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# Identifying adults approaching end of life

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## 1. Identifying adults approaching end of life

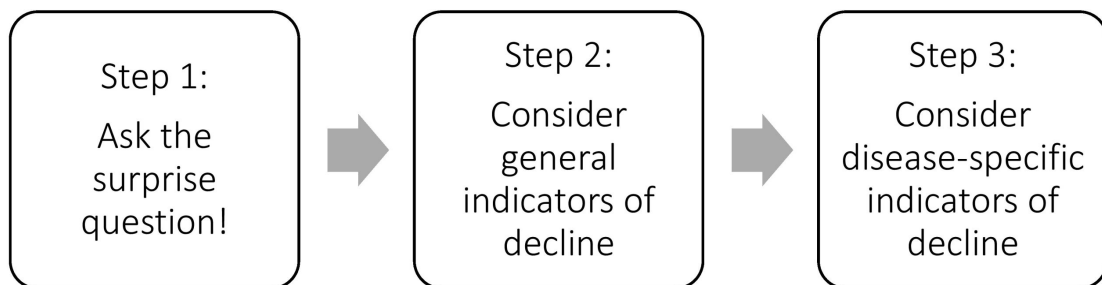
The Gold Standards Framework (GSF), NICE and the GMC all agree that we should aim, where possible, to identify people in the last 12 months of life to be able to address their beliefs and preferences about end-of-life care.

There is increasing evidence that, by doing this and offering additional supportive care in this context, we can improve patients' quality of life. You may also find the article on *Advance care planning, including resuscitation 'decisions'* helpful.

## 1.1. Identifying the last year of life

The [Gold Standards Framework](#) has been a key source of confidence and support for primary care in identifying people who may need additional supportive care as they near the end of life.

It was updated for its 7<sup>th</sup> edition in June 2022, and we summarise the key parts of its 'Proactive identification guidance' here.



### Step 1: The surprise question

This is the easiest bit! For patients with advanced or progressive life-limiting diseases, we are urged to ask ourselves the following question:

Would you be surprised if this person was to die in the next year, months, weeks or days?

And be reminded that our answer should be an intuitive one (drawing together everything we know about the person). Clearly, this is best done by the clinician who knows the patient, their medical history and their social situation the best.

If we **would not** be surprised, we are then encouraged to think about what steps could be taken to improve the person's quality of life now and in preparation for a future decline.

## **Step 2: General indicators of decline**

GSF (2022) identifies some common general indicators that could prompt us to think that a person might benefit from additional supportive care.

*These are useful because many of our patients in general practice do not have a single condition! As we read these, we might reflect that it is these factors that are contributing to our intuitive response to the surprise question.*

### General indicators of decline and increasing need

- Physical decline, increased dependence for activities of daily living, needs more support.
- Repeated acute crises at home.
- Repeated unplanned admissions.
- Advanced disease and unstable, complex symptom burden.
- Significant multimorbidity.
- Performance status declining (may be measured with scores such as Rockwood or Barthel).
- Limited self-care – in chair or bed for 50% of day or more.
- Decreasing response to treatments and symptoms less reversible.
- Person makes a choice for no (further) active treatment and wishes to focus on quality of life.
- Progressive weight loss (>10% in the past six months).
- Specific 'sentinel event', e.g. a serious fall, bereavement, transfer to nursing home, carer distress.
- Serum albumin <25g/l.

### Step 3: Disease-specific indicators

GSF (2022) has a useful way of helping us spot indicators related to specific disease trajectories that suggest that a shift towards a 'supportive care approach' might be indicated. It splits this into three groups that mirror the three disease trajectories discussed in the *End-of-life care: general principles, policies and guidelines* article.

As a reminder, these are:

- Rapid, predictable decline, e.g. cancer.
- Erratic, unpredictable decline, e.g. organ failure.
- Gradual decline, e.g. frailty, dementia and multimorbidity.

Cancer	
<ul style="list-style-type: none"> <li>• In people who are being treated for cancer, the following changes in status are significant:               <ul style="list-style-type: none"> <li>• Deteriorating functional ability due to metastatic cancer (or other comorbidities) which cannot be treated.</li> <li>• If spending more than 50% of the time in bed or lying down, prognosis is usually estimated in months.</li> <li>• Persistent symptoms despite optimal palliative oncology.</li> </ul> </li> </ul>	
Heart disease	COPD
<ul style="list-style-type: none"> <li>• Advanced heart failure (NYHA stage 3 or 4) and symptoms despite optimal therapy.</li> <li>• Repeated admissions, e.g. 3 or more admissions in 6 months or 1 admission aged over 75y (50% 1-year mortality).</li> <li>• Severe, untreatable coronary artery disease or peripheral vascular disease.</li> <li>• Difficult ongoing symptoms despite optimal therapy.</li> <li>• Additional indicators which <i>may</i> contribute include increasing age, low ejection fraction, arrhythmias, multimorbidity, declining renal function, anaemia, hyponatraemia.</li> </ul>	<ul style="list-style-type: none"> <li>• Severe disease (FEV &lt;30% predicted) and persistent distressing symptoms despite optimal therapy, e.g. breathlessness.</li> <li>• Recurrent hospital admissions, e.g. 3 or more in past 12 months.</li> <li>• Hypoxia.</li> <li>• Meet criteria for long-term oxygen therapy.</li> <li>• MRC grade 4/5 (short of breath after 100m on a level surface).</li> <li>• Required ITU/ NIV on admission.</li> <li>• Additional factors which may contribute are right heart failure, anorexia, cachexia, &gt;6 weeks of</li> </ul>

	steroids in the past 6 months, on palliative medication for breathlessness.
<b>Kidney disease</b>	<b>Liver disease</b>
<ul style="list-style-type: none"> <li>• Stage 4/5 CKD with deteriorating eGFR &lt;30ml/min.</li> <li>• Repeated unplanned admissions (more than 3 per year).</li> <li>• Poor tolerance of dialysis of any modality.</li> <li>• Patient choice of no dialysis/dialysis withdrawal.</li> <li>• Difficult physical or psychological symptoms not responding to treatment.</li> <li>• Symptomatic renal failure in those who are not dialysing, e.g. fluid overload, nausea and vomiting, anorexia, pruritus, reduced functional status.</li> </ul>	<ul style="list-style-type: none"> <li>• Advanced cirrhosis (you may find the <b>Child-Turcotte-Pugh</b> score helpful).</li> <li>• Hepatocellular carcinoma.</li> <li>• Liver transplant not possible.</li> <li>• Other factors, e.g. malnutrition, abnormal clotting, bacterial infection, hyponatraemia.</li> </ul>
<b>Neurological diseases (including motor neurone disease and Parkinson's disease)</b>	<b>Stroke</b>
<p>In general:</p> <ul style="list-style-type: none"> <li>• Progressive deterioration in physical and/or cognitive function.</li> <li>• Cannot communicate basic needs.</li> <li>• Complex symptoms that are too difficult to control.</li> <li>• Increasing hospital admissions not returning to baseline.</li> </ul>	<p>Can be difficult to predict prognosis after acute stroke, and 1 in 20 die within 72 hours.</p> <p>Care should always involve symptomatic comfort.</p> <p>Poorer prognostic features include:</p> <ul style="list-style-type: none"> <li>• Persistent paralysis with significant loss of function, medical complications, and ongoing</li> </ul>

<ul style="list-style-type: none"> <li>• Swallowing problems with recurrent aspiration/infection and/or respiratory failure.</li> <li>• Mobility problems with increasing falls.</li> <li>• Deteriorating communication and/or progressive dysphasia.</li> <li>• Deteriorating psychiatric signs, e.g. depression, anxiety, hallucinations and psychosis.</li> </ul> <p>In motor neurone disease (in addition to the above):</p> <ul style="list-style-type: none"> <li>• Episodes of aspiration pneumonia.</li> <li>• Low vital capacity (&lt;70% predicted) or NIV needed.</li> </ul> <p>In Parkinson's disease (in addition to the above):</p> <ul style="list-style-type: none"> <li>• Drug treatment less effective or increasingly complex (less well controlled with increasing 'off' periods).</li> <li>• Dyskinesias, mobility problems and falls.</li> </ul>	<p>disability with no improvement.</p> <ul style="list-style-type: none"> <li>• Persistent vegetative state.</li> <li>• Minimal conscious state.</li> <li>• Cognitive impairment/post-stroke dementia.</li> <li>• Dense paralysis.</li> </ul>
<b>Frailty indicators</b>	<b>Dementia-specific indicators</b>
<p>We should consider the need for additional supportive care in:</p> <ul style="list-style-type: none"> <li>• Older people with deteriorating complex comorbidities with frequent fluctuations in health needs.</li> </ul> <p>If we are using scoring systems, the following may be significant:</p> <ul style="list-style-type: none"> <li>• Electronic Frailty Index <math>\geq 0.24</math>.</li> </ul>	<p>In addition to the frailty indicators, triggers to consider that someone is entering later stages are moderate to severe stage dementia with:</p> <ul style="list-style-type: none"> <li>• Inability to recognise family members.</li> <li>• Inability to hold meaningful conversations.</li> </ul>

- Rockwood Score  $\geq 7$ .

A Comprehensive Geriatric Assessment (CGA – see separate article) may highlight cumulative factors, including progressive weakness, weight loss, fatigue, progressive frailty, mobility problems.

- Complete dependence on carers for activities of daily living.
- Recurrent episodes of delirium.
- Aspiration pneumonia.
- Urinary/faecal incontinence.

In addition, consider: weight loss, pressure sores, reduced oral intake, recurrent fever, UTI.

## 1.2. Supportive and Palliative Care Indicators Tool (SPICT)

To implement this, some people use [SPICT](#) which helps to identify those approaching the end of life or at risk of deterioration. It can be downloaded and used for free, and is based on the [Gold Standards Framework Proactive Identification](#) guidance as detailed above.

Interestingly, the tool used to include the ‘surprise’ question: would you be surprised if this person died in the next 6–12m? However, it has moved away from this question as it felt this resulted in ‘prognostic paralysis’, and all the planning around palliative care can be made in the presence of uncertainty.

*How do we have these conversations? It is all about good communication skills (which in many ways is the easier bit) and time (which, clearly, in the current climate can be difficult). Here are some ideas:*

## 1.3. What next?



Having identified that someone may benefit from additional supportive care, we need to begin a conversation with the person and, if they wish, their family and carers about:

- Advance care planning.
- Reviewing current treatments and medication to minimise polypharmacy and maximise symptom management and quality of life.
- Support for carers.
- Considering referral for management of complex or difficult symptoms (this often won't be necessary).
- Planning ahead for possible loss of decision-making capacity.
- Recording and sharing these plans.

## 1.4. Useful communication skills

### Raising the issue

[The SPICT tool \(2021\)](#) suggested some great conversation openers to start talking about deteriorating health; here are some examples and more can be found on the SPICT site.

If you got less well in the future, what would be important to you?

Can we talk about how we manage not knowing exactly what will happen to you and when?

Some people want to talk about whether to go to hospital or stay at home if they are seriously ill

### Building a greater understanding

This is an older paper, but one that the Red Whale team frequently uses with trainees to help discuss the potential of good supportive care. It focuses on a model of supportive care that transcends symptom management, resuscitation decisions and preferred place of care. It instead concentrates on how we can help the patient to remain an individual, right through to the end of life (JAMA 2002;287:2253).

The most useful thing in this paper was the suggested phrases and questions we can use to open up communication, included in the table below.

*The questions near the top are ones we probably remember, but, as you move down, ask yourself, could you try them out?*

Dignity-related questions		Therapeutic interventions to consider
Physical distress	<i>How comfortable are you?</i>	Vigilance to symptom management.
	<i>Is there anything that could make you more comfortable?</i>	Frequent assessment.
Psychological distress	<i>How are you coping with what is happening to you?</i>	Empathetic listening/counselling.
Medical uncertainty	<i>Is there anything further about your illness you would like to know? Are you getting all the information you need? Are there things about</i>	Can tailor information to the patient's request, and talk through strategies to manage future crises.

	<i>the later stages of your illness you would like to discuss?</i>	
<b>Functional independence</b>	<i>Has your illness made you more dependent on others?</i>	Facilitate participation in decision-making.
	<i>Are you having difficulty with your thinking?</i>	Treat delirium and reduce sedation.
	<i>How much are you able to do for yourself?</i>	Physio and OT as appropriate.
<b>Conserving sense of self</b>	<i>Are there things about you the disease does not affect?</i>	Enable participation in meaningful activity.
	<i>What things did you do before you were sick that were most important to you?</i>	Take an interest and acknowledge areas of life most important to the individual – they are worthy of respect and esteem.
	<i>What about yourself or your life are you most proud of?</i>	Take an interest and acknowledge areas of life most important to the individual – they are worthy of respect and esteem.
	<i>What is still possible?</i>	Encourage activities that enhance wellbeing, e.g. light exercise, meditation, prayer.
	<i>How in control do you feel?</i>	Involve patient in decisions.
	<i>How do you want to be remembered?</i>	Life projects, e.g. journals, memory box.

	<i>How at peace are you with what is happening to you?</i>	–
	<i>What part of you is strongest right now?</i>	–
<b>Practices to conserve dignity</b>	<i>Are there things that take your mind off illness and offer comfort?</i>	Encourage participation where possible in normal day-to-day activities.
	<i>Are there things you still enjoy doing on a regular basis?</i>	Encourage participation where possible in normal day-to-day activities.
	<i>Is there a religious or spiritual community that you are, or would like to be, connected with?</i>	Involve spiritual community where appropriate.
<b>Social dignity</b>	<i>What about your privacy or your body is important to you?</i>	Take account of this in examination, etc.
	<i>Who are the people most important to you?</i>	Encourage liberal visiting.
	<i>Is there anything in the way you are treated which is undermining your sense of dignity?</i>	–
	<i>Do you worry about being a burden to others – if so, who and in what ways?</i>	Encourage explicit discussion about these issues.

	<i>What are your biggest concerns for the people you are leaving behind?</i>	Encourage settling affairs, e.g. will, advanced directive, paying for a funeral.

*We are not suggesting you use these as a 'tick list', but perhaps introduce a few questions on each visit, especially if you do not know the patient well.*

## **1.5. Identifying the last days of life**

I was listening to an interview on Radio 2 where Robert Peston, the BBC Economics Editor, talked about the loss of his wife to lung cancer. He described the last days of her life in a hospice, and how one evening she reported to the doctor that she “thought she might be a bit afraid of actually dying”. When the doctor left the room, she turned to her husband and said, “I bet he thought that was a really stupid thing to say”.

Identifying patients in their last few days and drawing the team around them is an important part of the ‘One Chance to Get It Right’ priorities of care.

The authors suggest the following is a useful aide memoire.

**Ask yourself or the team:**

**1. Could this patient be in the last days of life?**

Clinical indicators of this might include:

- Confined to bed or chair and unable to self-care.
- Difficulty taking fluids/feeding or medication.
- Increasing drowsiness.

**2. Was this patient's condition expected to deteriorate in this way?**

**3. Is further life-prolonging treatment inappropriate?**



- Treatment likely to be burdensome or ineffective.
- Patient or their healthcare proxy has refused treatment.
- Valid advance directive in place with position of non-treatment.

**4. Have reversible causes of deterioration been excluded, and would patient benefit from their treatment?**

- Infection.
- Dehydration.
- Biochemical disorder (calcium derangement).
- Drug toxicity.
- Traumatic injury.
- Anaemia.
- Acute renal or respiratory failure/hypoxia.
- Delirium.
- Severe constipation.
- Depression.

(if in doubt, give treatment and review in 24h)

**IF ANSWER TO ALL FOUR QUESTIONS IS YES, PLAN CARE FOR DYING PATIENT**

	<p><b>Identifying adults approaching end of life</b></p> <ul style="list-style-type: none"> <li>• Opening a dialogue with a patient about their values, wishes and end-of-life care can lead to better outcomes.</li> <li>• Identifying those who might benefit from supportive/palliative care is difficult.</li> <li>• There are some tools available to help, including the Gold Standards Framework and SPICT.</li> <li>• Recognising these transitions helps patients have a good death.</li> </ul>
	<p>Audit all deaths in your practice over the past 6m:</p> <ul style="list-style-type: none"> <li>• How many were unexpected or sudden?</li> <li>• How many were on the palliative care register?</li> <li>• How many non-cancer deaths were included on the register?</li> <li>• Discuss the results at your PHCT meeting. Can you identify any barriers that could be addressed to help more patients access palliative care and die at home if that is their wish?</li> </ul> <p>Could you develop a practice policy on advance care planning? Who will do this? How will it be communicated to relevant bodies, e.g. OOH, on hospital admission?</p>
	<p><b>Useful resources:</b></p> <p><u>Websites</u> (all resources are hyperlinked for ease of use in Red Whale Knowledge)</p> <ul style="list-style-type: none"> <li>• <a href="#">SPICT – supportive and palliative care indicators tool</a></li> <li>• <a href="#">The Gold Standards Framework</a> (the GSF is well known to most of us in primary care. The website contains training and audit tools, as well as helpful information for improving communication with out-of-hours providers)</li> <li>• <a href="#">GMC – treatment and care towards the end of life: good</a></li> </ul>

practice in decision making

- **Hospice UK – Dying Matters** (Dying Matters is an end-of-life care charity. It is setting us the challenge of ‘finding the 1%’ of patients in the last year of life, and talking to them about it. The website contains useful resources, including a ‘to do list’ for patients to help them to plan the death they want and to deal with practicalities)

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