A QUICK GUIDE to Identifying Patients for Supportive and Palliative Care

Do they have a life-limiting, incurable condition?

What clues exist… to suggest they might be suitable for your register? *These cut across all disease groups*

1. The **Surprise** questions.
   a. No Surprise if they were to die in the next 6-12months.
   b. A surprise if they were to live longer than 6-12 months. Higher priority.
2. **General decline**. Symptomatic with low level activity**.**
   Formal measures of poor or deteriorating performance status include
   a. Limited self-care; in bed or chair over 50% of the day
   b. MRC Breathlessness scale 4/5
   c. NYHA Grade 3/4
   d. WHO Performance Grade 3/4
   Remember "…before they shuffle off this mortal coil they just shuffle[4]".
3. Two or more unplanned **hospital admissions** in the last 6 months.
4. Progressive **weight loss** > 10% over last 6 months.
5. **Co-morbidities.** More than one life-threatening illness.
6. **Burden of illness** - physical, psychological, financial or other.

Who will benefit… from their inclusion on the register?

1. The **Patient**
   - Increased focus on symptom control and burden of illness.
   - Chance to explore wishes, worries and priorities - now and for the future.
2. The **Practice**
   - Improved team awareness, planning and working for patients most likely to have acute events or crises
   - Reduced unplanned secondary care spend.
3. The **Patient's Support**
   - Support for the patient's carers and family through e.g. carer assessment, referral to a carers' organisation

What next… if you think they are suitable for your register?

1. **Optimal Care**
   Are they receiving best practice care for their disease group e.g. heart failure or COPD? This is good for both long term prognosis and palliation of symptoms.
2. **Tell the Patient: e.g.**
   - We have a practice 'GSF/priority/gold/Supportive and Palliative Care' register of people with the greatest health needs.
   - The register helps us to focus our best efforts on improving your quality of life and symptoms, and to support those who care for you.
   - We will discuss your case as a team and put an alert on your record so that everyone is aware of your priority status if your record is brought up.
   - We will take a step back and consider whether we can improve your treatment, to ensure that you are receiving 'best practice' care for your condition.
   - We will give you the opportunity, where you wish, to discuss any preferences you might have if your health was to deteriorate in the future.

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Specific disease related indicators

Look for two or more of the following

Heart disease

- NYHA Class III/IV heart failure, severe valve disease or extensive coronary artery disease.
- Breathless or chest pain at rest or on minimal exertion.
- Persistent symptoms despite optimal tolerated therapy.
- Systolic blood pressure <100mmHg and /or pulse > 100.
- Renal impairment (eGFR <30 ml/min).
- Cardiac cachexia.
- Two or more acute episodes needing intravenous therapy in past 6 months.

Kidney disease

- Stage 5 chronic kidney disease eGFR< 15ml/min).
- Conservative kidney management due to multimorbidity.
- Deteriorating on renal replacement therapy; persistent symptoms and/or increasing dependency.
- Not starting dialysis following failure of a renal transplant.
- New life limiting condition or kidney failure as a complication of another condition or treatment.

Respiratory disease

- Severe airways obstruction (FEV1<30%) or restrictive deficit (vital capacity < 60%, transfer factor <40%).
- Meets criteria for long term oxygen therapy (PaO2 < 7.3 kPa).
- Breathless at rest or on minimal exertion between exacerbations.
- Persistent severe symptoms despite optimal tolerated therapy.
- Symptomatic right heart failure.
- Low body mass index (< 21).
- Increased emergency admissions for infective exacerbations and/or respiratory failure.

Liver disease

- Advanced cirrhosis with one or more complications:
  - intractable ascites,
  - hepatic encephalopathy,
  - hepatorenal syndrome,
  - bacterial peritonitis,
  - recurrent variceal bleeds.
- Serum albumin < 25g/l and prothrombin time raised or INR prolonged.
- Hepatocellular carcinoma.

Cancer

- Performance status deteriorating due to metastatic cancer and/ or co-morbidities.
- Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment.

Neurological disease

- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Symptoms which are complex and difficult to control.
- Speech problems; increasing difficulty communicating; progressive dysphagia.
- Recurrent aspiration pneumonia; breathless or respiratory failure.

Dementia

- Unable to dress, walk or eat without assistance; unable to communicate meaningfully.
- Increased eating problems; now needing pureed/ soft diet or supplements or tube feeding.
- Recurrent febrile episodes or infections; aspiration pneumonia.
- Urinary and faecal incontinence.

Reference

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