The Gold Standards Framework for end-of-life care in the community

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Our group's vision

Is for better Palliative Care

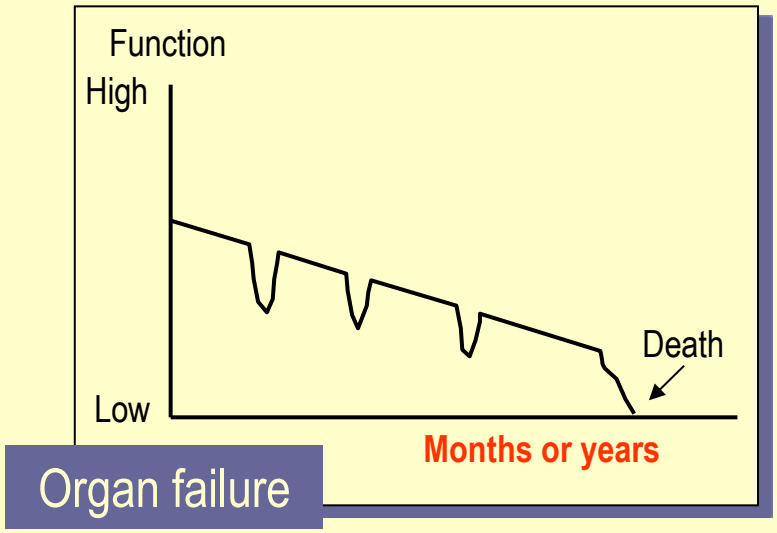
- in the community
- beyond cancer.
- including spiritual aspect.

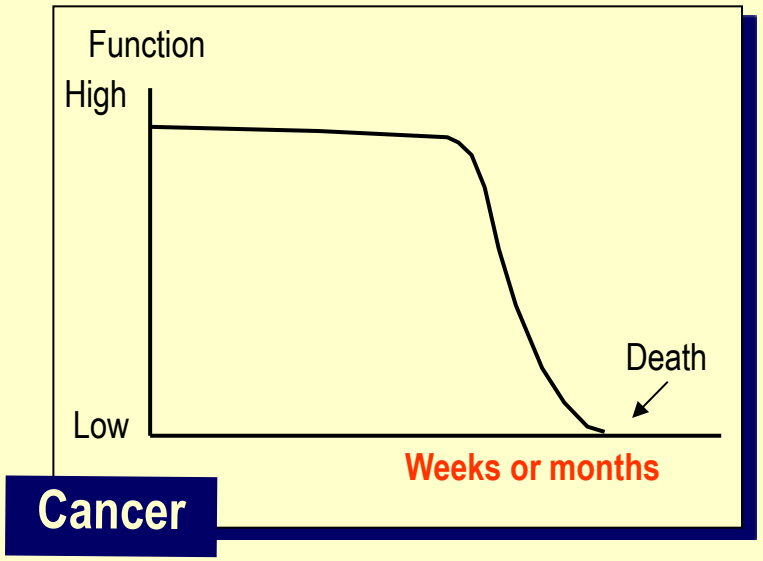
Dying in developed countries: a century of Change

	1900	2000
Age at death	46 years	82 years
Top Causes	Infection	Cancer
	Accident	Organ system failure
	Childbirth	Frail / Dementia

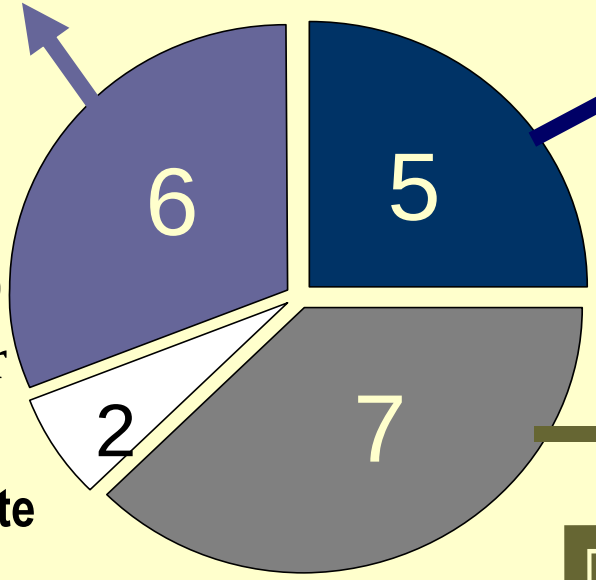

World Mortality Rate
100%
1992
100%
1993
100%
1994
100%
1995

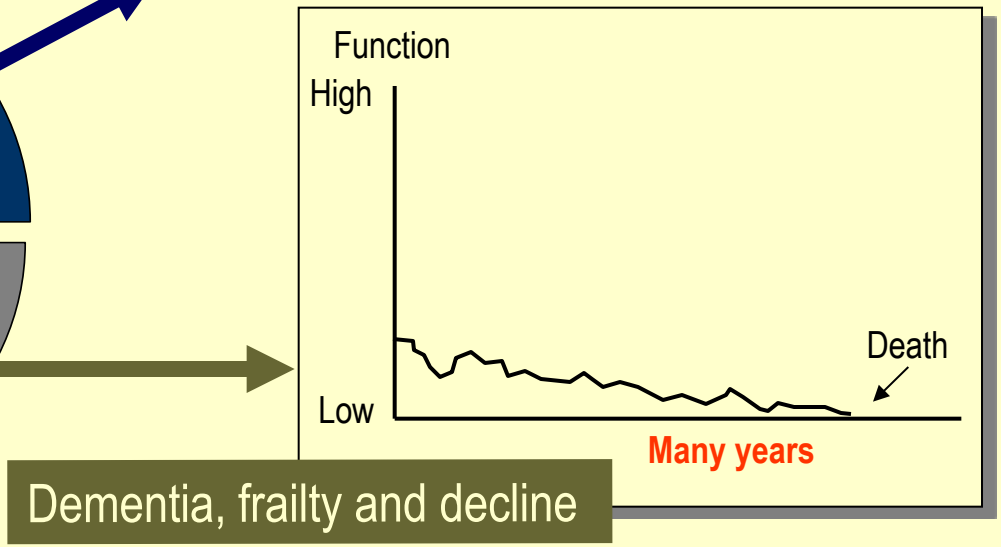
[Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ. 2005; 330:1007-1011.]





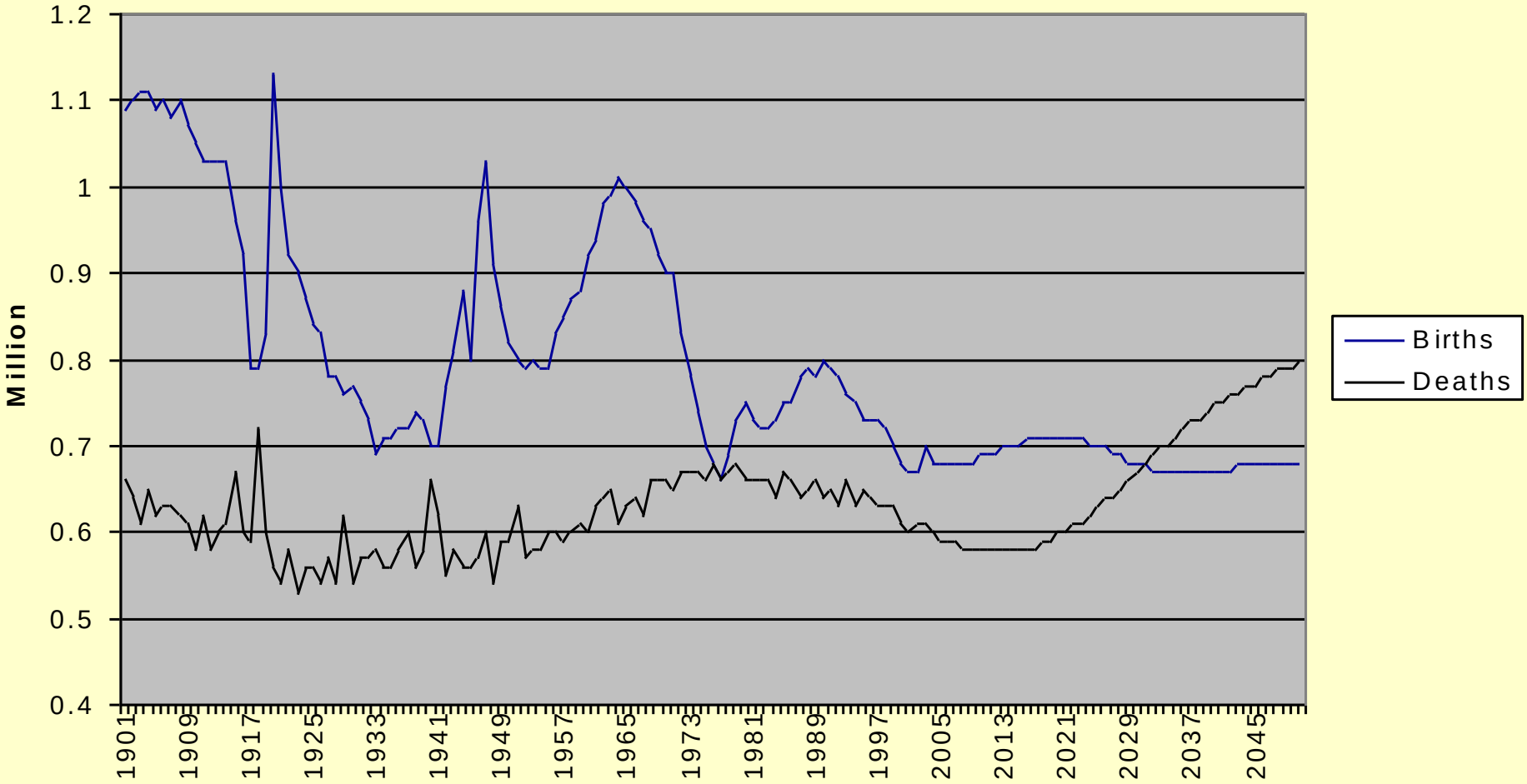
GP has 20 deaths per list of 2000 patients per year



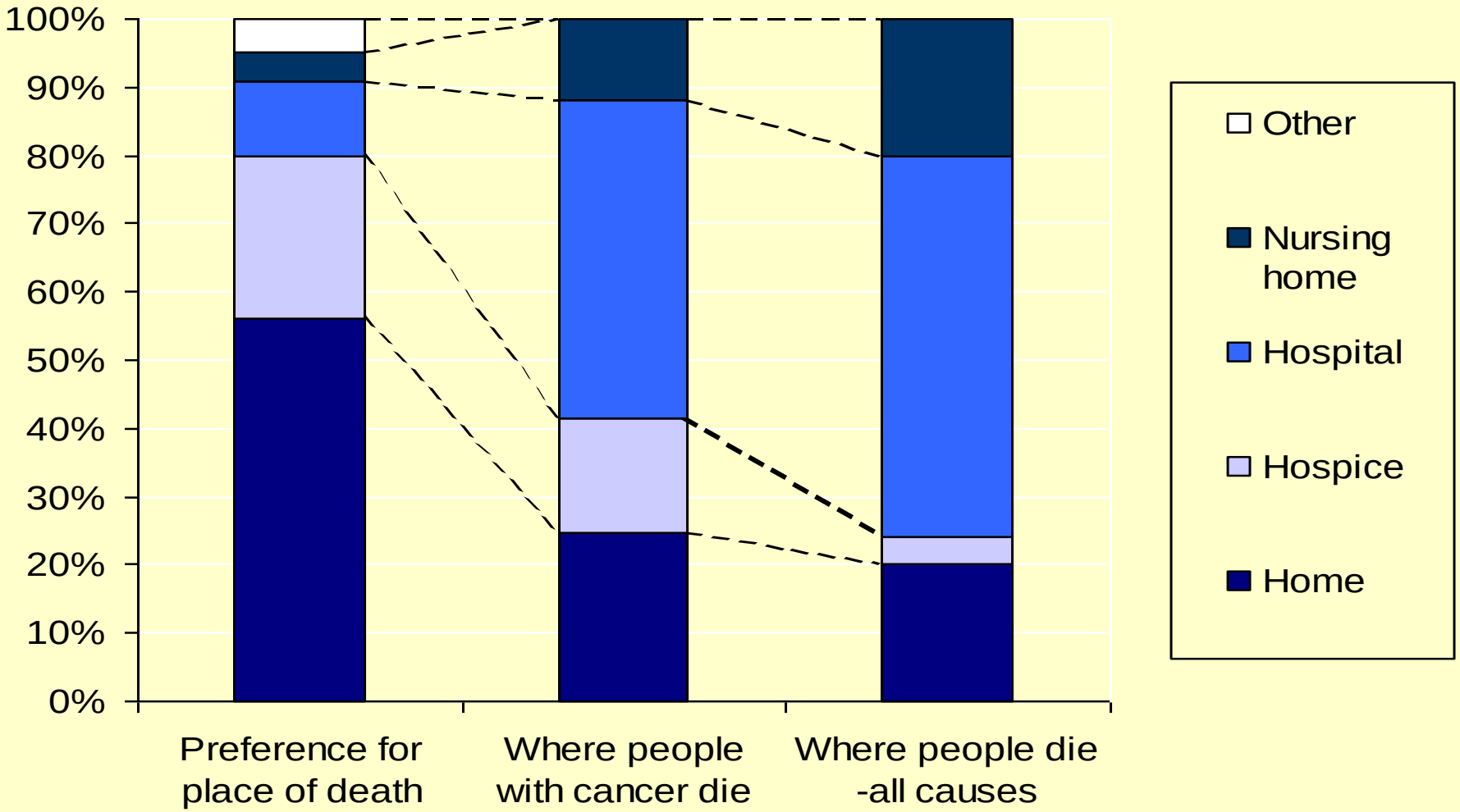


Actual and predicted births and deaths in UK 1901 - 2051

http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/facts/UK/index20.aspx?ComponentId=7041&SourcePageId=14975



Choice- preferred and actual place of death



How well do GPs deliver palliative care: systematic review

Mitchell GK Pall Med 2002 16:457-464

Patients appreciate GPs' contribution

- As they listen, allowing ventilation of feelings
- Being accessible
- Basic symptom control

GPs deliver sound and effective pall care

- Best with specialist support
- Increasing exposure/formalised engagement

5 Key factors in enabling home death

Factors influencing death at home in terminally ill patients with cancer: systematic review.

Gomes, B and Higginson, I J. BMJ 2006: 515-518

1. Intense sustained reliable home care
   - *Primary care working optimally,*
   - *Supportive care in the home*
2. Self care - public education
3. Support for families and carers
4. Advance Care planning- risk assessment
5. Training practitioners

the gold standards framework

Caring for the dying in the community.

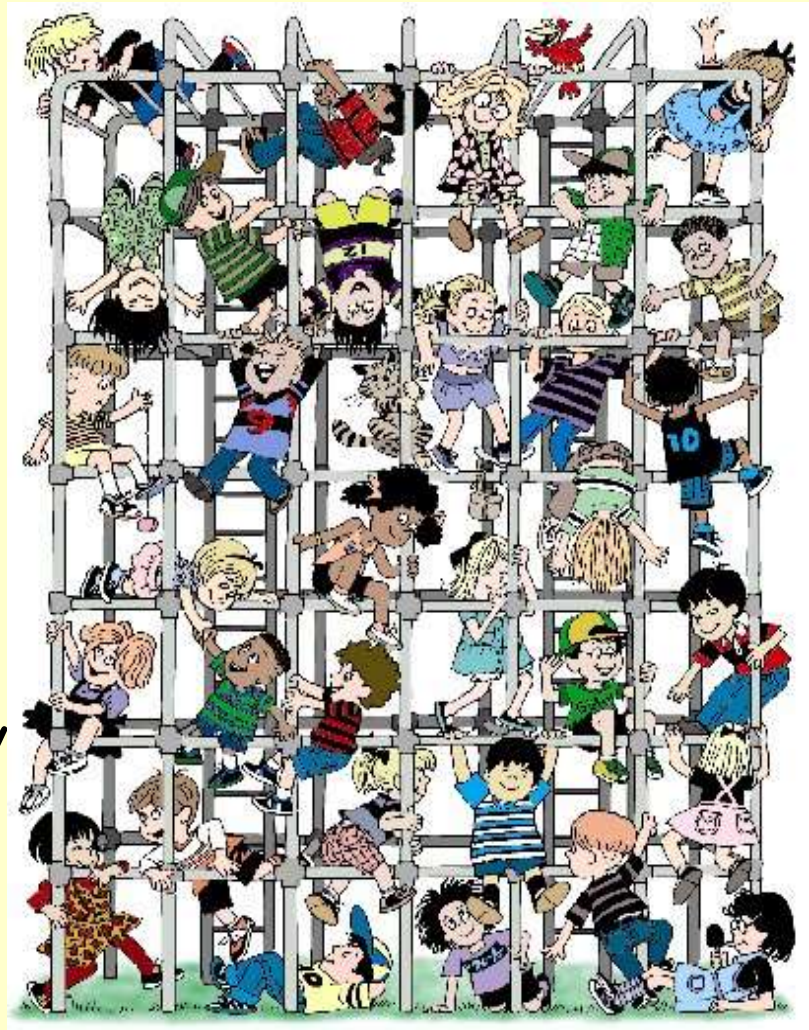
Acknowledgments to Dr Keri Thomas
National Clinical Lead for the GSF Centre
RCGP End of Life Care Clinical Champion
Senior Clin. Lecturer University of Birmingham

www.goldstandardsframework.nhs.uk

The Gold Standards Framework

A framework to deliver a 'gold standard of care' for all people approaching the end of their lives

A systematic approach to **optimising** the care delivered by generalist healthcare professionals



The Framework

- System developed by primary care for primary care
- Common sense approach
- Formalises the best standards of care into normal practice
- Builds on the good work that many are doing already

GSF - Why?

- **Patients** – improve quality of life in last year, in preferred place of care, with fewer crises
- **Carers** - feel supported, informed, involved, acknowledged, empowered
- **Staff** - increase in confidence, teamwork, communication, job satisfaction

A positive approach: allowing health promotion in the face of death

How can we make the best of the final months and years?

"Its all about living well until you die!"

The Key Tasks or 7 Cs

- Communication
- Co-ordination
- Control of symptoms
- Continuity out of hours
- Continued learning
- Carer support
- Care in the last days/week

C1 - Communication

- Palliative care register

- Regular primary care team meetings
  - Identify patients/carers
  - Assess and anticipate need
  - Plan care
  - Share information with team

C2 - Co-ordination

- Identify co-ordinator/lead nurse/lead GP
- Maintain "palliative care" register
- Organise multidisciplinary team meetings

C3 - Control of Symptoms

- Assessment tools
- Plan and review treatment
- Physical, psychological, social, practical and spiritual

C4 - Continuity

- Send handover form to out-of-hours provider
- Information to patients, carers, use of home pack
- Continuity with practice team
- Dovetailing with specialist palliative care services

C5 - Continued Learning

- Learn as you go
- Audit/review meetings
- Significant Event Analysis sessions
- Team identifies own learning needs

C6 - Carer Support

- Identify carers (carer register)
- Practical information
- Emotional and bereavement support

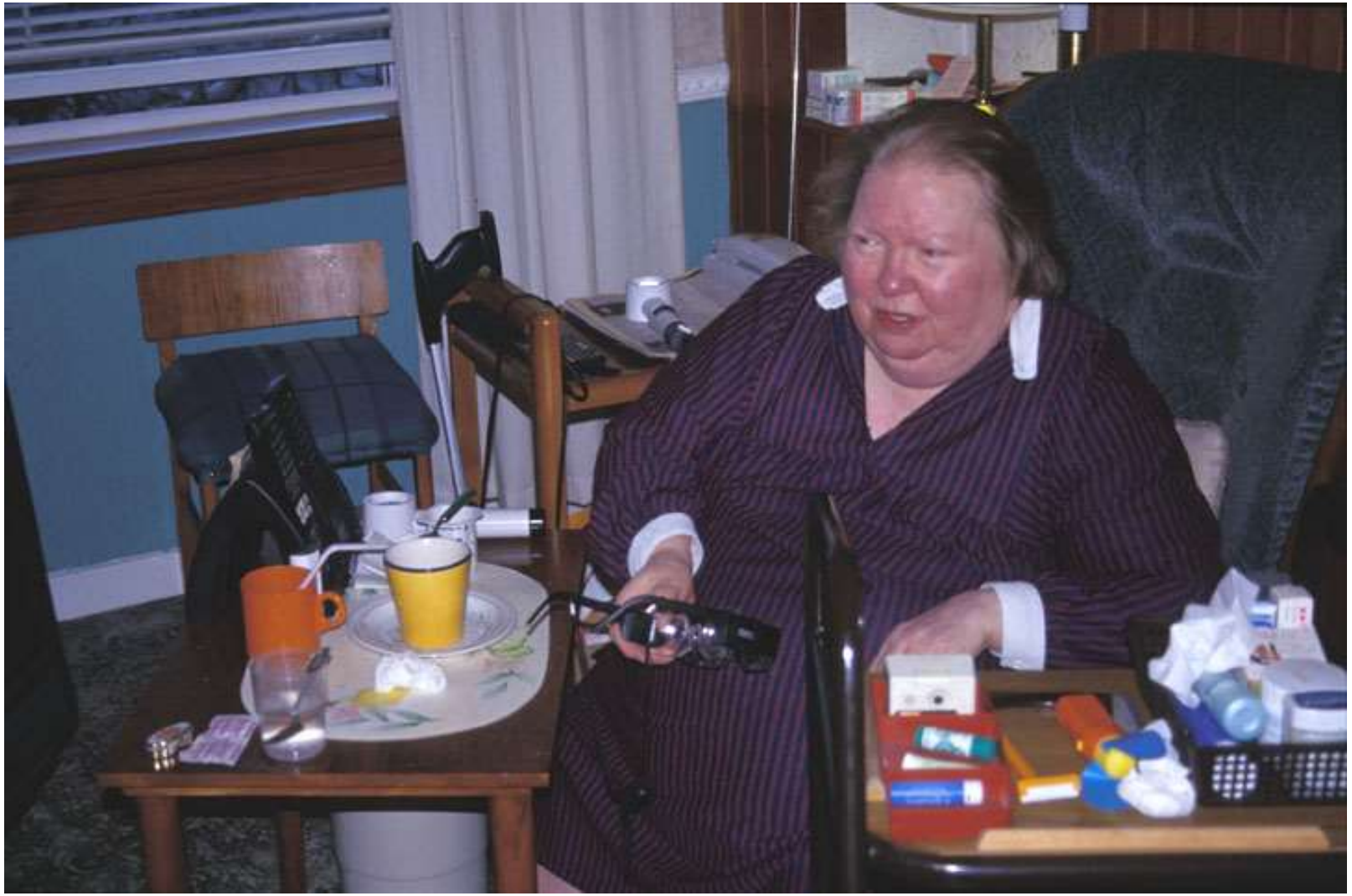
C7 - Care of the Dying

- Protocol checklist for care of the dying
- Anticipatory care
- Care Pathway eg Liverpool Care Pathway

3 steps of GSF

- **Identify** palliative care patients and use a register
- **Assess** physical, psychosocial and spiritual needs of patients (and carers)
- **Plan** ahead and share appropriate information across teams

Organ failure trajectory



Frailty trajectory

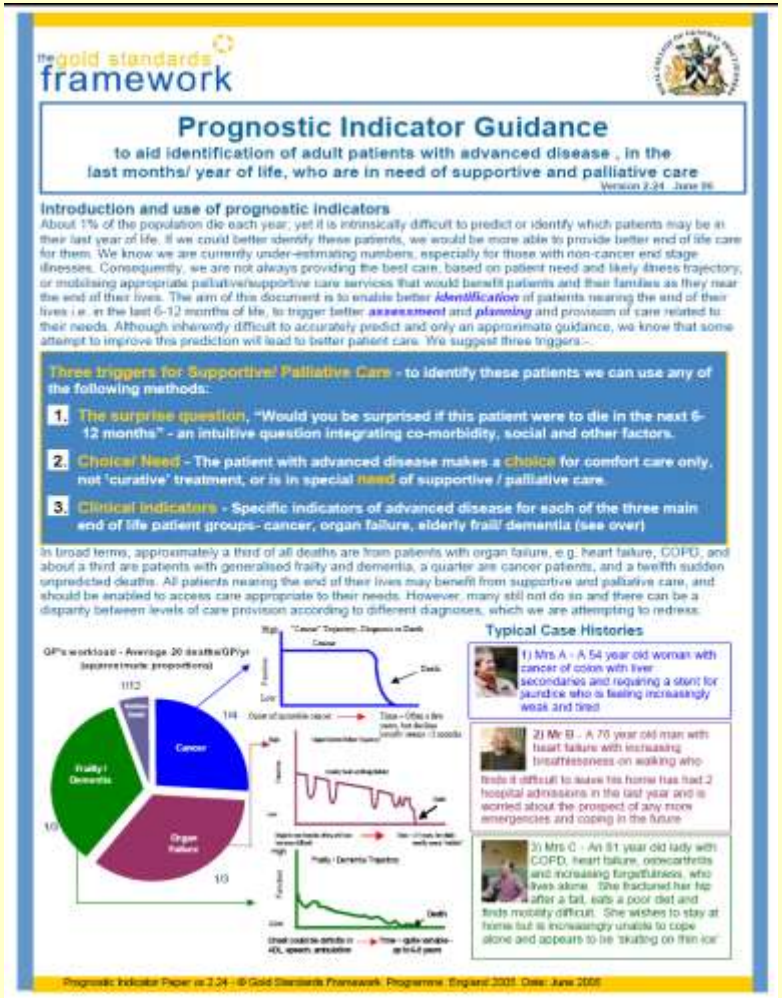
GSF "Prognostic" Indicator Guidance- identifying pts with advanced disease in need of palliative/ supportive care/for register

Three triggers

1. **Surprise question-** would you be surprised if the pt was to die within a year?

2. **Critical/events-** hospital admission, admission to care home?

3. **Clinical indicators** for each disease area eg Ca metastases, NY Stage FEV1, Karnowski, etc



the gold standards framework

Prognostic Indicator Guidance

to aid identification of adult patients with advanced disease , in the last months/ year of life, who are in need of supportive and palliative care

Version 2.24 June 06

Introduction and use of prognostic indicators

About 1% of the population die each year; yet it is intrinsically difficult to predict or identify which patients may be in their last year of life. If we could better identify these patients, we would be more able to provide better end of life care for them. We know we are currently under-estimating numbers, especially for those with non-cancer end stage illnesses. Consequently, we are not always providing the best care, based on patient need and likely illness trajectory, or mobilising appropriate palliative/supportive care services that would benefit patients and their families as they near the end of their lives. The aim of this document is to enable better *identification* of patients nearing the end of their lives i.e. in the last 6-12 months of life, to trigger better *assessment* and *planning* and provision of care related to their needs. Although inherently difficult to accurately predict and only an approximate guidance, we know that some attempt to improve this prediction will lead to better patient care. We suggest three triggers:-

Three triggers for Supportive/ Palliative Care - to identify these patients we can use any of the following methods:

1. **The surprise question, "Would you be surprised if this patient were to die in the next 6-12 months" - an intuitive question integrating co-morbidity, social and other factors.**
2. **Choice/ Need - The patient with advanced disease makes a choice for comfort care only, not 'curative' treatment, or is in special need of supportive / palliative care.**
3. **Clinical indicators - Specific indicators of advanced disease for each of the three main end of life patient groups- cancer, organ failure, elderly frail/ dementia (see over)**

In broad terms, approximately a third of all deaths are from patients with organ failure, e.g. heart failure, COPD, and about a third are patients with generalised frailty and dementia, a quarter are cancer patients, and a twelfth sudden unpredicted deaths. All patients nearing the end of their lives may benefit from supportive and palliative care, and should be enabled to access care appropriate to their needs. However, many still not do so and there can be a disparity between levels of care provision according to different diagnoses, which we are attempting to redress.

GP's workload - Average 20 deaths/GP/yr (approximate proportions)

112 Cancer 10 Organ Failure 10 Frailty / Dementia

Typical Case Histories

1) Mrs A - A 54 year old woman with cancer of colon with liver secondaries and requiring a stent for jaundice who is feeling increasingly weak and tired

2) Mr B - A 70 year old man with heart failure with increasing breathlessness on walking who finds it difficult to leave his home has had 2 hospital admissions in the last year and is worried about the prospect of any more emergencies and coping in the future

3) Mrs C - An 81 year old lady with COPD, heart failure, osteoarthritis and increasing forgetfulness, who lives alone. She fractured her hip after a fall, eats a poor diet and finds mobility difficult. She wishes to stay at home but is increasingly unable to cope alone and appears to be 'skating on thin ice'

Prognostic Indicator Paper ver 2.24 - © Gold Standards Framework Programme England 2005. Date: June 2006

Extract from the Prognostic Indicator Guidance, GSF

2. Organ Failure Patients

2.1 Heart Disease

- CHF NYHA stage IV – shortness of breath at rest
- Patient thought to be in the last year of life - the 'surprise' question
- Repeated hospital admissions with symptoms of heart failure

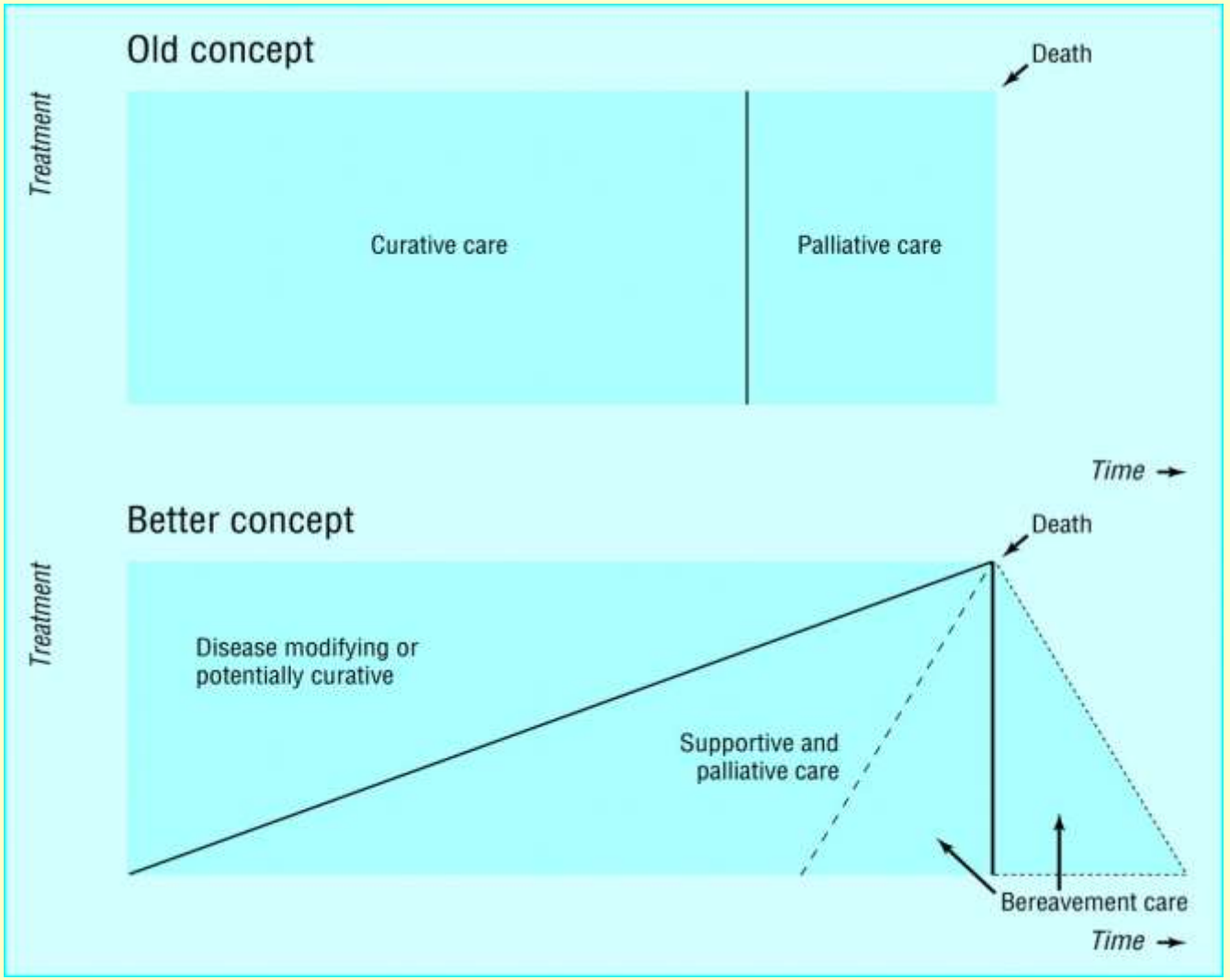
2.2 Chronic Obstructive Pulmonary Disease

- Disease assessed to be severe e.g. (FEV1 <30%predicted)
- Recurrent hospital admission exacerbations)
- Long Term Oxygen Therapy Criteria
- MRC grade 4/5 – shortness of breath

2.3 Renal Disease

- Patients with stage 5 kidney disease who are not seeking or are discontinuing dialysis or renal transplant.

Appropriate care near the end of life: from disease modifying to active palliation.



Murray, S. A et al. BMJ 2005;330:1007-1011

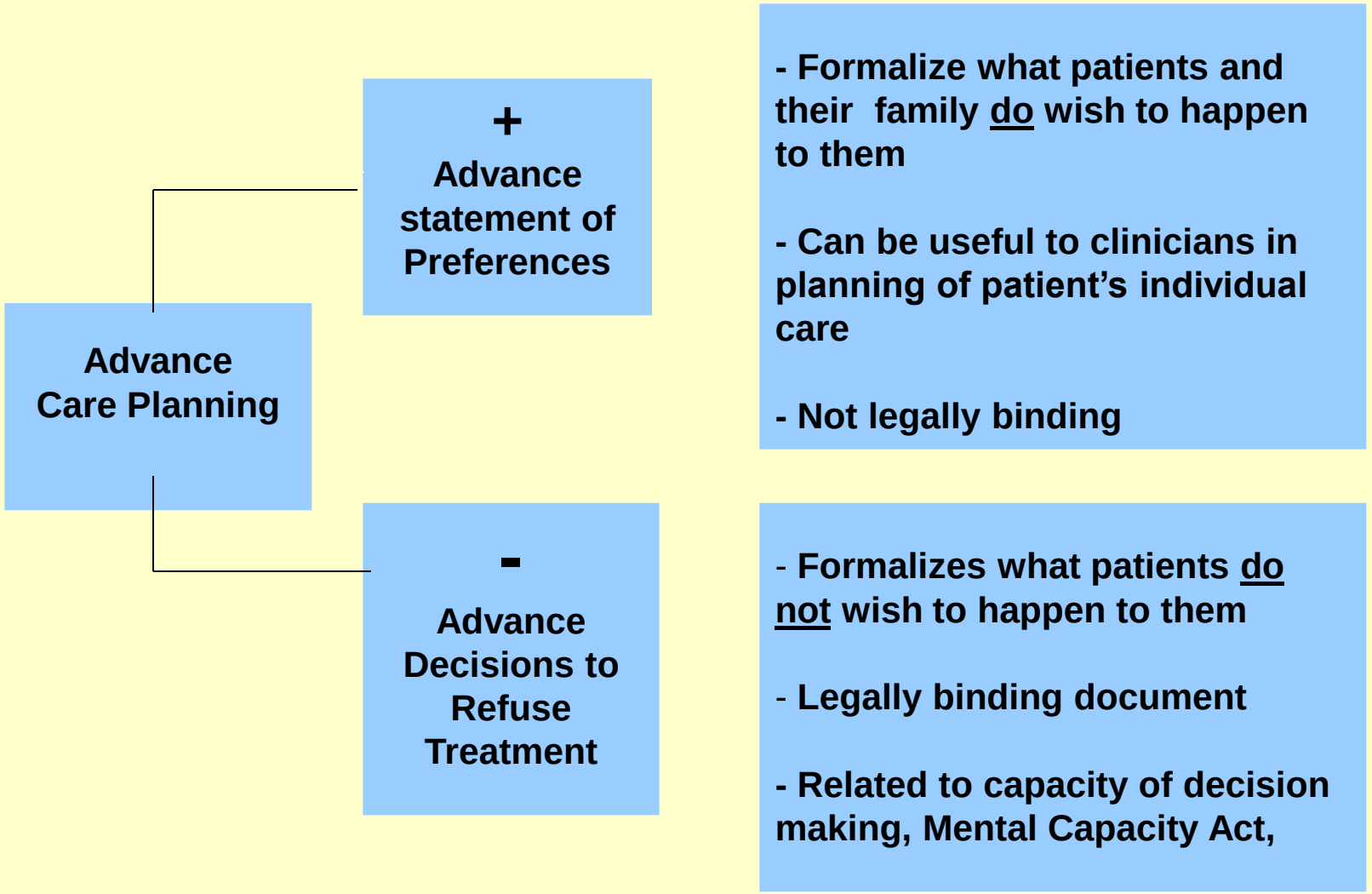
bmj.com

Assess: possible questions

Murray SA, Boyd K, and Sheikh A. Palliative care in chronic illness. BMJ. 2005; 330:611-612

- Holistic assessment
- What's the most important issue in your life right now?
- What helps you keep going?
- What is your greatest problem?
- You usually seem quite cheerful, but do you ever feel down?
- If things got worse, where would you like to be cared for?

Advance Care planning



Why do it ?

- Better planning
- Better provision of care and services to meet needs and preferences
- Preferred place of care/ death- Home death rates
- Prevent inappropriate admissions/resuscitations
- Begin realistic dialogue
- Catalyst for deeper discussions
- Enhanced Communication
- Control – self determination
- Empowerment
- Dispel fear
- Hope

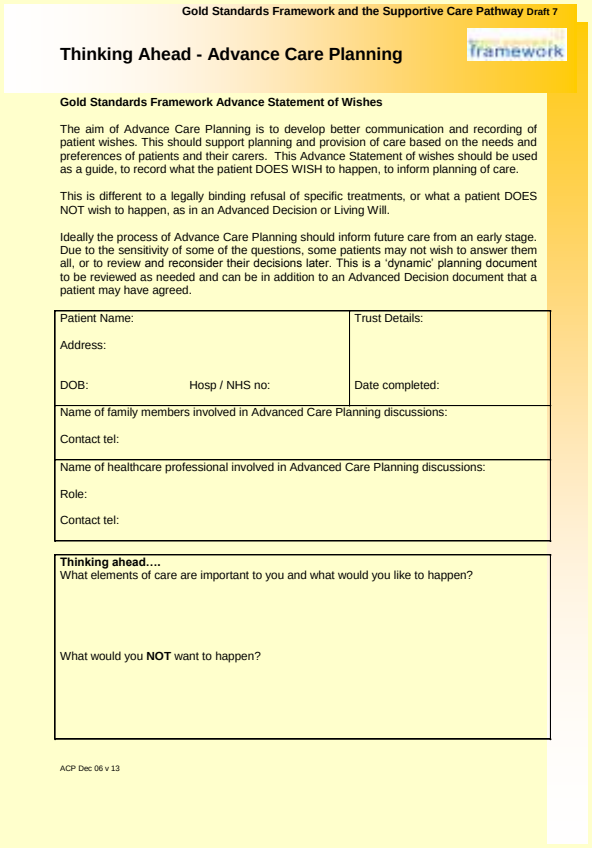
Murray SA, Sheikh A, Thomas K. Advance care planning in primary care. BMJ 2006;333: 868-869

- **What** elements of care are important to you and what would you like to happen?
- If your condition deteriorates, **where** would you like to be cared for (first and second choices)?
- Do you have a view on resuscitation if your heart suddenly stops?
- This can engender hope rather than dissipate it

GSF - Advance Care Planning

GSF template includes:

- Thinking ahead - open questions
  - what matters to pt/ carer
  - what to do and what not to do
- Proxy - who else involved (LPOA)
- Who to call in a crisis
- Preferred place of care & death, options
- Other requests eg organ donation / special instructions
- + DNAR / Allow Natural Death



Gold Standards Framework and the Supportive Care Pathway Draft 7

Thinking Ahead - Advance Care Planning

framework

Gold Standards Framework Advance Statement of Wishes

The aim of Advance Care Planning is to develop better communication and recording of patient wishes. This should support planning and provision of care based on the needs and preferences of patients and their carers. This Advance Statement of wishes should be used as a guide, to record what the patient DOES WISH to happen, to inform planning of care.

This is different to a legally binding refusal of specific treatments, or what a patient DOES NOT wish to happen, as in an Advanced Decision or Living Will.

Ideally the process of Advance Care Planning should inform future care from an early stage. Due to the sensitivity of some of the questions, some patients may not wish to answer them all, or to review and reconsider their decisions later. This is a 'dynamic' planning document to be reviewed as needed and can be in addition to an Advanced Decision document that a patient may have agreed.

Patient Name: Address: DOB: Hosp / NHS no:	Trust Details: Date completed:
Name of family members involved in Advanced Care Planning discussions: Contact tel:	
Name of healthcare professional involved in Advanced Care Planning discussions: Role: Contact tel:	

Thinking ahead….
What elements of care are important to you and what would you like to happen?

What would you **NOT** want to happen?

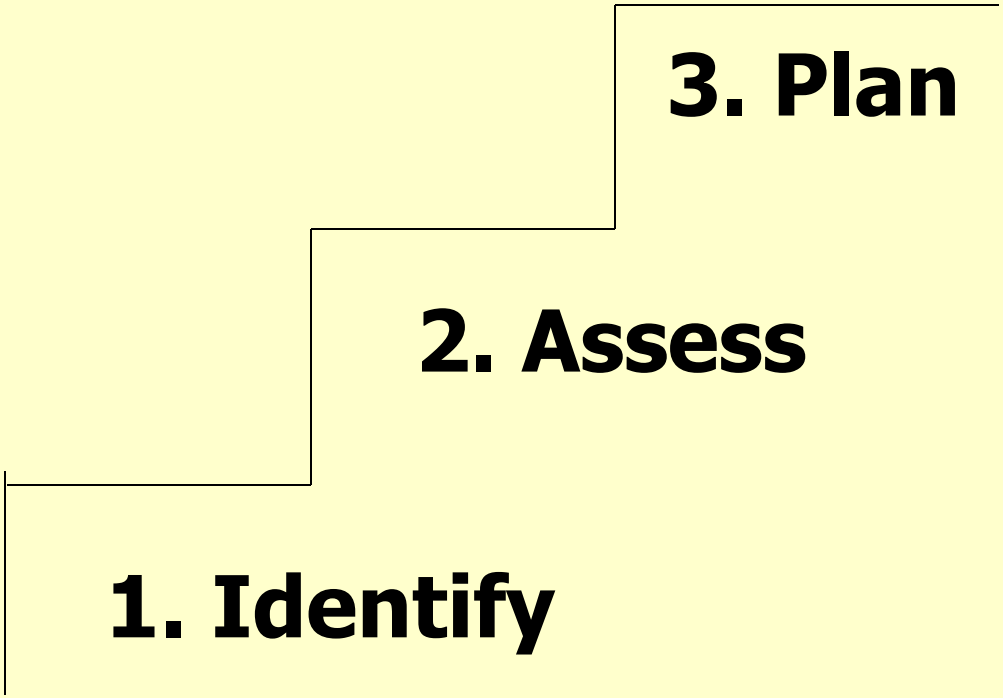
ACP Dec 06 v 13

C7 Care of the dying pathway

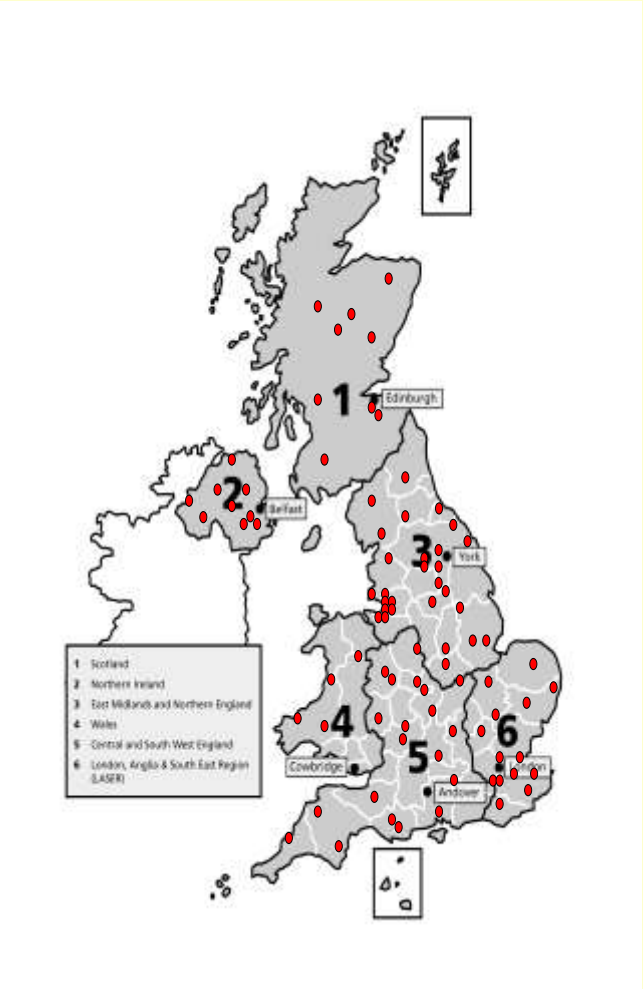
http://www.mcpcil.org.uk/liverpool_care_pathway

- Initiate specific document
- All possible reversible causes have been considered
- Multi-disciplinary team confirmed patient is dying
- Non-essential meds stopped
- Write up prn Sub-cut meds
- Communicate with relatives……

GSF 3 Steps



1. GSF Primary care Spread most GP practices using GSF basic level 1



- **90% practices GSF Level 1 (register and planning meeting)** Mainstreaming through GP contract

- **60%+** practices using GSF in UK, covering almost 3/4 of the population (2 surveys)

- **15%** Estimated using GSF Level 4

Evaluation of GSF

- King N, Thomas K, Martin N, Bell D, Farrell S, & "Now nobody falls through the net Practitioners perspectives on the Gold Standards Framework for community palliative care *Palliative Medicine2005:19:619-627*
- Murray S, Boyd K, Sheikh A, Thomas K , Higginson I Developing primary palliative care Editorial *BMJ* 2004:329:1056-1057
- Thomas K (2003) The Gold Standards Framework in Community Palliative Care, *European Journal Palliative Care* 03:10(3) 113-115
- Munday D, Dale J. The Gold Standards framework BMJ Editorial 2007

Successes with using GSF

1.Attitude awareness and approach –

- **Better quality** of care perceived
- Greater confidence and job satisfaction
- Immeasurable benefits- communication, teamwork, roles respected esp DNs
- Focus + proactive approach**,**

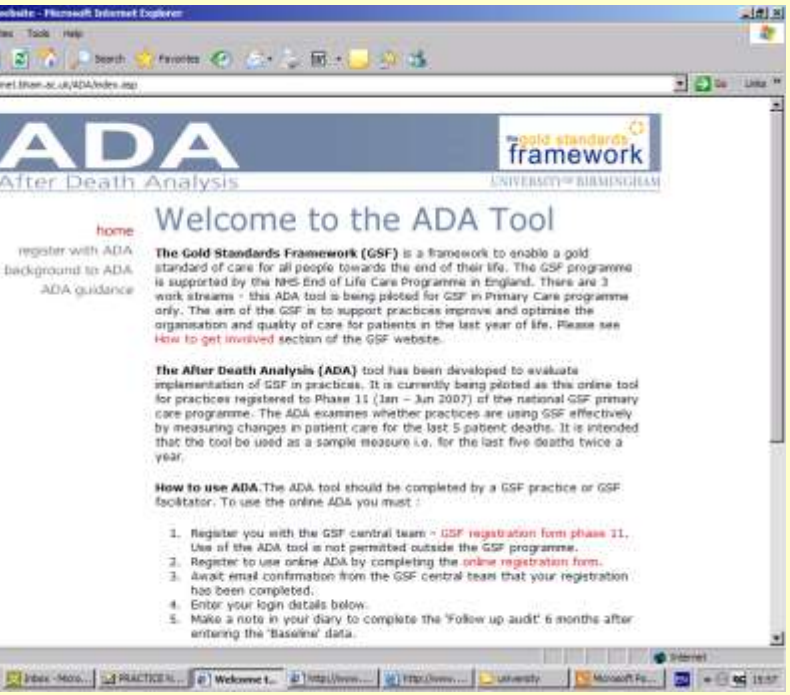
2.Patterns of working, structure/ processes

- **Better organisation + consistency** of standards, even under stress
- Fewer slipping through the net- raising the baseline
- Better communication within and between teams, co-working with specialists
- Better recording ,tracking of pts and organisation of care

3. Patient Outcomes

- **Reduced crises/ hospital admissions /**length of stay
- Some doubled home death rate- more pts dying in preferred place
- More recorded Advance care planning discussions

Online After Death Analysis (ADA) Audit Tool



ADA measures patient outcomes eg place of death, preferences, use of services etc

1. Comparative- before and after
2. Benchmarking

Gold Patients !

- Patients know they are on the 'gold' register
- Implies best care
- Encouraging if heard no more can be done for them

GSF Care Homes Programme

- Over **600** nursing homes so far in UK

- **Structured programme**
  - *3 stages-Preparation, training, consolidation over 18 months*
  - *4 gears, 4 workshops + homework*
  - *Facilitator training and support*

- **Fully resourced+ Locally facilitated**

- **Quality assurance- Accreditation process**

- **Evaluation**-Improved quality of care, Decreased hospital admissions by **12%** , Decreased hospital deaths by **8%**

Identification of need in Care Homes patients- GSFCH

Prognostic coding ABCD

A - All residents on admission- **years**

B - Benefits (DS1500) - **months**

C - Continuing care funding - **weeks**

D - Last days of life pathway- **days**

Overall conclusions

Clifford C. Badger F.
University of Birmingham

1. **The GSFCH programme makes a positive difference to the quality of end of life care in Care Homes**

2. **Evidence of reduction of crisis admissions to hospital - changing place of death.**

3. **The ADA tool is a simple effective measurement tool for end of life care- ongoing benchmarking potential.**

Using GSF can enable…

- Improved attitude, processes + outcomes
- Increase numbers dying where prefer
- Increase home death rate
- Decrease hospital death rate
- Improve collaboration + teamwork
- Improved knowledge + confidence of staff
- Contribute to better end of life care

This is about life before death

"Our aim is that every person should be able

to live well

and die well

in the place and in the manner of their choosing"

Living & Dying in Style

Dr. Eric Fairbank

physical

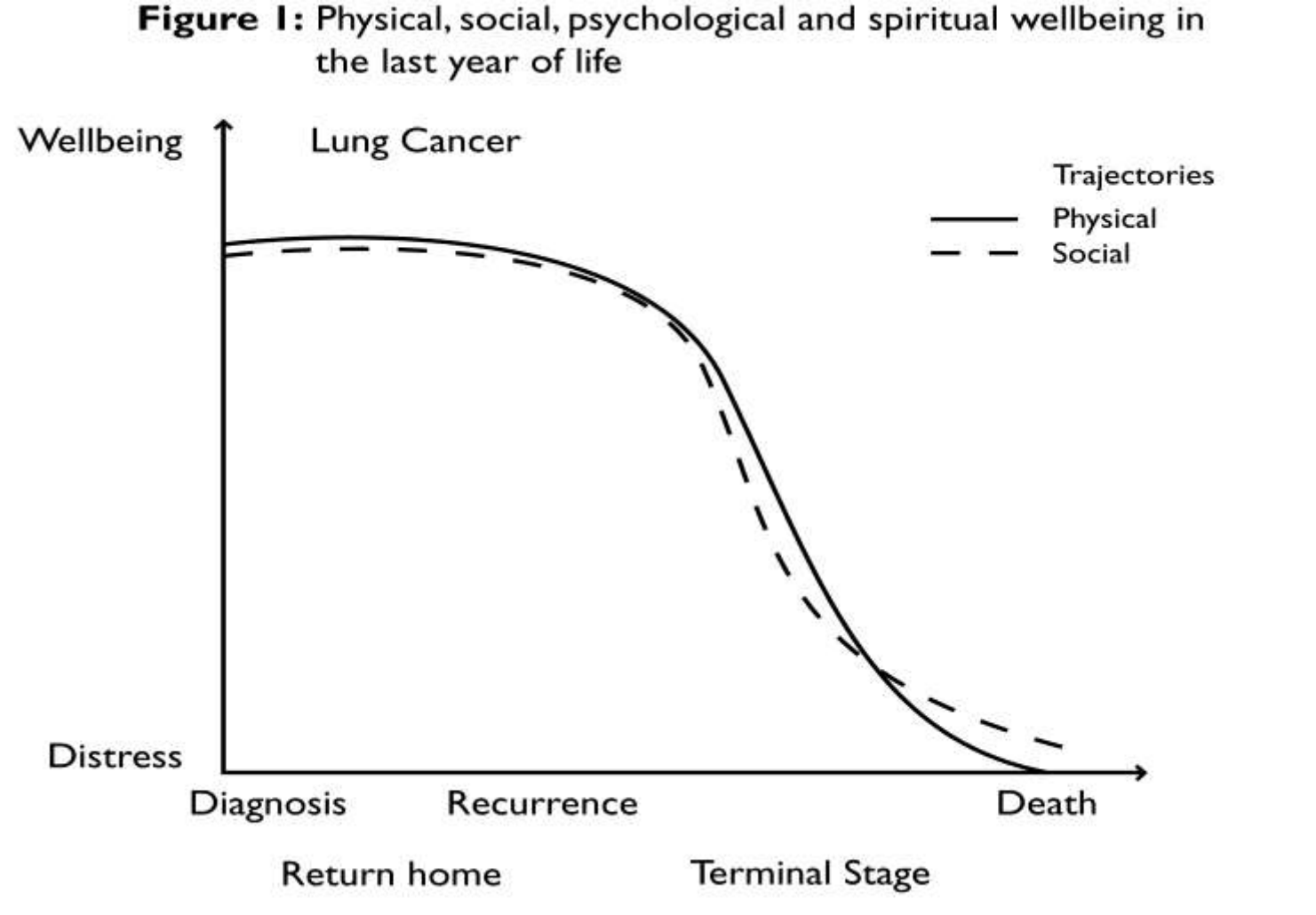
psychological

social

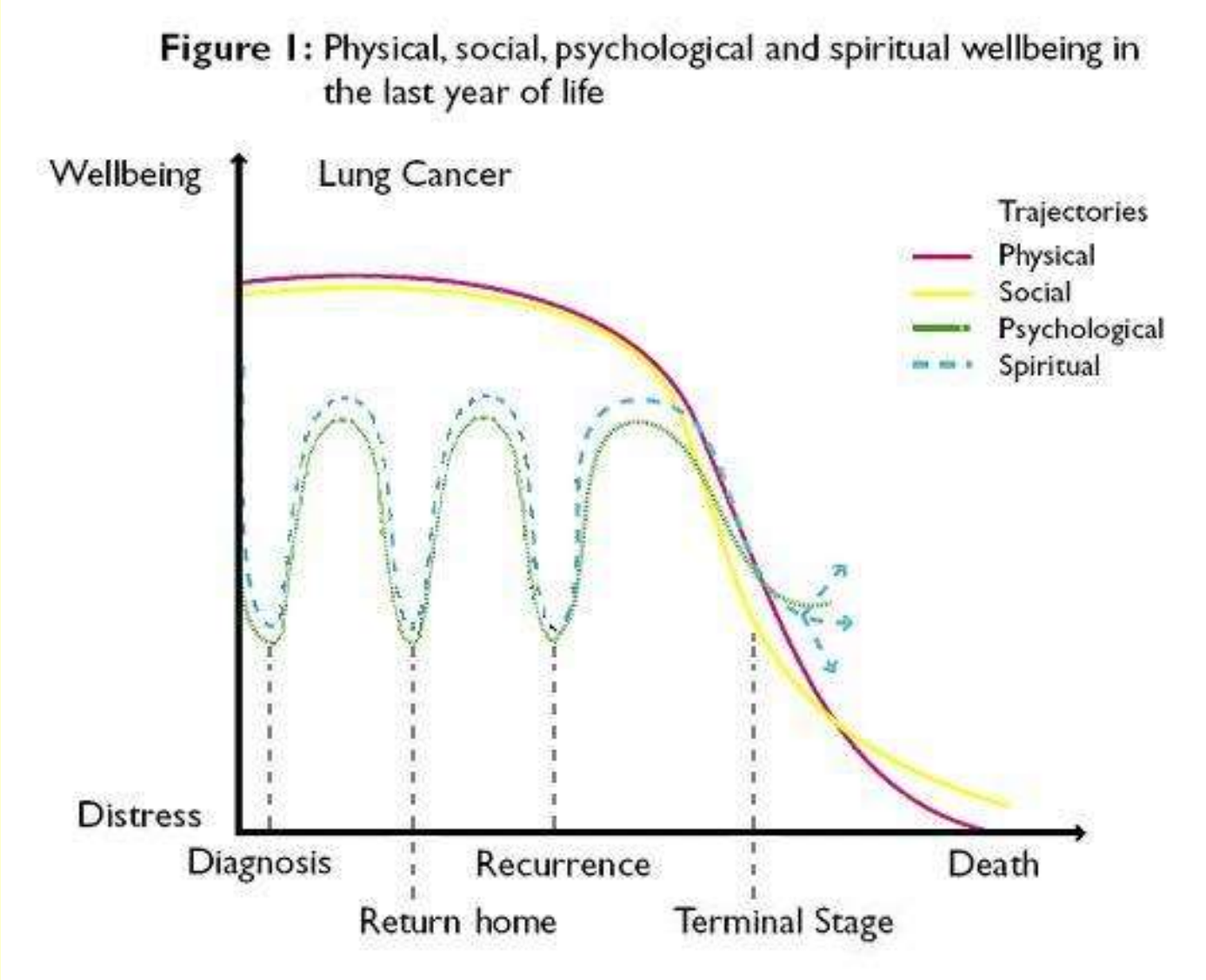
spiritual

Death is multi-dimensional

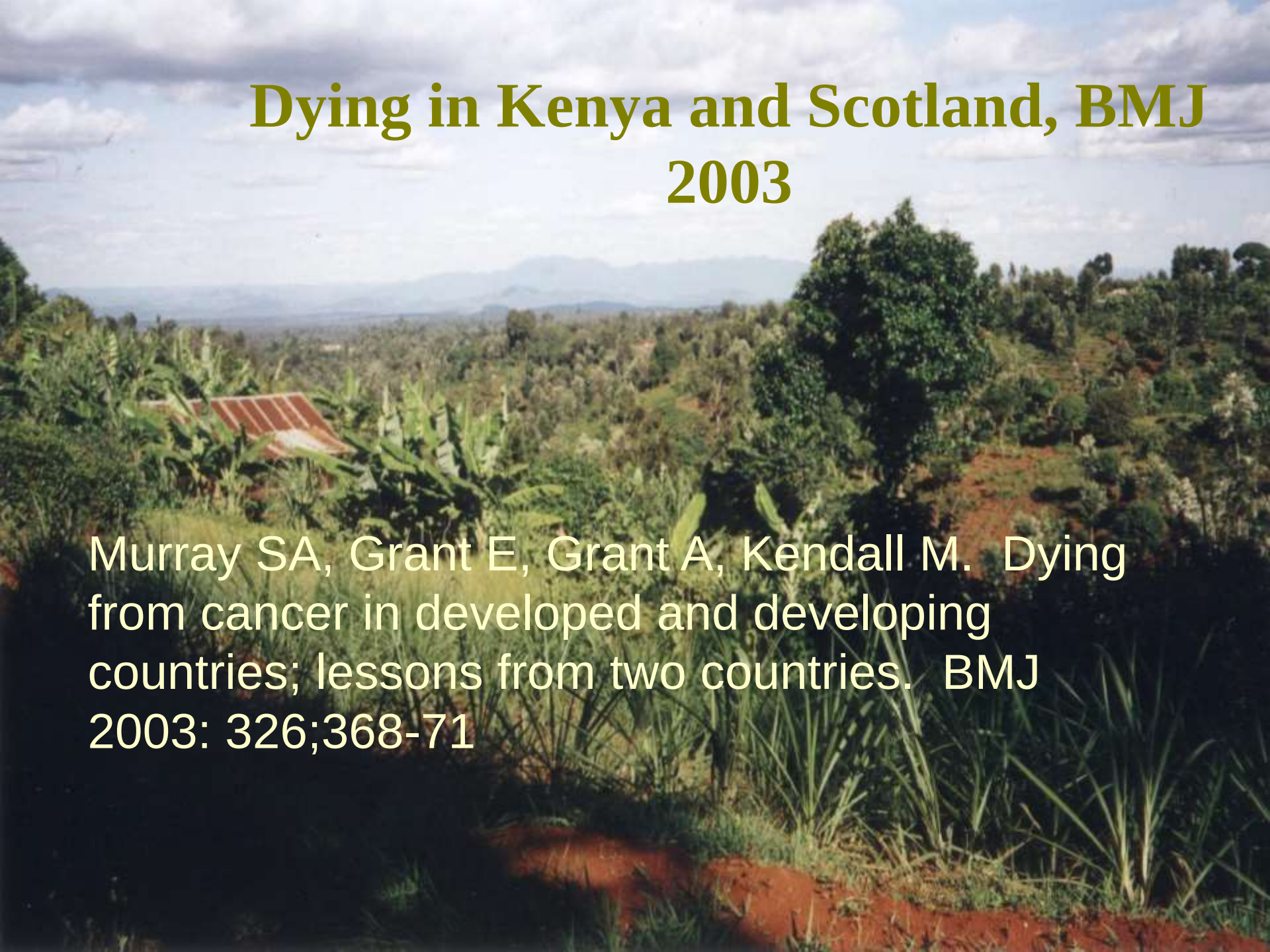
His old friends won't even take a cup of tea with me now I've got cancer" Mrs LR.



Murray et al, J Pain & Symptom Management 2007;34(4):393-402.



Dying in Kenya and Scotland, BMJ 2003



Murray SA, Grant E, Grant A, Kendall M. Dying from cancer in developed and developing countries; lessons from two countries. BMJ 2003: 326;368-71

Kenya

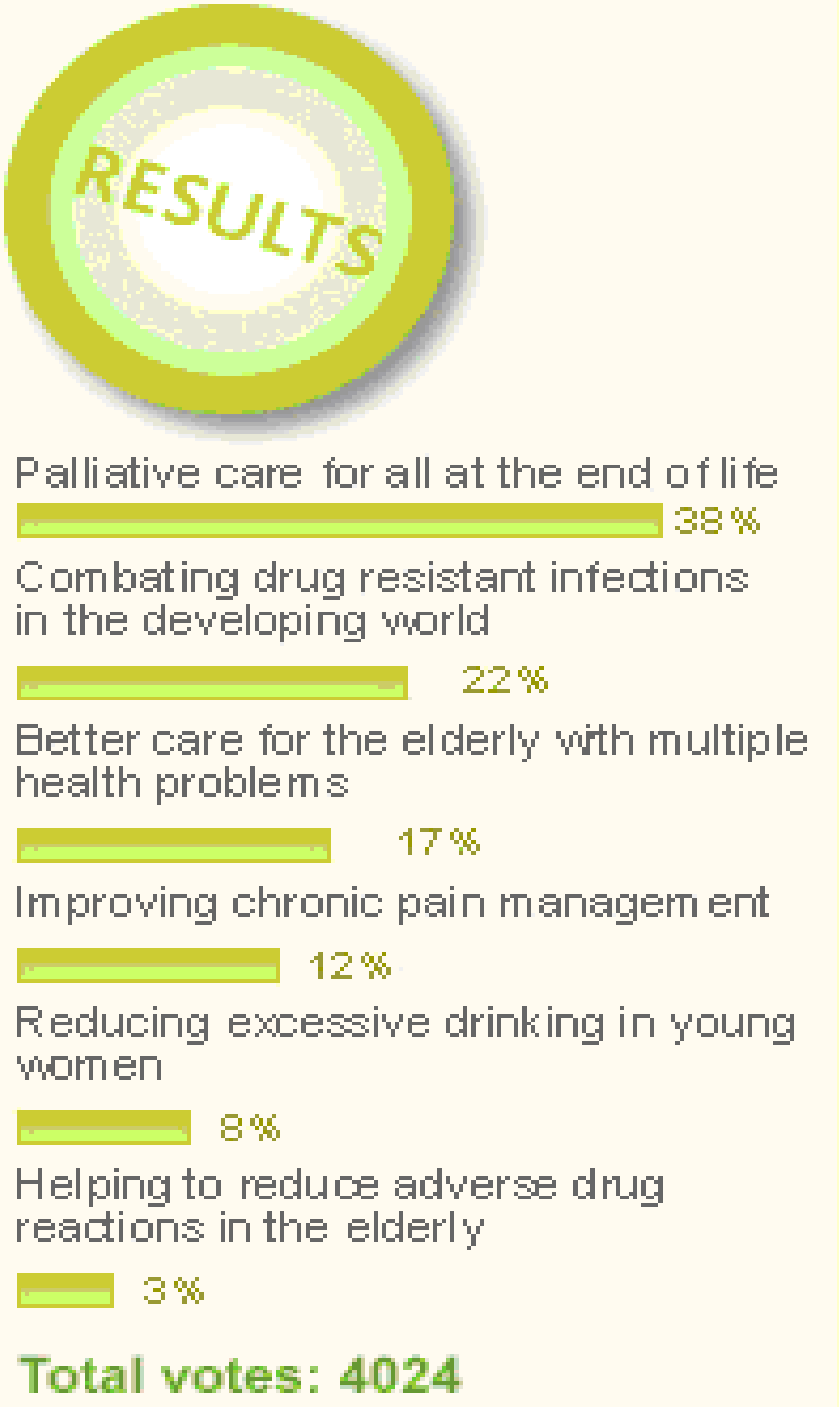
- Pain
- Peace

- We can learn about public awareness and community support

Scotland

- Little pain
- Angst

- We can go to help establish and train in pain control



Dr Fiona Godlee, BMJ Editor said:

- *Care for non-malignant disease will now be prioritised by the BMJ publishing group over the coming years, by commissioning and inviting work in the BMJ Group's 24 specialist journals, in BMJ Clinical Evidence, Best Treatments, and BMJ learning ".*

Develop, evaluate and publish

Better end-of-life care

- in the community
- beyond cancer- PCFA
- including spiritual aspect

Shifting Terms

- **End of Life care**
  - ***'Care that helps all those with advanced progressive incurable illness to live as well as possible until they die'***
  - *Pts living with the condition they may die from- weeks/months/ years*
  - *All illnesses*

  Supportive Care
  - *Helping the patient and family cope better with their illness*
  - *not disease or time specific, '*
- **Palliative care**
  - *holistic care (physical psychological, social, spiritual)*
  - *specialist and generalist palliative care*
  - *Can overlap with curative treatment*
- **Terminal care/ Final days**
  - *Diagnosing dying-care in last hours and days of life*