Palliative & End of Life Care in Frailty & Dementia

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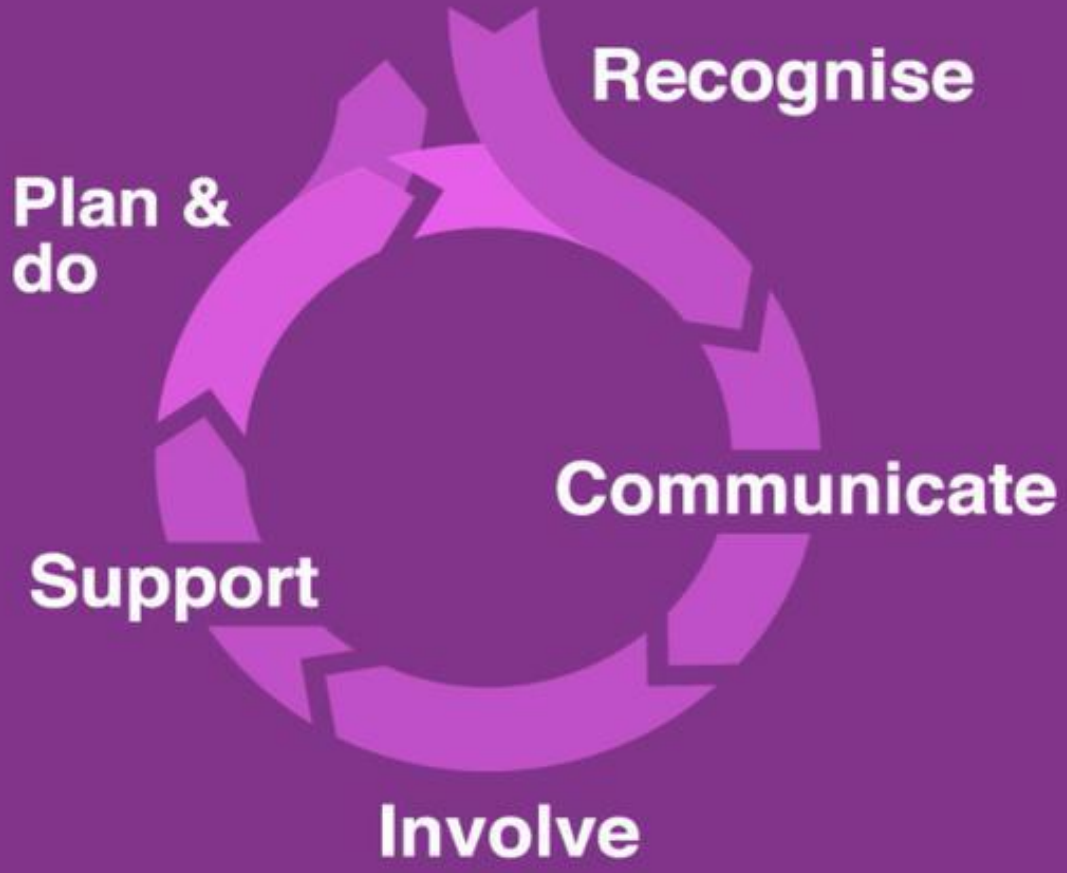
One Chance to get it right

How people die remains in the memory of those who live on

Dame Cicely Saunders (1918 - 2005) founder of the modern hospice movement

Priorities of Care for the Dying Person



Leadership Alliance for the Care of Dying People 2014

“Recognise”

- Prognostication
- Diagnosing/recognising dying

Why prognosticate?

To predict ***needs,***

not exact prognosis

Prognostication

Examples of prognostic indicators:

- NYHA
- WHO/ECOG performance status
- Barthel Index
- Karnofsky performance status
- MRC grade
- Aspiration pneumonia
- Readmission rates
- Responsiveness to treatment

THE GOLD STANDARDS FRAMEWORK (GSF) PROGNOSTIC INDICATOR GUIDANCE

GSF Prognostic Indicator for Dementia

< 12 months prognosis

Unable to walk without assistance and:

- Urinary and faecal incontinence
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score <3.

Plus any of the following:

- Weight loss
- Urinary tract Infection
- Severe pressures sores – stage three or four
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia.

GSF Prognostic Indicator for Frailty

< 12 months prognosis

- Multiple comorbidities with signs of impairments in day to day functioning
- Deteriorating functional score eg EPOC/Karnofsky
- Combination of at least 3 symptoms of: weakness, slow walking speed, low physical activity, weight loss, reduced weight loss, self reported exhaustion

The ‘Surprise’ Question

“Would you be surprised if the patient were to die in the next few months, weeks, days?”

- The answer should be an intuitive one
- Not attempting to answer the question: ‘how long have I got?’

Responds to the underlying *sometimes unspoken* questions from people facing a new reality ‘If I haven’t got long, then *what should I do* and *how can you help*?’

How can you help?

Rainy day thinking:

"Hope for the best, prepare for the worst"

Boiler break down insurance analogy

"Paths" or "Roads" analogy

Communication skills tips

- Best guess based on scientific evidence but I’m very glad whenever I’m proven wrong in this situation

- Rate of change: Month to month, week to week, day to day explanation

Given what we know about your current condition what are your main priorities?

What is most important to you at this time?

“Would you be surprised if…”

Palliative Care Registers (*Needs Based Coding*) to deliver the right care at the right time for the right patient

A – All – stable from diagnosis - years

B – Unstable, advanced disease - months

C – Deteriorating, exacerbations - weeks

D – Last days of life – days

What is a more useful question?

"Would a palliative approach be helpful now?"

Is he palliative now?

Is he end of life now?

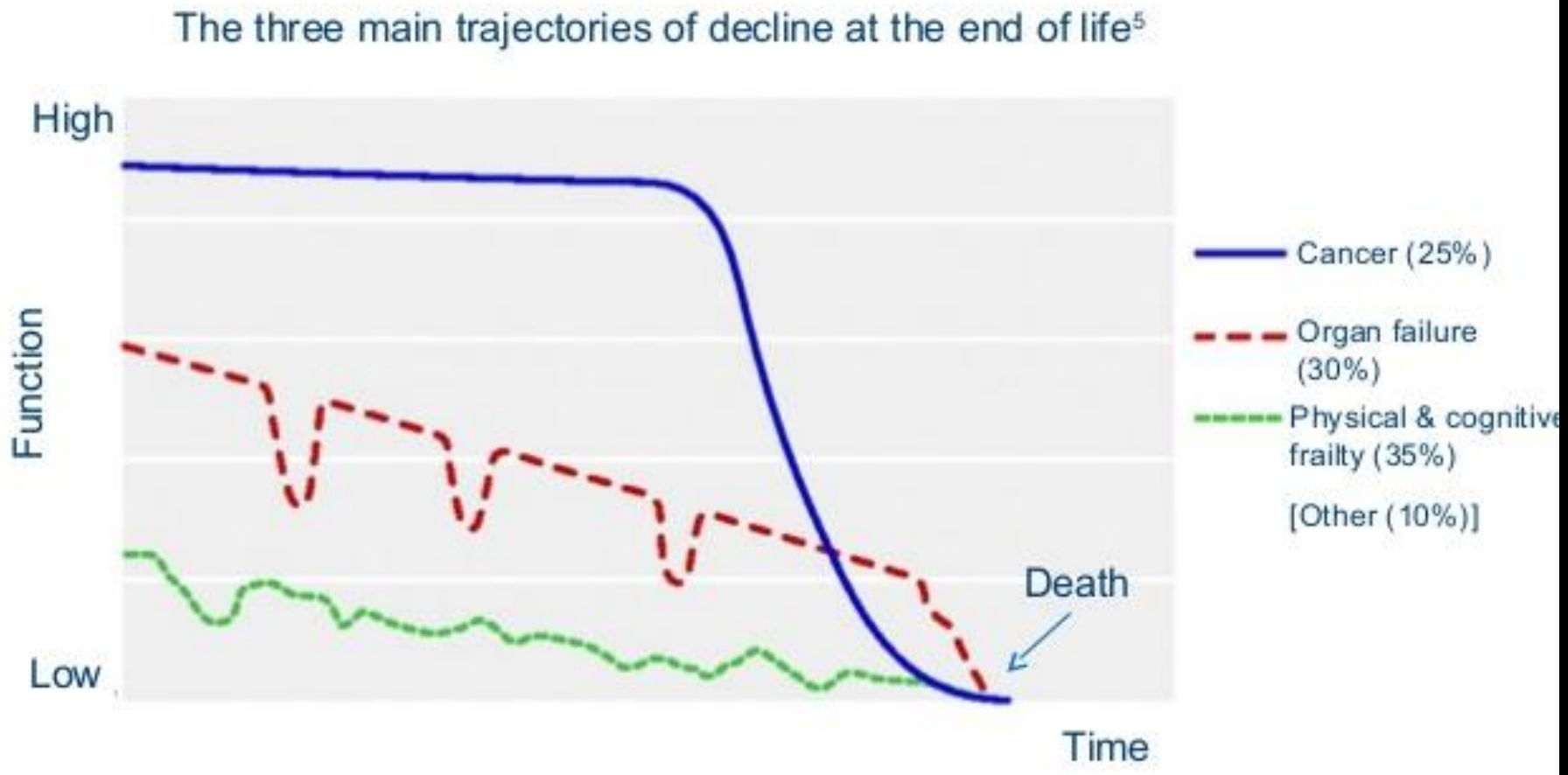
"PALLIATIVE"

- Quality of life
- Holistic care

"END OF LIFE"

- Last 12 months
- Last days of life

Background



5. Murray SA, Kendall M, Boyd K, Sheikh A. 2005. Illness trajectories and palliative care. *BMJ2005;330:1007-11.*

Recognition that the patient might die

- Cause of deterioration no longer responding to treatment

  Can this or anything else be reversed?

- Reversible causes of deterioration no longer appropriate to treat

  Should we attempt to reverse?

- Complex
- Experience helps

Case vignette: Dementia

GEORGE

George

- 81, retired teacher
- Lives with wife, Susan
- Dementia was diagnosed 5 years ago and has gradually been deteriorating
- Now dependent for all aspects of care, is doubly incontinent and has difficulty communicating
- He is able to take only 2-3 steps

George

- 3 admissions to hospital in last 12 months
  - For fall and pneumonia and UTI
  - Last admission lasted 4 weeks
  - After each episode he did not recover back to his baseline before that admission

Would a palliative approach be useful now?

WOULD YOU BE SURPRISED…

Mortality from Dementia

- Dementia registry followed 521 patients diagnosed with dementia
- Median survival from diagnosis
  - 4.2 years men
  - 5.7 years women
- Disease severity at time of diagnosis most strongly associated with survival

Larson et al. Ann Int Med 2004

George

Deteriorating again at home with pneumonia and failure to thrive:

- Had not eaten for a week
- Minimal fluid intake
- Minimally responsive
- Seems in discomfort: frowning, moaning especially when moved or changed in bed

Preferred place of care at the end of life

Will

Finances

Funeral arrangements

Other personal/family business

Resuscitation

Life-prolonging treatments

DO YOU KNOW WHAT GEORGE WOULD WANT? DOES SUSAN?

What does Susan want?

To understand.

Susan said:

How can he be dying? Doctors told me his heart and lungs are fine. I don't understand. I thought you need a heart attack, stroke or cancer to die. I never thought it would be so soon

Barriers to Palliative Care for Dementia

- Dementia not viewed as a terminal illness
- Difficulty in judging time of death
- Perceived as less rewarding
- Ageism and mental health-ism

(National Council for Hospice and Specialist Palliative Care Services and Scottish Partnership Agency for Palliative and Cancer Care, 2000)

Discussion with Susan

- Explained that it treatment in hospital is unlikely to be successful this time, may prolong death
- Explained the normal process of dying
- Asked Susan to talk about what George wants

What would George want?

Susan feels he would likely say:

- To die at home
- Surrounded by family
- Symptom free
- For the priest to attend
- Had prepared his will and funeral arrangements

George died peacefully in his own bed, in his own home, with his wife and his children around him.

Take home message

1. Prognosticate in order to anticipate needs not to predict exact time left
2. Would you be surprised if…
3. Would a palliative approach be helpful now?