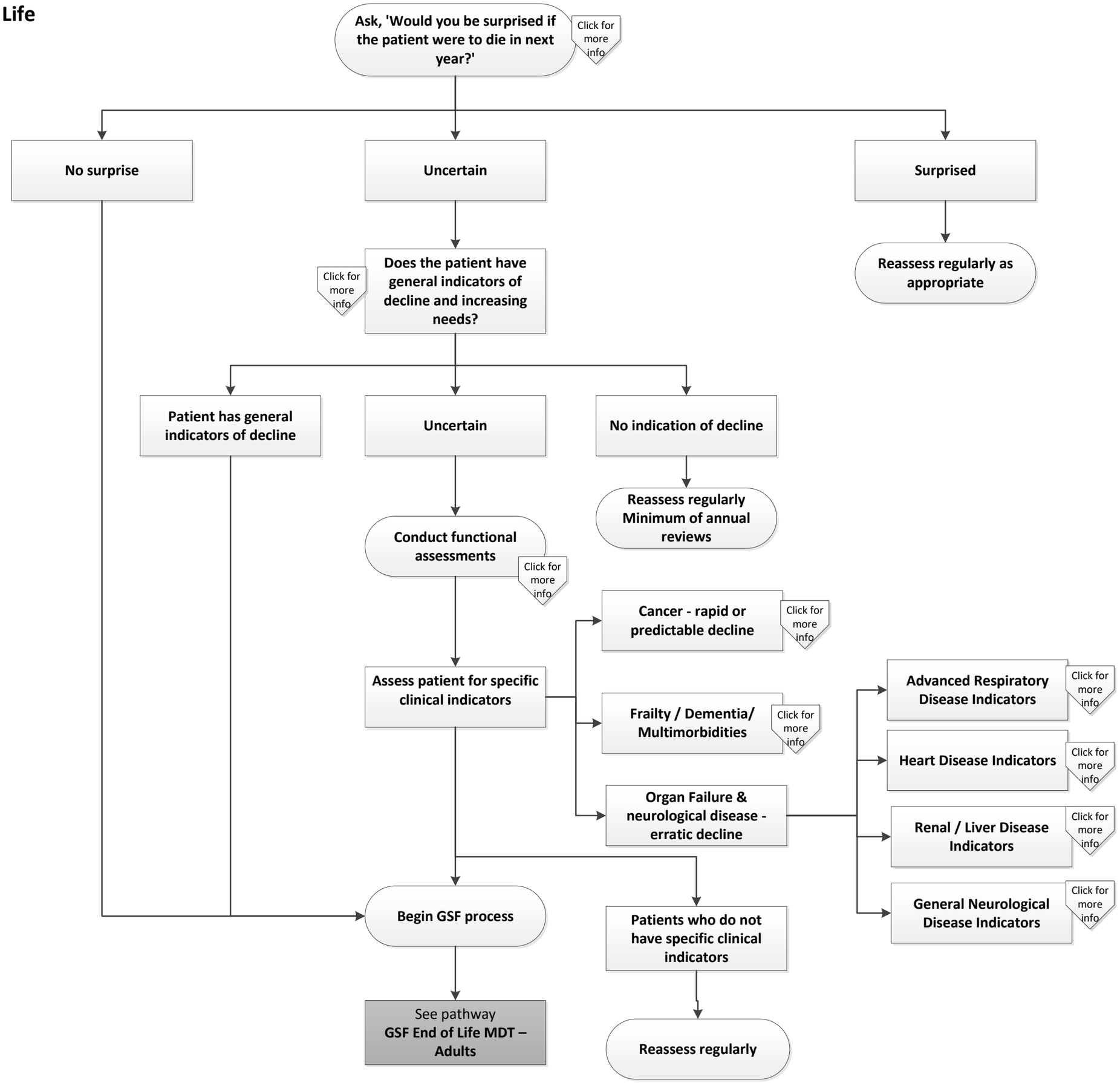
Identification of Adults nearing End of Life

A working estimate of the prevalence of end of life i.e. in the final year or so of life is approximately 1% of your practice population as
1% of the population die each year.

If the proportion of your practice dying is >1% per year that will means more than 1% should be on the end of life register.

Your register should include about 25% cancers and 75% non-cancer conditions to reflect mortality. If your proportion of cancer patients is higher it may be that many patients with long-term conditions or general decline have not been identified.

See link:
http://www.goldstandardsframework.org.uk/library-tools-amp-resources



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Ask, 'Would you be surprised if the patient were to die in next year?'

- For patients with advanced disease of progressive life limiting conditions the answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, 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?
- Consider severely frail – see Frailty pathway:

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Does the patient have general indicators of decline and increasing needs?

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

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Conduct Functional Assessments

Rockwood Frailty Scale 7,8 or 9. See https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2022/02/rockwood-frailtyscale_.pdf

Barthel Index describes basic Activities of Daily Living (ADL) as 'core' to the functional assessment. E.g. feeding, bathing, grooming, dressing, continence, toileting, transfers, mobility, coping with stairs etc. Fuller details here: https://www.gpnotebook.co.uk/simplepage.cfm?ID=429522946

WHO/ECOG Performance Status - 0-5 scale of activity. For full details: http://ecog-acrin.org/resources/ecog-performance-status

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Frailty / Dementia - gradual decline

Frailty

•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

British Geriatric Society - https://www.bgs.org.uk/topics/multimorbidity

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Cancer - rapid or predictable decline

- 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 available e.g. PPS, IPOS, ECOG

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Advanced Respiratory Disease Indicators

- 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 (PaO_2<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

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Heart Disease Indicators

Advanced heart failure – CHF NHYA 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, depressions, hyponatraemia, high B{, declining renal function, anaemia
- See NICE guidance httlp://cks.nice.org.uk/topics/hert-faiulre-chronic

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Renal / Liver Disease Indicators

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
- Hapatocellular carcinoma
- Liver Transplant in considered potentially difficult or not amenable to treatment of underlying condition

Other adverse factors including malnutrition, bacterial infection, raised INR, hyponatraemia

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General Neurological Disease Indicators

- 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 DIASEASE 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 significant loss of function, medical complications, lack of improvement or ongoing disability
- Persistent vegetive, minimal conscious state or dense paralysis
- Cognitive impairment / Post-stoke dementia

Pathway reference:
GSF Proactive Identification Guidance' https://goldstandardsframework.org.uk/proactive-identification-guidance-pig