

IDENTIFYING THE DYING · A GP & IMG TEACHING AID

Recognising the Last Year of Life

How to spot patients who are nearing the end of life — and how to give honest, useful estimates of how long they may have.

Modernised from the GSF **Prognostic Indicator** papers (2005–06). Rebuilt on the current **GSF Proactive Identification Guidance v7 (2022)**, **NICE QS13 (2021)** & **NG142 (2019)**, the **GMC** end-of-life definition, and validated prognostic tools.

! Why bother identifying people early?

Because the patients we miss are the ones who die badly — in crisis, in hospital, without a plan.

About **1 in 100 people die each year**. For an average GP that is roughly **20 deaths a year**. We are usually good at recognising a dying **cancer** patient — but we miss most of the others: those dying slowly from **organ failure, frailty and dementia**. When we miss them, no plan is made, symptoms go unmanaged, and they are admitted and die in the wrong place. The fix is simple and powerful: **find these patients earlier**, so care can be planned around what matters to them.

~1%

of the population die each year

~20

deaths per GP, per year

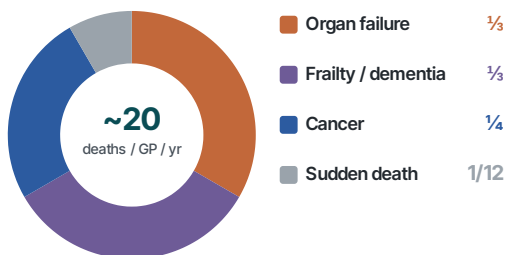
3/4

of those deaths are **not** cancer

30%

of hospital inpatients are in their last year of life

Who dies, and from what



Four patients in five die from non-cancer illness or frailty. Yet palliative care has historically reached mainly the cancer quarter — the gap this guidance exists to close.

✓ THE ONE IDEA TO REMEMBER

If you wait until a patient *looks* like they are dying, **you have already missed the window to plan**. Early identification is not about predicting the date of death. It is about asking **“might this person be in their last year of life?”** early enough to do something useful about it.

🕒 WHAT EARLY IDENTIFICATION UNLOCKS

- ▶ Care planned around the patient’s **own wishes**, recorded before a crisis
- ▶ **Fewer emergency admissions** and fewer deaths in the wrong place
- ▶ Earlier **advance care planning** and DNACPR/ReSPECT conversations
- ▶ The right support and benefits (e.g. the **SR1** fast-track) put in place in time

1 Three roads to death

Almost every *expected* death follows one of three patterns. Recognise the road, and you know what to watch for — and roughly how the end will arrive.

Think of dying as travelling downhill by one of three different roads. The shape of each road is the single most useful mental model in end-of-life care: it tells you **when to start watching, what decline looks like, and why some patients are so easily missed.**



▲ WHY WE MISS SO MANY

The **cancer cliff** is visible — so we plan for it. The **organ-failure stumbles** and the **frailty slope** are quiet and gradual, so they slip past us. That is exactly why three-quarters of dying patients reach the end without a plan. **Knowing the road is what lets you act before the cliff, the next stumble, or the bottom of the slope.**

▶ The same three roads, in three real patients

● Mrs A · the cliff

54, bowel cancer with liver spread, stented for jaundice, now increasingly weak and tired. High-functioning until recently — a classic **cancer** trajectory entering its steep final stretch.

● Mr B · the staircase

76, heart failure, breathless on walking, now housebound. **Two admissions this year** and dreading the next crisis — the stumbling **organ-failure** staircase.

● Mrs C · the slope

81, COPD, heart failure, OA and increasing forgetfulness, living alone. Fractured hip, eats poorly, “skating on thin ice” — the long **frailty & dementia** slope.

2

How to find them: three triggers

One simple question, one general check, one disease-specific check. **Any single trigger is enough** to act.

STEP 1 · SURPRISE QUESTION
"Would I be surprised if this patient died within the next 12 months?"

If "No, I would not be surprised" →

STEP 2 · GENERAL DECLINE
Look for general indicators of decline

STEP 3 · DISEASE INDICATORS
Check condition-specific indicators

ACT — ANY ONE TRIGGER IS ENOUGH
Add to register · assess needs · start advance care planning

1 Ask the Surprise Question

"Would I be surprised if this patient died in the next year — or months, weeks, or days?" Answer it by instinct, pulling together everything you know: the illness, the comorbidities, the social picture. If your honest answer is "No, I would not be surprised," that is your trigger to act.

2 Look for general decline

General signs that **any** patient is slipping toward the end of life (listed below).

3 Check disease-specific indicators

Specific red flags for the patient's main condition (Section 3).

● Step 2 — general indicators of decline

APPLIES TO EVERYONE

- ▶ Physical decline — more dependent, needs more help
- ▶ Repeated **unplanned admissions** or crises at home
- ▶ Advanced disease — unstable, deteriorating, hard symptoms
- ▶ Several serious conditions at once (multi-morbidity)
- ▶ In bed or a chair **≥ 50% of the day**; failing self-care
- ▶ Treatments working **less well**; less reversible
- ▶ Patient **chooses comfort** over further active treatment
- ▶ Progressive **weight loss > 10%** over 6 months
- ▶ A **sentinel event** — bad fall, carer breakdown, bereavement, move to a nursing home
- ▶ Serum **albumin < 25 g/L**
- ▶ Now eligible for the **SR1** fast-track benefit

✓ THE RULE

You do not need all of these. One trigger — a "no" to the Surprise Question, one general sign, or one disease indicator — is enough to add the patient to the register and begin planning. When in doubt, **include them and review**; the cost of acting early is small, the cost of missing them is large.

▲ WHAT'S CHANGED FROM OLDER TEACHING

The Surprise Question now spans "**year → months → weeks → days**," not just "the next 6–12 months." And the old **DS1500** benefit form has been replaced by the **SR1** (England, Wales & NI; **BASRiS** in Scotland), which now uses a **12-month** criterion rather than 6 months — completing an SR1 is itself a useful identification prompt.

Disease-specific indicators

Step 3 in detail. Each card is a quick checklist for one condition — **RECOGNISE** the indicators, then **ACT** (register + plan). Red boxes flag the very-poor-prognosis features that mean **DAYS-WEEKS**.

A Cancer & organ failure — the cliff and the staircase

● Cancer

- ▶ Performance status falling because cancer is **metastatic** or not treatable
- ▶ Spending **> 50% of the day in bed / lying down** → **prognosis in months**
- ▶ Persistent symptoms despite optimal palliative oncology
- ▶ Track with PPS, IPOS or ECOG (Section 5)

Very poor prognosis: brain, liver or lung metastases · refractory hypercalcaemia · uncontrolled tumour bleeding.

● Heart failure

- ▶ NYHA **stage 3–4** — breathless at rest or on minimal exertion, despite optimal therapy
- ▶ **≥ 3 admissions in 6 months**, OR one admission aged > 75 (≈ 50% die within a year)
- ▶ Reduced ejection fraction (HFrEF) carries a worse outlook than preserved (HFpEF)
- ▶ Difficult symptoms or severe untreatable coronary / peripheral vascular disease

Very poor prognosis: haemodynamic failure needing inotropes · worsening renal function.

Source: NICE CKS — Heart failure (chronic)

● COPD

- ▶ Severe disease, e.g. **FEV₁ < 30% predicted**; breathless despite optimal therapy
- ▶ **≥ 3 admissions in the last year** for COPD
- ▶ Meets long-term oxygen criteria — **PaO₂ < 7.3 kPa**
- ▶ MRC dyspnoea **grade 4–5** (breathless after 100 m on the flat, or housebound)
- ▶ Needed ITU/NIV, or ventilation would not be appropriate; > 6 weeks steroids in 6 months

Very poor prognosis: respiratory failure.

● Kidney disease

- ▶ CKD **stage 4–5** with deteriorating **eGFR < 30 mL/min**
- ▶ Choosing **conservative (no-dialysis) care**, withdrawing from dialysis, or not restarting after a failed transplant
- ▶ **≥ 3 unplanned admissions a year**; poor tolerance of dialysis
- ▶ Symptomatic uraemia — nausea, anorexia, itch, intractable fluid overload

Very poor prognosis: stopping dialysis · untreated severe hyperkalaemia.

● Liver disease

NEW IN 2022

- ▶ Advanced cirrhosis — grade with the **Child–Pugh** score
- ▶ Hepatocellular carcinoma
- ▶ Transplant not possible, or the underlying cause is untreatable
- ▶ Adverse signs: malnutrition, bacterial infection, raised INR, low sodium

⊙ READING ORGAN FAILURE

Organ-failure patients look deceptively stable *between* crises. Do not be reassured by recovery from an exacerbation — **the trend across admissions is what matters**. A patient who needed three admissions this year, each leaving them weaker, is on the staircase down even if they look “back to normal” today.

B Neurological disease

● Neurological disease (general)

- ▶ Progressive decline in physical and/or cognitive function despite optimal therapy
- ▶ Can no longer communicate basic needs; complex symptoms that are hard to control
- ▶ **Swallowing problems** → recurrent aspiration pneumonia, sepsis or respiratory failure
- ▶ More admissions, not returning to baseline; increasing falls; needs help with daily living

● Stroke

- ▶ **1 in 20 die within 72 hours** — early prognosis is hard to call
- ▶ Persistent dense paralysis with major loss of function; medical complications; no improvement
- ▶ Persistent vegetative or minimal-conscious state; post-stroke dementia
- ▶ Focus on comfort; do **not** impose burdensome restrictions

● Parkinson's disease

- ▶ *All of the above, plus:*
- ▶ Drug treatment less effective or increasingly complex; more "off" periods
- ▶ Dyskinesias, falls and swallowing problems

● Motor neurone disease

- ▶ *All of the above, plus:*
- ▶ Consider **from diagnosis** — it is rapidly progressive
- ▶ Episodes of aspiration pneumonia
- ▶ Vital capacity < **70% predicted**, or starting NIV

C Frailty, dementia & multi-morbidity — the long slope

● Frailty

NEW IN 2022

- ▶ **Clinical Frailty Scale (Rockwood) ≥ 7** , or electronic Frailty Index ≥ 0.24
- ▶ Comprehensive Geriatric Assessment: cumulative morbidities, weakness, weight loss, fatigue
- ▶ e.g. a man > 85 with multiple problems, reduced activity, housebound, needs regular help, uses a stick/walker

● Dementia (moderate-severe)

- ▶ Cannot recognise family / no meaningful conversation
- ▶ Fully dependent for care and daily living; **Barthel < 3**
- ▶ Recurrent delirium; aspiration pneumonia; double incontinence
- ▶ *Plus any of:* weight loss, UTI, stage 3-4 pressure ulcers, recurrent fever, reduced intake

● Multi-morbidity

- ▶ ≥ 2 **long-term conditions** (physical, mental, learning disability, frailty, sensory, alcohol)
- ▶ Not managing daily living or treatments; using multiple services; frequent falls or crisis admissions

Source: NICE NG56 — Multimorbidity · British Geriatrics Society

✓ BOTTOM LINE FOR THE LONG-SLOPE GROUP

This group is the **hardest to spot and the most under-served**. If an older person with several conditions is becoming housebound, losing weight and needing more help — **that is the trigger**. Do not wait for a single dramatic event; on this road, there often isn't one. A useful instinct: *"this person is skating on thin ice."*

⊙ A WORD ON SWALLOWING

Across **every** neurological condition, new or worsening **dysphagia** is a powerful warning sign — it drives aspiration, weight loss and infection, and reliably marks a step down the slope. Treat a swallowing change as a prompt to review goals of care.

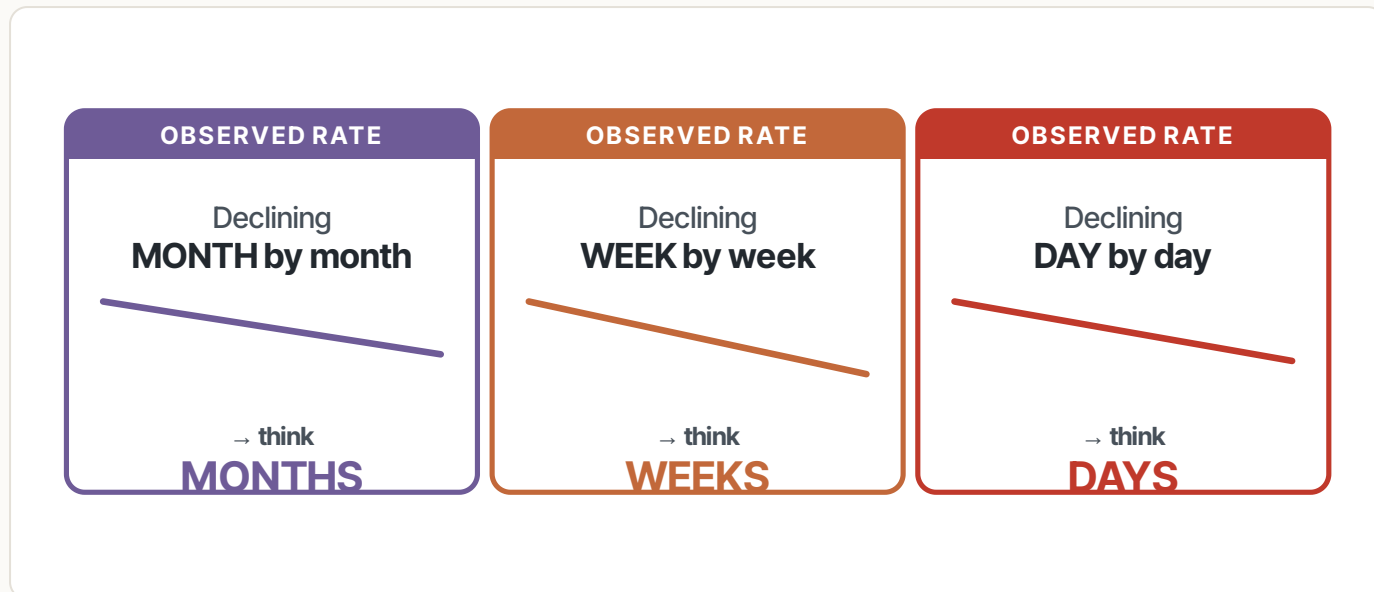


Estimating how long: the rules that change the conversation

Identifying the dying is half the job. The other half is answering the question every family asks — “how long?” — honestly and usefully. Three rules transform how you do it.

RULE 1 Watch the speed, not just the disease

The body tends to decline at a **consistent rate** as the end nears: fast stays fast, slow stays slow (though the very final change is often quick). So the pace of recent change is your best bedside estimate of what is left.

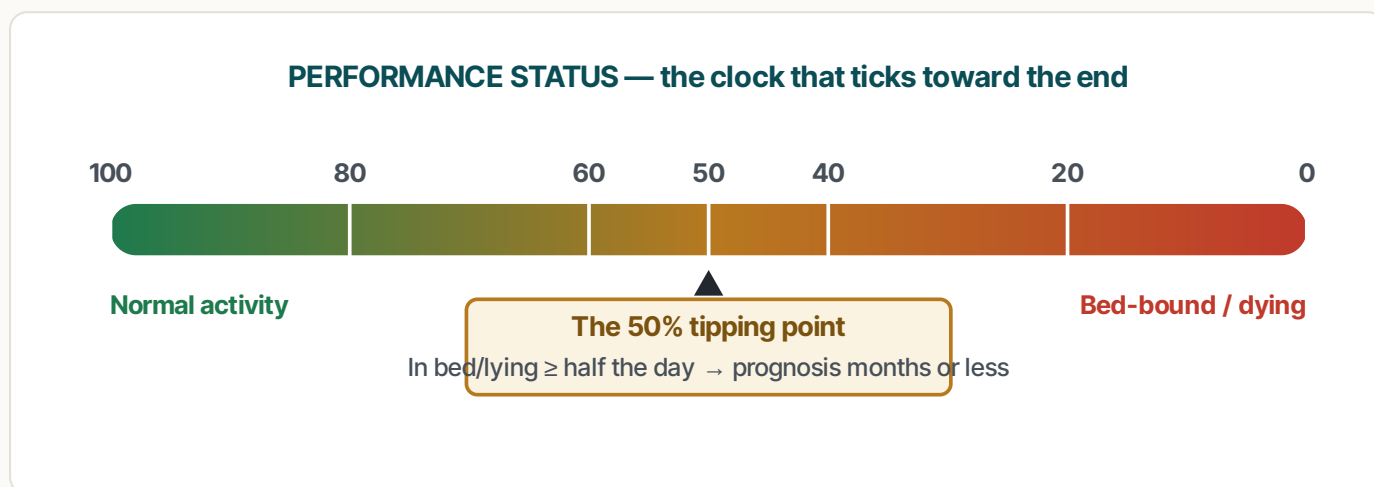


✓ THE SINGLE MOST USEFUL SENTENCE IN PROGNOSIS

Getting worse **month by month** → think months. **Week by week** → weeks. **Day by day** → days. Ask the family or carers: “*compared with a month ago — and a week ago — how different are they?*” The answer is often more accurate than any single test.

RULE 2 Function is the clock

Performance status — how much a patient can still do — is the single strongest predictor of survival, especially in cancer. As function falls, the clock speeds up. One threshold is worth memorising:



A cancer patient who spends more than half the day in bed or lying down has a prognosis usually measured in **months or less**. This one observation, made at the bedside, outperforms most investigations.

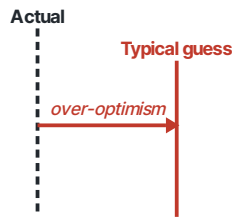


Estimating how long (continued)

The third rule keeps you honest — plus the shortcuts and the words to use.

RULE 3 We almost always say too long

We usually say TOO LONG



Predictions are wrong $>2\times$ / $<1/2$ about $1/3$ of the time — $2/3$ of errors too hopeful.

Even in expert hands, survival predictions are wrong — out by more than double or less than half — about **a third of the time**, and **two-thirds of those errors are over-optimistic**. Over-estimating robs families of time to prepare; under-estimating costs your credibility.

✓ SO, IN PRACTICE

Give a **range, not a number** — “short weeks,” “days to a week or two.” Frame it as “**hope for the best, prepare for the worst**.” Lean slightly toward the shorter end to counter your own optimism.

► Two fast shortcuts

▲ THE CANCER “UNDER-4-WEEKS” TRIAD

In advanced cancer, all **three** of these together predict survival of **under 4 weeks** ($\approx 74\%$ accurate):

- ▶ Weight loss ≥ 10 kg
- ▶ MMSE < 24 (cognitive failure)
- ▶ Dysphagia to solids or liquids

● Diagnoses that almost always carry a poor prognosis

- ▶ Pancreatic cancer
- ▶ Most biliary tract cancers
- ▶ Metastatic cancer of **unknown primary**
- ▶ Untreated small-cell lung cancer

Circumstances that signal a very poor prognosis

If the patient has...	...these features point to days–short weeks
Cancer	Brain, liver or lung metastases · refractory hypercalcaemia · uncontrolled bleeding or marrow failure without transfusion
Heart failure	Needing inotropes · worsening renal function · repeated admissions
Kidney failure	Stopping dialysis · untreated severe hyperkalaemia
COPD	Respiratory failure
Any illness	Sepsis in a frail, bedbound patient · coma where fluids are not given

⊙ THE WORDS TO USE — AND TWO MYTHS TO RETIRE

Reassure families with the evidence: *pain does not predict survival*, and — crucially — **opioids for symptom control do not shorten life**. Fear of “the morphine hastening the end” is common and wrong; say so plainly. Estimates are not guarantees, and things can change fast — keep talking with the patient and family as the picture changes.

● How to phrase it at the bedside

WORKED PHRASING

Instead of a single number...

- ▶ “I’m afraid we may be looking at **months rather than years**.”
- ▶ “Things are changing **week by week**, so I think we could be looking at weeks.”
- ▶ “I hope I’m wrong, but I’d **prepare for the possibility this is short**.”

And to open the door...

- ▶ “Would it help to talk about **what matters most** to you now?”
- ▶ “Some people like to plan ahead **while they feel well enough** — shall we?”
- ▶ “If things did change quickly, **where would you want to be?**”

5

The measuring tools

If function is the clock, these scales are how you read it. Use the quick one daily; reach for the detailed scores when an estimate really matters.

Kamofsky Performance Status (KPS)

Score	What the patient can do
100	Normal; no evidence of disease
90	Normal activity; minor symptoms
80	Normal activity with effort; some symptoms
70	Cares for self; cannot do normal activities
60	Needs occasional help; manages most needs
50	Needs considerable help & frequent care
40	Disabled; needs special care
30	Severely disabled
20	Very sick; active supportive care needed
10	Moribund

ECOG — the quick everyday scale (0–5)

Grade	Description
0	Fully active; no restriction
1	Restricted in strenuous activity; does light work
2	Up & about > 50% of the day; self-care, but no work
3	In bed/chair > 50% of the day; limited self-care
4	Completely disabled; totally bed/chair-bound
5	Dead

◆ QUICK GUIDE

ECOG is the fast, everyday scale — easy to record at every visit. KPS and PPS give finer detail for documentation and for feeding into the prognostic scores on the next page.

Palliative Performance Scale (PPS) — the palliative version of KPS

%	Ambulation	Activity & disease	Self-care	Intake	Consciousness
100	Full	Normal activity; no disease	Full	Normal	Full
90	Full	Normal activity; some disease	Full	Normal	Full
80	Full	Normal activity with effort	Full	Normal/↓	Full
70	Reduced	Unable to do normal work	Full	Normal/↓	Full
60	Reduced	Unable to do hobbies/housework	Occasional help	Normal/↓	Full / confusion
50	Mainly sit/lie	Unable to do any work	Considerable help	Normal/↓	Full / confusion
40	Mainly in bed	—	Mainly assistance	Normal/↓	± drowsy/confusion
30	Totally bed-bound	—	Total care	Reduced	± drowsy/confusion
20	Bed-bound	—	Total care	Minimal sips	± drowsy/confusion
10	Bed-bound	—	Total care	Mouth care only	Drowsy / coma

✓ THE NUMBER TO REMEMBER

At PPS ≤ 50% (in bed or chair at least half the day, needing considerable help), **only about 1 in 10 patients live beyond 6 months**. A falling PPS is one of the clearest signals to step up planning.

◆ AT THE BEDSIDE — ONE PATIENT, ONE SCORE

Mr B (heart failure) now spends most of the day in his chair, needs help to wash and dress, and eats only small amounts. That reads as **PPS ≈ 40–50, ECOG 3**. No blood test needed — that single observation says **review now and step up planning**.

The measuring tools (continued)

Two validated scores that add clinical signs to performance status for a sharper estimate — useful when eligibility or planning hinges on the number.

Palliative Prognostic Index (PPI)

Factor	Finding	Points
Palliative Performance Scale	10–20	4.0
	30–50	2.5
	≥ 60	0
Oral intake	Severely reduced (mouthfuls)	2.5
	Moderately reduced	1.0
	Normal	0
Oedema	Present	1.0
	Absent	0
Dyspnoea at rest	Present	3.5
	Absent	0
Delirium	Present	4.0
	Absent	0
Score > 6 → survival < 3 weeks		/15

⊙ PPI — at a glance

Built on the PPS plus oral intake, oedema, dyspnoea at rest and delirium. A score **over 6 predicts survival under 3 weeks** (sensitivity 80%, specificity 85%).

Palliative Prognostic Score (PaP)

Factor	Finding	Points
Dyspnoea	No / Yes	0 / 1
Anorexia	No / Yes	0 / 1.5
Karnofsky status	> 30 / ≤ 20	0 / 2.5
Clinical prediction (wks)	>12 ... 1–2	0 ... 8.5
Total WBC	Normal / High / V.high	0 / 0.5 / 1.5
Lymphocyte %	Normal / Low / V.low	0 / 1.0 / 2.5
Total score		30-day survival
0 – 5.5		> 70%
5.6 – 11.0		30 – 70%
11.1 – 17.5		< 30%

⊙ PaP — at a glance

Combines symptoms, KPS, your own clinical estimate and two simple blood results into a **30-day survival** probability group.

◆ A HONEST CAVEAT ON ALL SCORES

These tools were validated mainly in **advanced cancer**. The organ-failure and frailty trajectories are far more erratic, so scores are **less reliable there** — use them to support, never to replace, your judgement, the momentum of decline, and conversation with the patient and family.

● Which tool, and when?

QUICK CHOOSER

Every visit

Record an **ECOG** or **PPS**. A change over time is more informative than any single value — it shows you the **momentum**.

When days–weeks matter

Add the **PPI** at the bedside — it needs no bloods and flags survival under 3 weeks.

When a figure is needed

Use the **PaP** (it includes an FBC) to place a cancer patient in a 30-day survival group for service or eligibility decisions.

Worked PPI: a patient with PPS 30 (4.0) + severely reduced intake (2.5) + dyspnoea at rest (3.5) + delirium (4.0) scores **14 / 15** → well over 6 → **survival likely under 3 weeks**.

6 Once you've identified them — act

Identification is worthless without follow-through. Here is the simple machinery that turns a name on a register into a better death.

- ◆ Add to the practice **palliative care / GSF / QOF register**
- ◆ Discuss at the **MDT** — ideally monthly, at minimum every 3 months
- ◆ Apply **needs-based RAG coding** (right) to match care to current need
- ◆ Offer **advance care planning** and DNACPR/ReSPECT early, before a crisis
- ◆ Run the cycle: **Identify → Assess → Plan**, communicating throughout



Needs-based coding (current GSF) — match care to need, not to a countdown

GREEN	AMBER	RED
Advanced, unstable or declining disease	Deteriorating, weeks of life likely	Last days of life
Stable on the register; plan ahead	Review more often; confirm wishes	Care of the dying; family support

▲ WHAT'S CHANGED FROM OLDER TEACHING — AT A GLANCE

- ▶ **Renamed:** "Prognostic Indicator" → "Proactive Identification" Guidance (still "PIG") — focus shifted from **predicting time to anticipating needs**
- ▶ **Surprise Question** now spans year → months → weeks → days
- ▶ **Coding:** old time-based A/B/C/D bands → **needs-based RAG** (green/amber/red)
- ▶ **New groups** added, e.g. **liver disease** (Child–Pugh)
- ▶ **Frailty** now scored with validated tools (CFS ≥ 7 / eFI ≥ 0.24), not impressions
- ▶ **Kidney** simplified to CKD 4–5, eGFR < 30 (was "stage 5, eGFR < 15 ")
- ▶ **DS1500** → **SR1** form, now a 12-month criterion (was 6)
- ▶ Anchored to **NICE QS13 / NG142**, the GMC definition & the NHS Long Term Plan

✓ FIVE THINGS TO WALK AWAY WITH

- 1 Three roads to death: the **cliff** (cancer), the **staircase with stumbles** (organ failure), the **long slope** (frailty & dementia). $\frac{3}{4}$ of deaths are not cancer — and those are the ones we miss.
- 2 Trigger care with three checks: the **Surprise Question** + general decline + disease indicators. **Any one is enough.**
- 3 To estimate length, watch the **speed of decline**: month → months, week → weeks, day → days. **Function is the clock.**
- 4 We almost always **say too long** — give ranges, lean shorter, and reassure families that **opioids do not shorten life.**
- 5 Act on it: **register → needs-based RAG coding → advance care planning**, and **communicate at every step.**



Sources & how to verify

Everything in this aid is anchored to the named UK sources below. Where guidance is absolute, the wording is deliberately strong; where judgement applies, softer wording is used on purpose.

Primary guidance — GSF Proactive Identification Guidance (PIG), 7th edn, June 2022 · NICE QS13 *End of life care for adults* (2021) · NICE NG142 *End of life care for adults: service delivery* (2019) · NICE NG56 *Multimorbidity* · NICE CKS *Heart failure – chronic* · GMC *Treatment and care towards the end of life* · NHS Long Term Plan (2019) · DWP *SR1/ Special Rules for end of life* (2022).

Prognostic tools & evidence — Karnofsky & Burchenal (1949) · Palliative Performance Scale, Anderson et al. (1996) & Morita et al. (1999) · Palliative Prognostic Index (PPI), Morita et al. (1999) · Palliative Prognostic Score (PaP), Maltoni et al. (1999) · Bruera et al. (1992) cancer survival factors · Chow et al., *Clinical Oncology* (2001) prediction accuracy · Fox et al., *JAMA* (1999) · illness-trajectory model after Lynn & Adamson. Original source papers: GSF Prognostic Indicator Guidance v2.25 (2005–06); Woelk & Harlos, *Estimating Length of Survival in Palliative Patients*.

🕒 SCOPE & A FEW HONEST LIMITS

All prognostication is inexact — these are **triggers and rough guides, not guarantees**. The frailty group is the hardest to call, because the slope is so variable. The prognostic **scores were validated mainly in cancer** and are weaker in organ failure and frailty. Local registers, QOF templates and coding systems vary — check your own practice and area systems.

📌 The whole aid on one card — your memory hooks

1 · FIND them

Three roads: **the cliff** (cancer) · **the staircase** (organ failure) · **the slope** (frailty). Trigger on the **Surprise Question** — *any one sign is enough*.

2 · ESTIMATE how long

Watch the **speed**: month→months, week→weeks, day→days. **Function is the clock**. Give ranges — and remember we usually say **too long**.

3 · ACT on it

Register → **needs-based RAG** coding → **advance care planning**. Reassure: **opioids do not shorten life**. Communicate at every step.

⚠️ DISCLAIMER — BRADFORD VTS TEACHING AIDS

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