RECOGNITION OF DYING AND END OF LIFE CARE

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Acknowledgement of Country

In the spirit of reconciliation, we acknowledge the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

Source: Commonwealth of Australia National Indigenous Australians Agency (2021) Welcome to Country or Acknowledgement of Country [online at] https://www.indigenous.gov.au/contact-us/welcome_acknowledgement-country

Palliative Care

Most importantly there is **increasing recognition** that caring for people who are approaching and reaching the end of life is **everybody's business** – everybody in health, aged and community care has a role to play.

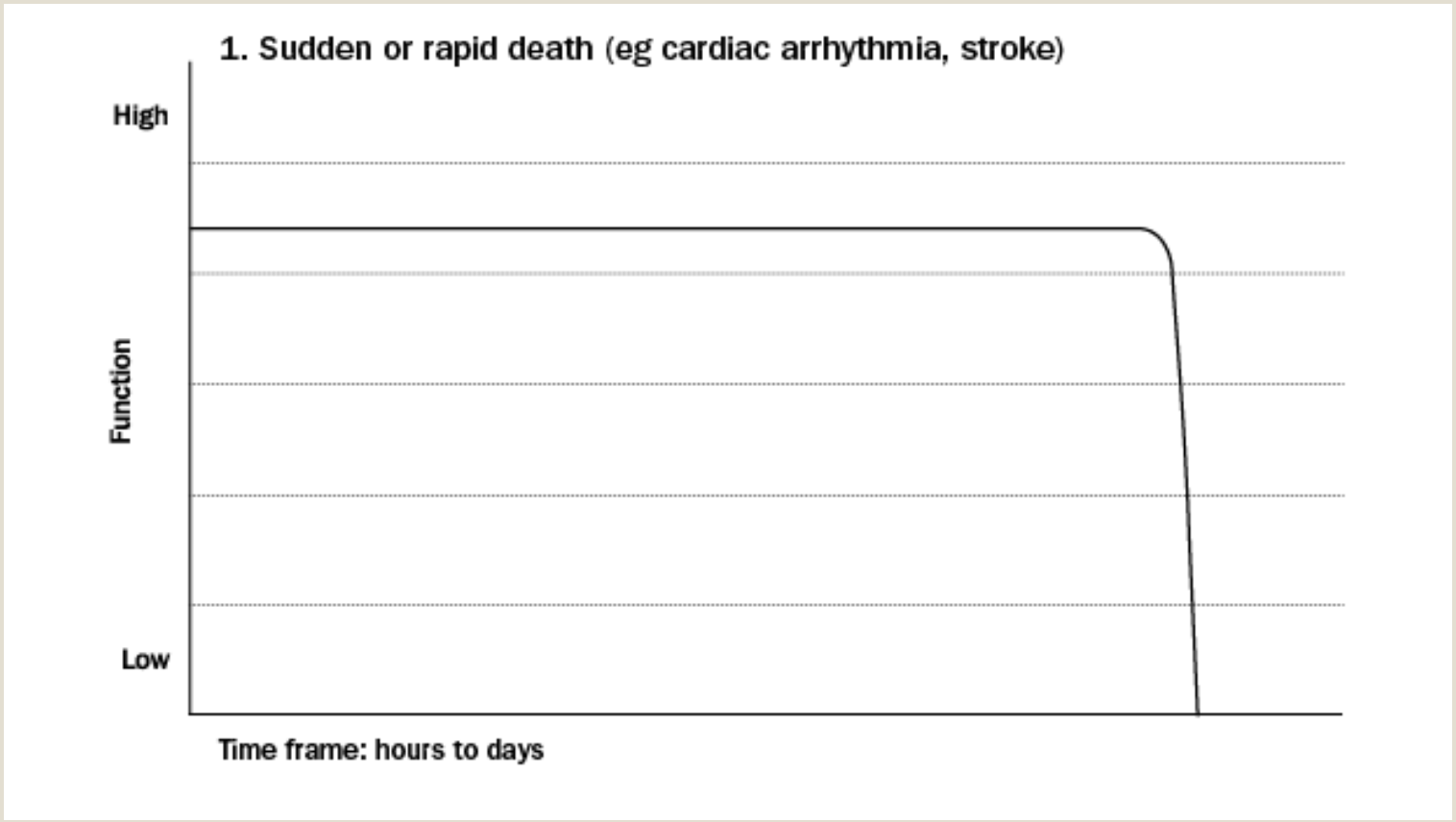
(National Palliative Care Standards)

What is Palliative Care?

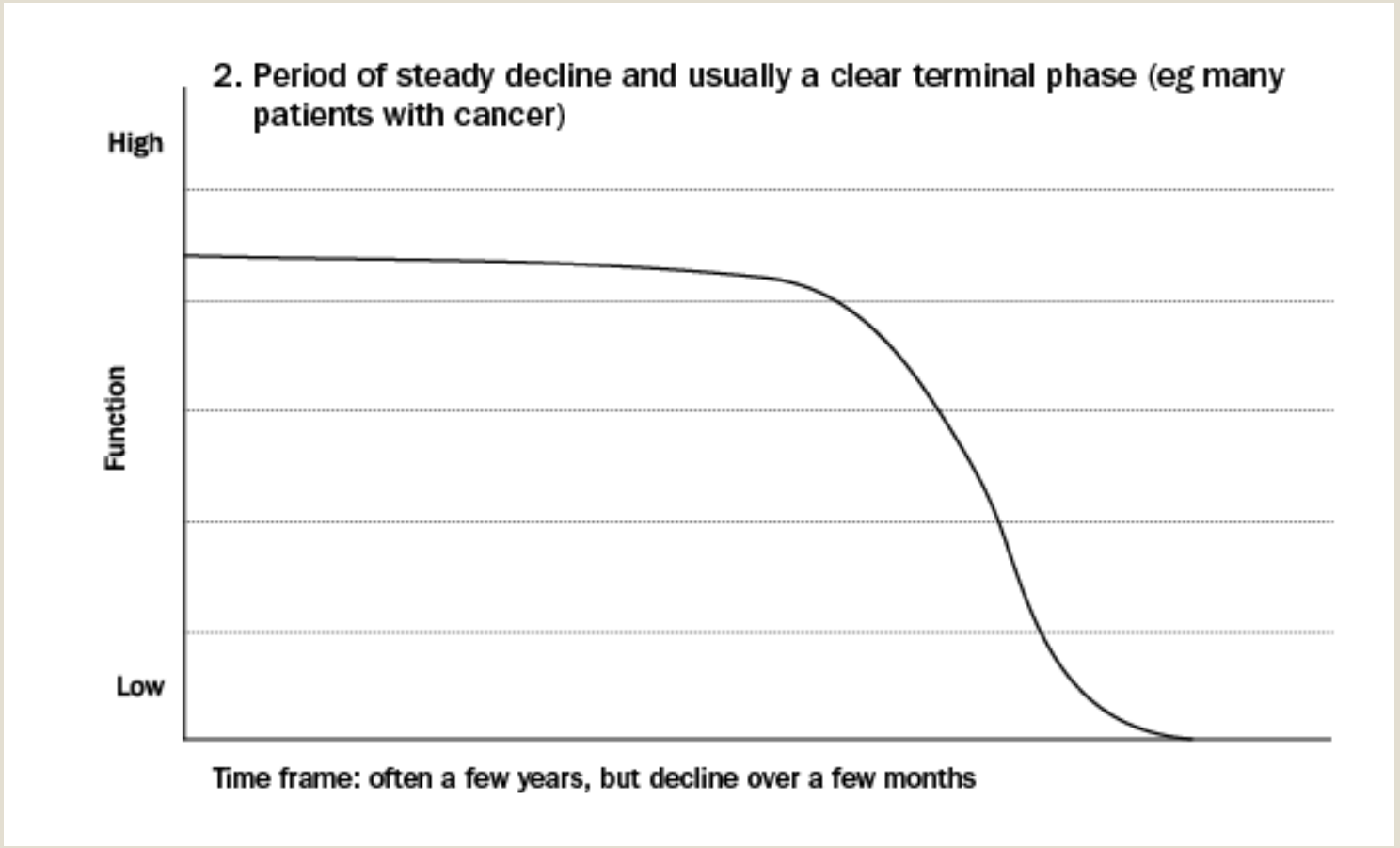
- Palliative Care is an approach that improves the **quality of life** of patients and their families facing the problem associated with **life-threatening illness**, through the **prevention and relief of suffering** by means of **early identification and impeccable assessment** and **treatment of pain and other problems, physical, psychosocial and spiritual**

- Helping to live well with a life-limiting illness

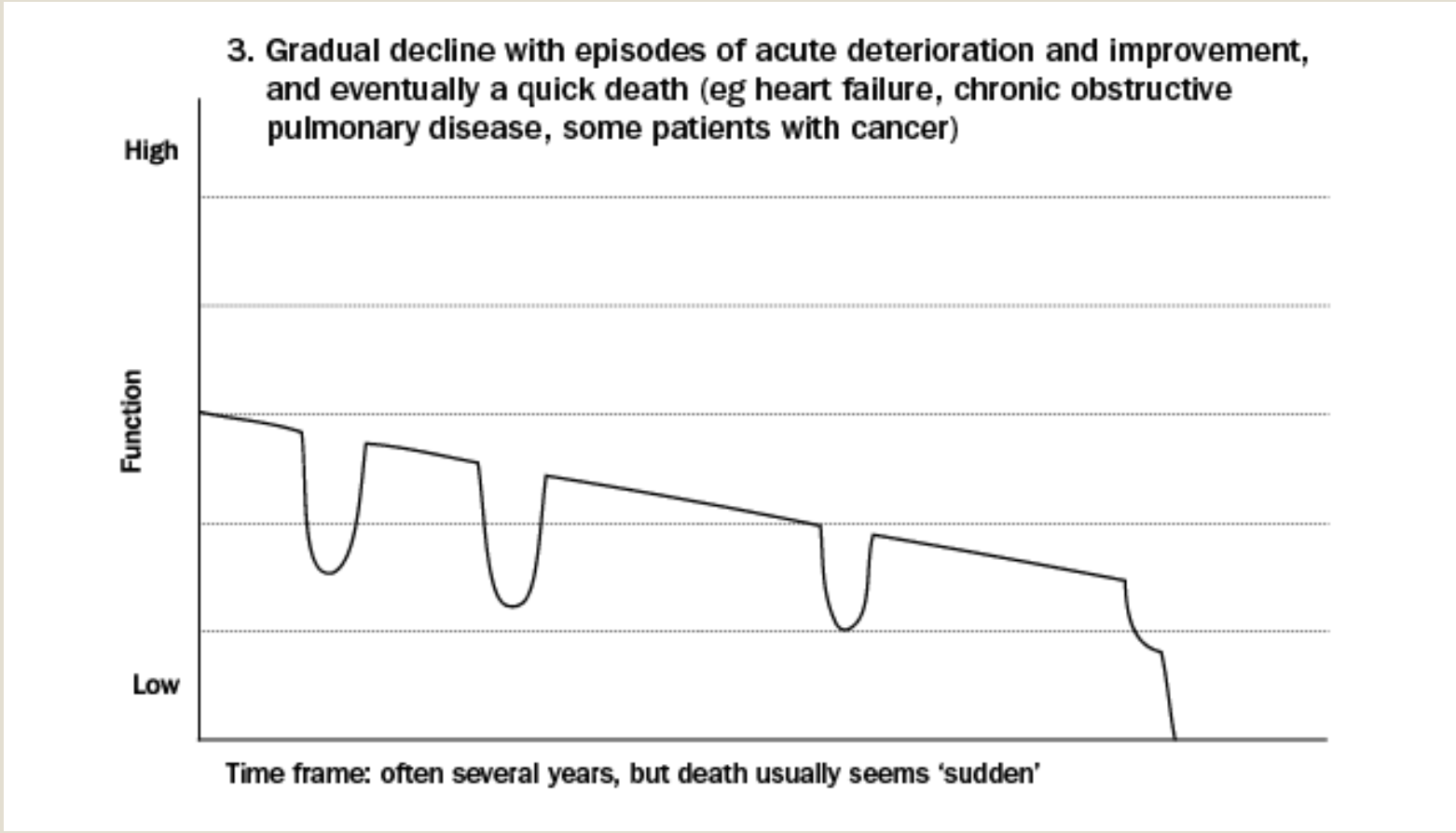
- Looks at clinical, social and emotional needs of patients AND their loved ones
- Involves a tailored &timely approach
- Anticipatory & proactive care
- Allows choice &control over decisions
- Good life & good death as per patient
- Engages with families to make decisions collectively
- Interdisciplinary approach



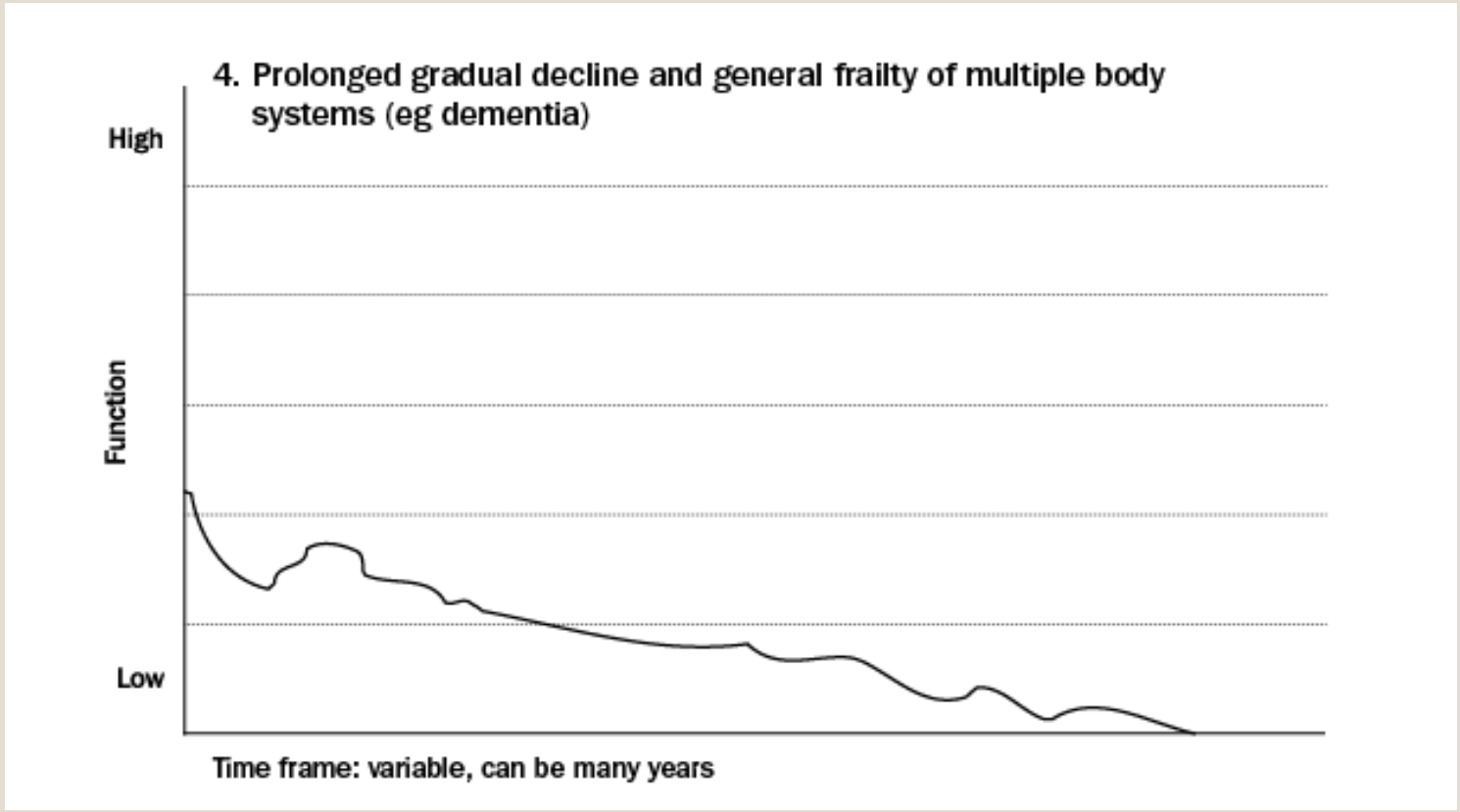
Trajectory: Sudden or rapid death



Palliative trajectory- malignant disease



Palliative trajectory- chronic disease



Palliative trajectory- Dementia

Recognising a deteriorating patient

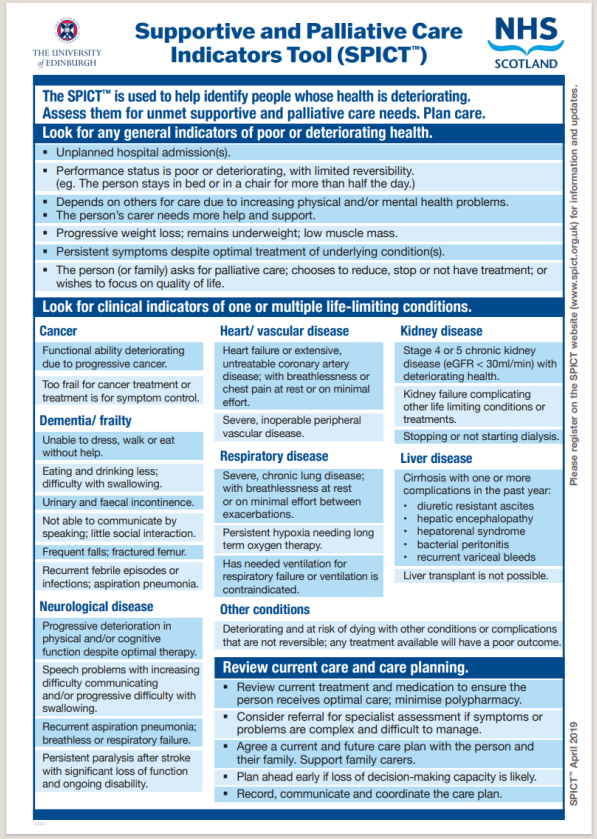
- "A deteriorating patient is one who moves from one clinical state to a worse clinical state which increases their individual risk of morbidity, including organ dysfunction, protracted hospital stay, disability, or death" **Defining Clinical Deterioration (Jones et al 2012)**
- "deterioration refers to signs of person's decline or reduced state of health." – as per PalliAGED website.
- Value in knowing a person over time – recognition of small changes
- Consider instigating palliative needs outcome rounds

Clinical indicators of a deteriorating patient

- Spend more time in bed
- Increased fatigue
- Functional decline
- Reduced oral intake
- Difficulty swallowing
- Change in breathing
- Fluctuating consciousness
- Increasing symptoms
- Weight loss
- Poor recovery to below baseline
- Unplanned (emergency) hospitalisation
- Skin changes
- weak pulse and falling blood pressure
- Reduced urine output

Recognising a dying patient

- No definitive criteria for diagnosing dying
- "Surprise question"
- Identifying that a patient is dying & there is nothing reversible
- Recognising clinical deterioration and probable death is fundamental to quality care provision
- Care Plan for the dying person Victoria



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Supportive and Palliative Care Indicators Tool (SPICT™)

NHS SCOTLAND

The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Other conditions

Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping or not starting dialysis.

Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

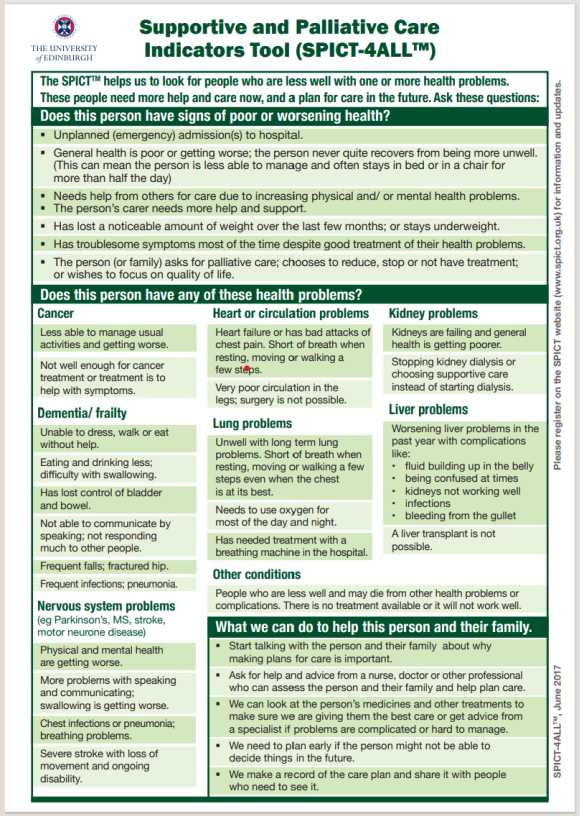
Liver transplant is not possible.

Review current care and care planning.

- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™ April 2019



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Supportive and Palliative Care Indicators Tool (SPICT-4ALL™)

The SPICT™ helps us to look for people who are less well with one or more health problems. These people need more help and care now, and a plan for care in the future. Ask these questions:

Does this person have signs of poor or worsening health?

- Unplanned (emergency) admission(s) to hospital.
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This can mean the person is less able to manage and often stays in bed or in a chair for more than half the day)
- Needs help from others for care due to increasing physical and/ or mental health problems.
- The person's carer needs more help and support.
- Has lost a noticeable amount of weight over the last few months; or stays underweight.
- Has troublesome symptoms most of the time despite good treatment of their health problems.
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Does this person have any of these health problems?

Cancer

Less able to manage usual activities and getting worse.

Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Has lost control of bladder and bowel.

Not able to communicate by speaking; not responding much to other people.

Frequent falls; fractured hip.

Frequent infections; pneumonia.

Nervous system problems

(eg Parkinson's, MS, stroke, motor neurone disease)

Physical and mental health are getting worse.

More problems with speaking and communicating; swallowing is getting worse.

Chest infections or pneumonia; breathing problems.

Severe stroke with loss of movement and ongoing disability.

Heart or circulation problems

Heart failure or has bad attacks of chest pain. Short of breath when resting, moving or walking a few steps.

Very poor circulation in the legs; surgery is not possible.

Lung problems

Unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest is at its best.

Needs to use oxygen for most of the day and night.

Has needed treatment with a breathing machine in the hospital.

Other conditions

People who are less well and may die from other health problems or complications. There is no treatment available or it will not work well.

Kidney problems

Kidneys are failing and general health is getting poorer.

Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

Worsening liver problems in the past year with complications like:

- fluid building up in the belly
- being confused at times
- kidneys not working well
- infections
- bleeding from the gullet

A liver transplant is not possible.

What we can do to help this person and their family.

- Start talking with the person and their family about why making plans for care is important.
- Ask for help and advice from a nurse, doctor or other professional who can assess the person and their family and help plan care.
- We can look at the person's medicines and other treatments to make sure we are giving them the best care or get advice from a specialist if problems are complicated or hard to manage.
- We need to plan early if the person might not be able to decide things in the future.
- We make a record of the care plan and share it with people who need to see it.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT-4ALL™, June 2017

Useful tools:

SPICT Tool & App

AUSTRALIA-MODIFIED KARNOFSKY PERFORMANCE STATUE (AKPS)

100	Normal with no complaints or evidence of disease
90	Able to carry on normal activity but with minor signs of illness present
80	Normal activity but requiring effort. Signs and symptoms of disease more prominent
70	Able to care for self, but unable to work or carry on other normal activities
60	Able to care for most needs, but requires occasional assistance
50	Considerable assistance and frequent medical care required
40	In bed more than 50% of the time
30	Almost completely bedfast
20	Totally bedfast requiring extensive nursing care by professionals and/or family
10	Comatose or barely rousable
0	Dead

AKPS

Australian modified Karnovsky Performance Scale

Why is it important to recognise our patient is dying?

- Lack of awareness of approaching death is associated with negative bereavement outcomes
- As important for the patient as for the family/loved ones

Why it matters

- Deliver appropriate care
- Support clinicians to respond appropriately
- Promote communication and set realistic expectations
- Review goals of care, care needs and treatment limitation (refer to ACP documents and MTDM)
- Implement pall care plan - Consider patient preferences (place of care and dying)
- Organise anticipatory medications and appropriate equipment
- Review and rationalise medications
- Withdraw treatment or investigations no longer appropriate
- Counselling and support
- Normalise death as a part of life

What factors influence our recognition of dying?

- Intuition and experience
- Clues and signs to indicate deterioration or dying
- Combination of intuition and clinical observation – not competing factors but both integral parts of holistic assessment

Caring for our dying patient

- Physical and emotional changes signifying a dying patient
- Not all deaths are the same however imminent dying often follows a pattern of events
- Responding to the care needs and symptoms we see
- Providing education and support to family
- What does dying look like?

Take home message

- The process of dying often follows a pattern however the timing and prognostication is often unpredictable
- Learning the signs of imminent death can verify our intuition
- We get one chance to guide patients and families well