Recognising Dying

DR KATE STEWART

CONSULTANT IN PALLIATIVE MEDICINE

Learning Objectives

1. To consider the signs that someone is approaching the last year of their life
2. To have an awareness of some of the tools available to help us identify people approaching the end of their life
3. To understand the pattern of imminent dying
4. To consider how we can describe the pattern and what to expect to patients and their families

The last year of life

The term ‘End of Life’ is commonly used to describe the final year of life

NICE guidance says that:

> “Adults who are likely to be approaching the end of their life are identified using a systematic approach.” (NICE, 2021)

Discussion:

Why do we need to recognise people who are in the last year of their life?

Why is it important?

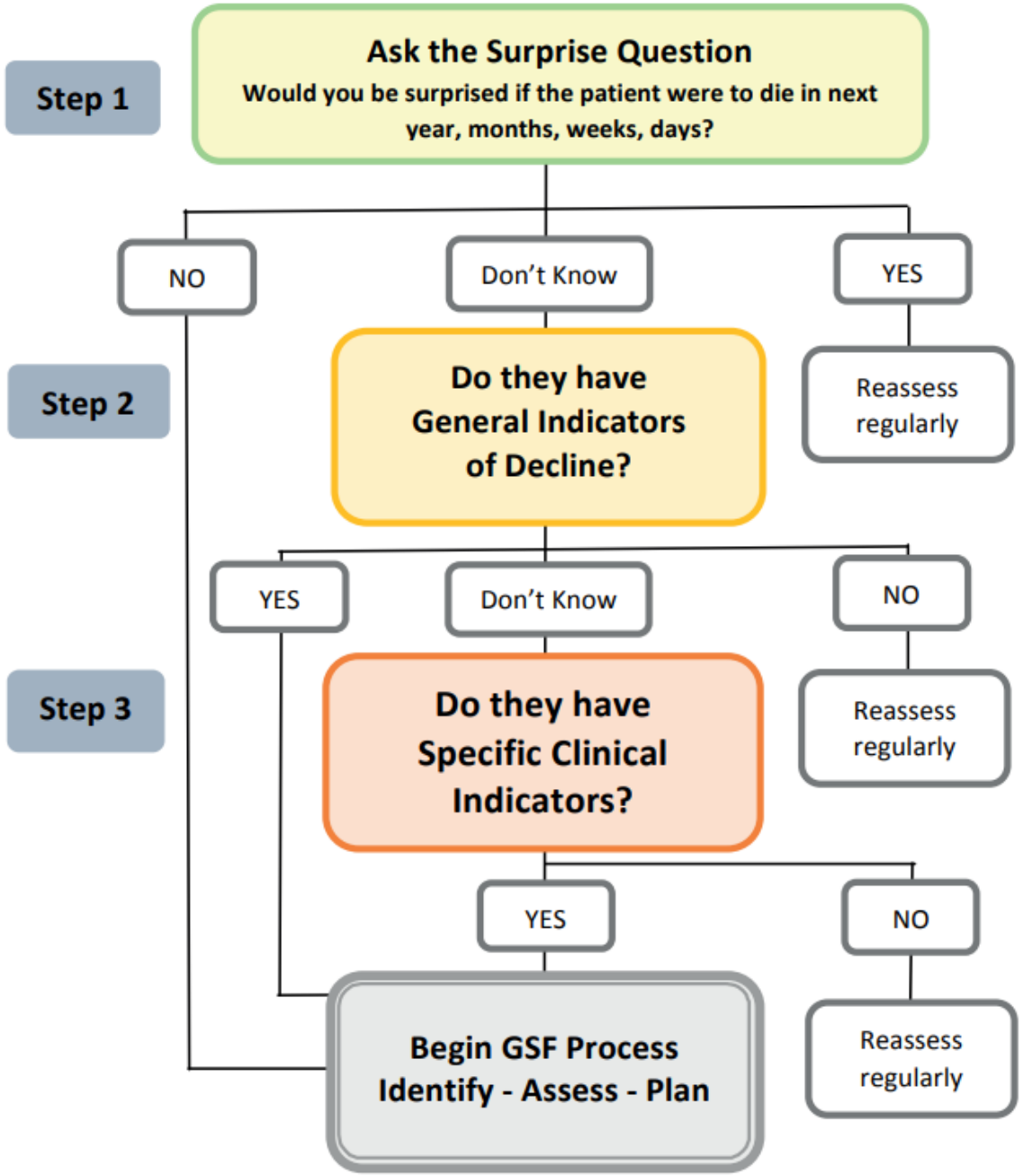
People can have their needs assessed and managed

Their carers and the people important to them can also be offered support.

Timely recognition gives people the opportunity to make informed decisions about their care.

Enables people to make plans for their future and establish their preferences for how and where they would like to be cared for and die.

Tools to help us: GSF Proactive Identification Guidance



General Indicators of Decline

- General physical decline, increasing dependence and need for support
- Repeated unplanned hospital admissions or acute crises at home
- Advanced disease - unstable, deteriorating, complex symptom burden
- Presence of significant multi-morbidities
- Decreasing activity – functional performance status declining (e.g., Barthel or Karnofsky Performance score, Rockwood) limited self-care, in bed or chair 50% of day and increasing dependence in activities of daily living
- Decreasing response to treatments, decreasing reversibility
- Patient choice for no further active treatment, focus on quality of life
- Progressive weight loss (>10%) in past six months
- Sentinel Event e.g., serious fall, carer distress, bereavement, transfer to nursing home, etc
- Serum albumin

GSF PIG

Disease Specific Indicators

STEP 1: The Surprise Question

For patients with advanced disease or progressive life limiting conditions, would you be surprised if the patient were to die in the next year, months, weeks, days?

The answer to this question should be an intuitive one, pulling together a range of clinical, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

This includes proactive planning of care and treatments and offering advance care planning and DNACPR discussions as early as possible.

STEP 2: General indicators of decline and increasing needs

- General physical decline, increasing dependence and need for support
- Repeated unplanned hospital admissions or acute crises at home
- Advanced disease - unstable, deteriorating, complex symptom burden
- Presence of significant multi-morbidities
- Decreasing activity – functional performance status declining (e.g., Barthel or Karnofsky Performance score, Rockwood) limited self-care, in bed or chair 50% of day and increasing dependence in activities of daily living
- Decreasing response to treatments, decreasing reversibility
- Patient choice for no further active treatment, focus on quality of life
- Progressive weight loss (>10%) in past six months
- Sentinel Event e.g., serious fall, carer distress, bereavement, transfer to nursing home, etc
- Serum albumin <25g/l
- Considered eligible for DS1500 payment

STEP 3: Specific Indicators related to single/multiple organ failure

1.CANCER

- Deteriorating performance status and functional ability due to metastatic cancer, multi-morbidities or not amenable to treatment – if spending more than 50% of time in bed/lying down, prognosis estimated in months
- Persistent symptoms despite optimal palliative oncology. More specific prognostic predictors for cancer are available, e.g., PPS, IPOS, ECOG.

2.ORGAN FAILURE

HEART DISEASE

- Advanced heart failure - CHF NYHA Stage 3 or 4 with symptoms despite optimal HF therapy – shortness of breath at rest/on minimal exertion
- Repeated admissions with heart failure – 3 admissions in 6 months or a single admission aged over 75 (50% 1yr mortality)
- Heart failure patients with reduced ejection fraction (HFrEF) have a poorer prognosis than those with preserved ejection fraction (HFpEF)
- Severe untreatable coronary artery or peripheral vascular disease
- Difficult ongoing symptoms despite optimal tolerated therapy
- Unpredictability but other indicators include age, low EF, ischaemic heart disease/arrythmias multi-morbidities including diabetes, obesity depression, hyponatraemia, high BP, declining renal function, anaemia
- See NICE Guidance https://cks.nice.org.uk/topics/heart-failure-chronic

CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

- Severe disease (e.g., FEV1 <30% predicted), persistent symptoms e.g., breathlessness despite optimal therapy, causing distress
- Recurrent hospital admissions (at least 3 in last year due to COPD)
- Hypoxia/fulfilling long term oxygen therapy criteria (PaO2<7.3kPa)
- Too unwell for surgery or pulmonary rehabilitation
- MRC grade 4/5 – shortness of breath after 100 metres on level surface
- Required ITU/NIV during admission or ventilation contraindicated
- Other factors e.g., right heart failure, anorexia, cachexia, >6 weeks steroids in preceding 6 months, despite specialist review/treatment optimisation, requires palliative medication for breathlessness.

KIDNEY DISEASE

- Stage 4/5 Chronic Kidney Disease (CKD) deteriorating eGFR<30ml/min
- Repeated unplanned admissions (more than 3/year)
- Patients with poor tolerance of dialysis with change of modality
- Patients choosing the 'no dialysis' option (conservative management), dialysis withdrawal or not opting for dialysis if transplant has failed
- Difficult physical or psychological symptoms that have not responded to specific treatments
- Symptomatic Renal Failure in patients who have chosen not to dialyse or complicating other life limiting conditions – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload

LIVER DISEASE

- Advanced cirrhosis - see the Child-Turcotte-Pugh (CTP) score for chronic liver disease and cirrhosis mortality - See CTP calculator https://www.hepatitisc.uw.edu/page/clinical-calculators/ctp
- Hepatocellular carcinoma
- Liver transplant is considered potentially difficult or not amenable to treatment of underlying condition
- Other adverse factors including malnutrition, bacterial infection, raised INR, hyponatraemia

GENERAL NEUROLOGICAL DISEASES

- Progressive deterioration in physical and/or cognitive function despite optimal therapy
- No longer able to communicate basic needs
- Symptoms which are complex and too difficult to control
- Increased hospital admissions not returning to previous baseline Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure
- Speech problems: increasing difficulty in communication and progressive dysphasia
- Mobility problems and falls increasing
- Reduced independence, needs ADL help, similar to frailty below
- Deteriorating cognition/psychiatric signs (depression, anxiety, hallucinations, psychosis)

PARKINSONS DISEASE including the above, and more specifically -

- Drug treatment less effective or increasingly complex drug regime, less well controlled with increasing "off" periods
- Dyskinesias, mobility problems and falls

MOTOR NEURONE DISEASE including the above, and specifically -

- Episodes of aspiration pneumonia
- Low vital capacity (below 70% predicted), or initiation of NIV

STROKE

- Predicting the prognosis after acute stroke can be challenging, yet 1:20 die within 72 hours. Care should include symptomatic comfort and not to impose burdensome restrictions
- Persistent paralysis after stroke with significent loss of function, medical complications, lack of improvement or ongoing disability
- Persistent vegetative, minimal conscious state or dense paralysis Cognitive impairment/Post-stroke dementia

3.FRAILTY, DEMENTIA and MULTI-MORBIDITIES

- For older people with complexity and multiple comorbidities, with frequent fluctuations in health needs and deterioration
- Electronic Frailty Index (0.24 or more) or Rockwood Score/ CFS 7 or above
- Comprehensive Geriatric Assessment (CGA) includes cumulative multiple morbidities, weakness, weight loss, fatigue, advancing frailty e.g., male over 85, health problems, reduced activity and need to stay at home, needs regular help, uses stick/walker regularly

DEMENTIA

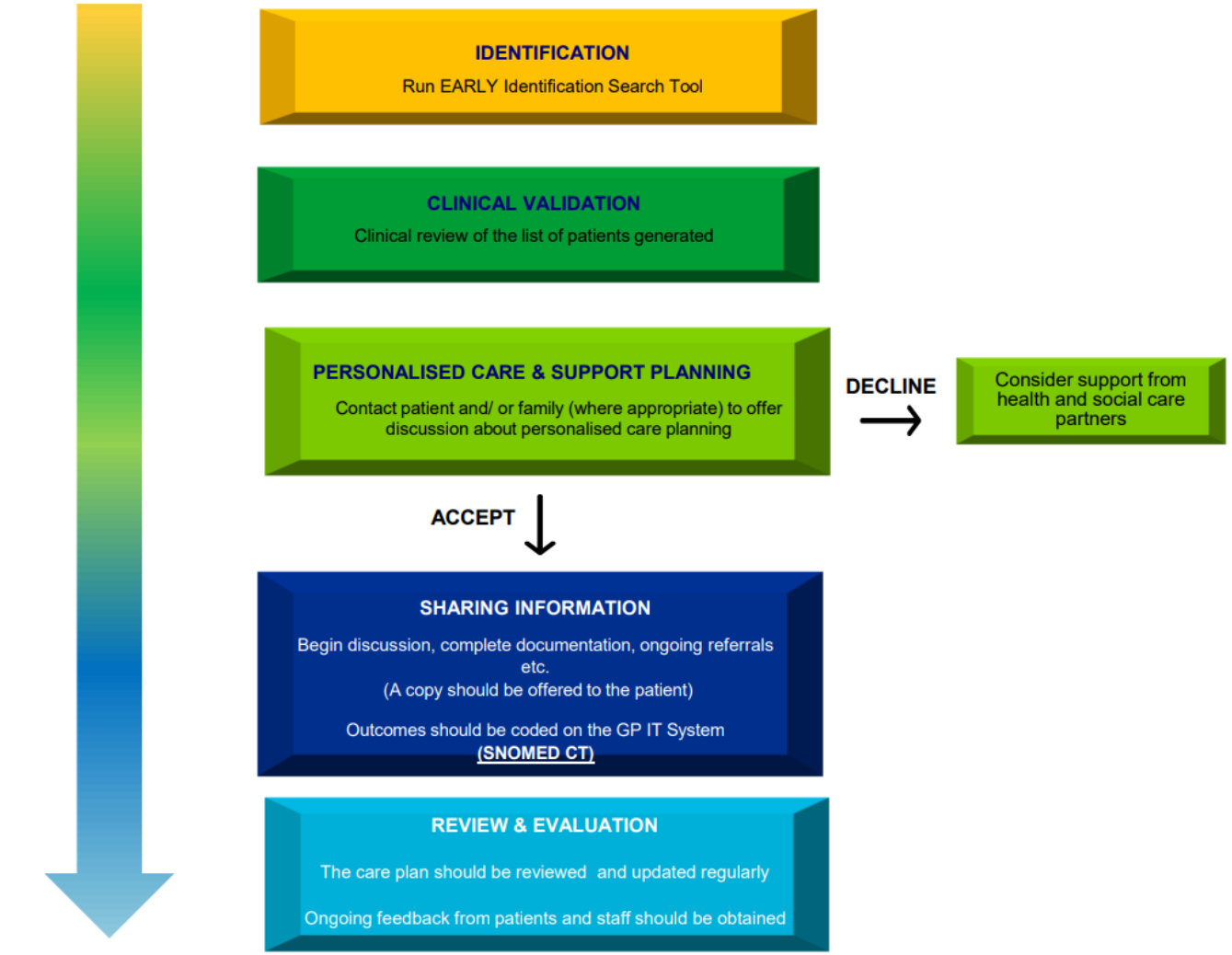
Identification of moderate/severe stage dementia using a validated tool or Comprehensive Geriatric Assessment (CGA) of frailty, Clinical Frailty Scale (CFS), Functional Assessment Staging, Electronic Frailty Index (EFI) or Rockwood scale, identifying decline in dementia or frailty. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to recognise family members or consistently unable to have meaningful conversations
- Completely dependent on others for care or unable to do ADL
- Recurrent episodes of delirium
- Aspiration pneumonia
- Urinary and faecal incontinence, and Barthel score <3

Plus: Weight loss, urinary tract Infection, skin failure or stage 3 or 4 pressures ulcers, recurrent fever, reduced oral intake

MULTI-MORBIDITIES

- Increasingly relevant in ageing population needing complex care
- 2 or more long term conditions including physical, mental, learning disability, frailty, sensory impairment, alcohol misuse
- Consider multi-morbidity approach if have frailty, physical + mental conditions, not managing ADL or treatments, using multiple services, frequent falls or crisis admissions
- See NICE Guidance - https://www.nice.org.uk/guidance/ng56
  BGS - https://www.bgs.org.uk/topics/multimorbidity



EARLY Identification

Supports colleagues in primary care settings to identify patients who may be in the last year of life.

The toolkit includes a clinical search tool

This search tool can be run on EMIS, SystmOne and Vision+

Questions to Support Clinical Validation

- Increasingly frequent attendance at GP Surgery?
- Does this patient already have a personalised care plan? If yes, has the pre-existing care plan been reviewed within the last 3 months?
- Has the patient had 3 or more admissions into hospital in the last 6 months?
- Has the patient had 3 or more encounters with emergency and out of hours services?
- Does the patient have pre-existing, long-term condition(s) which means that s/he is likely to deteriorate?
- Does the patient receive 24-hour care?
- Does the patient have a frailty index of moderate or severe?
- Is the person known to palliative care or end of life services?
- Has the person had recurrent falls?
- Does the patient have cancer that has progressed despite anti-cancer treatment, or cancer where there are limited treatments to save or prolong life? Has any specialist team or other professional involved in the patient's care identified that this patient may be in their last 12 months of life?
- Has the patient been considered for organ transplantation? *

**Consider liaison with specialist teams regarding whether discussion around personalised care plans would be appropriate.*

SHADOW: A tool for care homes

	Marker	Description	Scoring
S	Surprise question	'Would you be surprised if your resident were to die in the next few months, weeks, days?'	No = 1
H	Hospital	Your resident has attended and/or been admitted to hospital in recent weeks and months on more than one occasion	Yes = 1
A	less Active	Your resident now stays in bed or chair for longer than they used to or are no longer able to walk.	Yes = 1
D	Dependent	Your resident is more dependent on others for their ADLs (activities of daily living) e.g. feeding, toileting, etc.	Yes = 1
O	Overall decline	Staff/family have noticed a general progressive decline in the health of the resident, for example, increasingly withdrawn, showing lack of interest in food and drink over recent weeks and months.	Yes = 1
W	Weight loss	Your resident has lost weight over the past few weeks and months (10% or more over the past 6 months).	Yes = 1

A score of 1 or more should prompt a discussion

How do we recognise if someone is dying?

Everyone is different, but there is a pattern we recognise when a person is in the last weeks and days of their life

THE PATTERN OF DYING

Timeframe	Signs and Symptoms
Last days to short weeks of life	• Loss of appetite • Struggling to take PO medication • Not getting out of bed • Increased drowsiness/ fatigue • Worsening organ dysfunction • Social withdrawal • Decreasing response to treatments
Last hours to days	• Changes in breathing (agonal breathing/ Cheyne stoke breathing) • Changes in skin colour • Cool peripheries • Loss of consciousness • Noisy breathing/ upper resp secretions

If a dying person or their family asked you what to expect what would you say?

Kathryn Mannix TED Talk

HTTPS://WWW.TED.COM/TALKS/KATHRYN_MANNIX_WHAT_HAPPENS_AS_WE_DIE?LANGUAGE=EN

Questions?

References

- NICE Quality Standard QS13: End of Life Care for Adults, 2021 https://www.nice.org.uk/guidance/qs13
- The Gold Standards Framework, Proactive Identification Guidance, 2021 https://www.gsfinternational.org.uk/pig-tool
- NHS England, EARLY Identification Toolkit https://www.england.nhs.uk/north-west/north-west-coast-strategic-clinical-networks/our-networks/palliative-and-end-of-life-care/for-professionals/early-toolkit-for-primary-care/
- NHS England, SHADOW tool https://www.england.nhs.uk/north-west/north-west-coast-strategic-clinical-networks/our-networks/palliative-and-end-of-life-care/end-of-life-resources__trashed/shadow/
- TED Talk, Kathryn Mannix: What Happens As We Die? https://www.ted.com/talks/kathryn_mannix_what_happens_as_we_die?language=en