer/endoflife

Clinical Lead: Dr Keri Thomas GPwsl Palliative Care, National Clinical Lead Palliative Care CSC and NHS End of Life Care Programme, Clinical Director of Community Palliative Care Pan-Birmingham Palliative Care Network,

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

"The care of all dying patients should be raised to the level of the best"

NHS Cancer Plan 2000

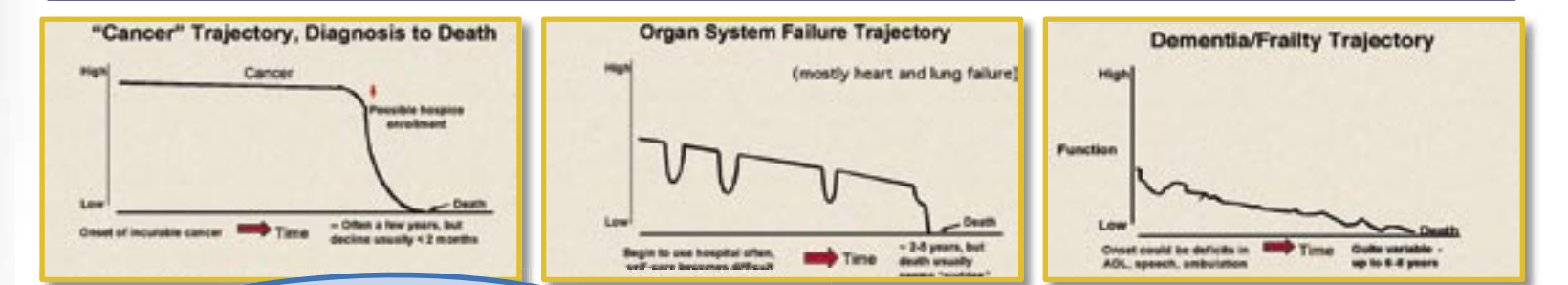
"Better care for the dying should become a touchstone for success in modernising the NHS"

Sir Nigel Crisp
Chief Executive of the NHS

"I commend the Gold Standards Framework community palliative care as a helpful tool to help improve and co-ordinate the care and support of seriously ill patients and their carers."

Hazel Blears, MP
Minister of Public Health

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

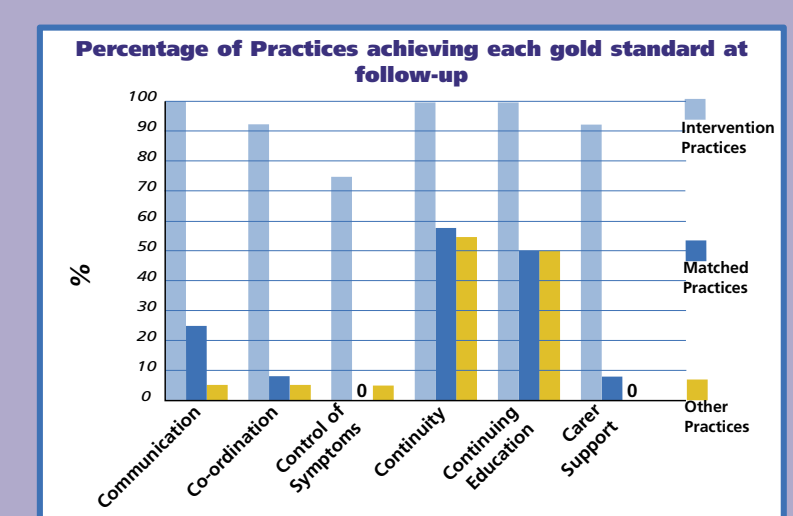
"That's what it (GSF) is all about - giving the dying person what they want. There's no argument in that"
Bereaved Carer

"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"
Graham Achard Vice Chairman RCGP

MEASURES

PHASE 1 - 2001

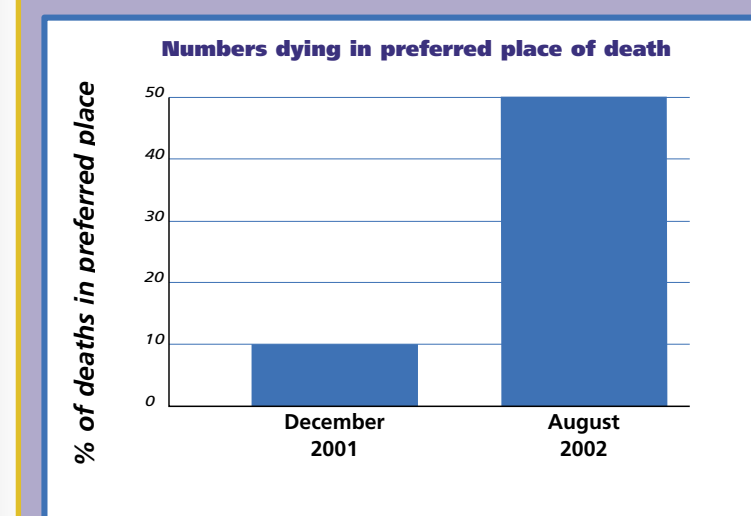
3 QUESTIONS



1. Was GSF acceptable to Primary Care teams?
Answer - Yes in terms of time and workload.
2. Did it change practice?
Answer - Yes - now practices measured and codified their care for dying patients, using a Supportive Care register, discussing them at meetings, giving written information, planning care etc
3. What were the effects of the change?
Answer - more organised care, more proactive, involving patients more, better communication, better teamworking etc

PHASE 2 - 2002

1. CSC EVALUATION
2. QUALITATIVE STUDY



Dr Nigel King - Huddersfield University Matched GSF and non GSF practices in 4 areas of the UK Findings - Fewer

patients 'slipping through the net', '..better organised care', improved communication' etc

PHASE 3/6 - 2003/4

MACMILLAN GSF EVALUATION Warwick University

