

Gold Standards Framework: General and Disease-Specific Indicators

General Indicators of Decline
<ul style="list-style-type: none"> • 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 • Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity • General physical decline and increasing need for support • Advanced disease - unstable, deteriorating complex symptom burden • Decreasing response to treatments, decreasing reversibility • Choice of no further active treatment • Progressive weight loss (>10%) in past six months • Repeated unplanned/crisis admissions • Sentinel Event e.g. serious fall, bereavement, transfer to nursing home • Serum albumen <25g/l

Disease Specific Indicators of Decline	
Cancer <ul style="list-style-type: none"> • Metastatic cancer • Performance status deteriorating due to metastatic cancer (PPS ≤ 50% life expectancy in order of only a few months) • Significant weight loss due to primary cachexia • Refer to prognostic indicator tools (PPS, PaP, PPI): can help but do not refer to them blindly 	Neurological Disease <ul style="list-style-type: none"> • Progressive deterioration in physical and/ or cognitive function despite optimal therapy • Symptoms which are complex and too difficult to control • Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure • Speech problems: increasing difficulty in communications and progressive dysphasia
Renal Disease Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least 2 of the indicators below: <ul style="list-style-type: none"> • Patient for whom the surprise question is applicable • Patients choosing the ‘no dialysis’ option, discontinuing dialysis or not opting for dialysis if their transplant has failed • Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy 	Respiratory Disease (≥ 2 of the following) <ul style="list-style-type: none"> • Severe airway obstruction (FEV1 <30%) or restrictive deficit (<60%) • Meets criteria for long-term oxygen therapy (PaO₂ < 7.3kPa) • Breathless at rest or on minimal exertion between exacerbations • Persistent severe symptoms despite optimal tolerated therapy • Symptomatic right heart failure • Loss of appetite and weight • Recurrent hospital admissions (≥ 3 in last 12 months) due to disease

Prognostic Indicator Guidance (PIG) 4th Edition Oct. 2011 © The Gold Standards Framework Centre In End of Life Care CIC, Thomas, K. et al.

Disease Specific Indicators of Decline	
Renal Disease cont'd <ul style="list-style-type: none"> • Symptomatic Renal Failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload. 	
Heart Disease (≥ 2 of the following) <ul style="list-style-type: none"> • NYHA Class III/IV-dyspnea at rest on minimal exertion • Repeated hospital admission with heart failure symptoms • Persistent severe symptoms despite optimal tolerated therapy • Significant weight loss due to cachexia 	Liver Disease <ul style="list-style-type: none"> • Advanced cirrhosis with one or more complications: <ul style="list-style-type: none"> - Intractable ascites - Hepatic encephalopathy - Hepatorenal syndrome - Bacterial peritonitis - Recurrent varicea bleeds • Serum albumin <25 g/l and PTT raised or INR prolonged > 2 • Hepatocellular carcinoma • Not fit for liver transplant
Dementia <ul style="list-style-type: none"> • Unable to walk without assistance • Urinary and fecal incontinence • Unable to communicate meaningfully • Unable to do Activities of Daily Living (ADL) • Plus any of the following: <ul style="list-style-type: none"> - Weight loss - Urinary tract Infection - Severe pressures sores – stage three or four - Recurrent fever (aspiration pneumonia, urinary tract infections) 	