Pilgrims Key Steps in the last year of life - H.O.S.P.I.C.E

HIGH-RISK PREGNANCY; SO WHY NOT HIGH-RISK DEATH?

ONE CHANCE TO GET IT RIGHT

SUPPORTING THE BEREAVED

PAIN IS WHAT THE PATIENT SAYS IT IS

IDENTIFY YOUR 1%

CARE PLANNING – DYING IS INEVITABLE; A BAD DEATH IS NOT

END OF LIFE IS FOR LIVING; NOT JUST ANTICIPATING DYING

Pilgrims Hospices has put together **seven short presentations**, which provide succinct guidance on the key steps in end of life care.

How do you identify patients approaching the end of life? How do you assess their needs and the needs of those close to them?

What are the key skills in communicating with them sensitively and effectively, managing their symptoms and planning for their future?

We hope this will **support clinical colleagues** in providing consistent, dignified and empathic care to patients approaching the end of life.

For more information please contact
Pilgrims Hospices Education & Training Department
on **education@pilgrimshospices.org**

www.pilgrimshospices.org/professionals

Pilgrims Hospices

High-risk pregnancy; so why not high-risk death?

High-risk deaths and how to recognise them

WHY?

People's physical, psychological, spiritual and social circumstances vary hugely; some need minimal input, others need expert care and close monitoring.

WHEN?

Early referral is ideal to give the Pilgrims team time to work with you to improve the quality of life, death and bereavement.

WHO?

Your knowledge of the patient and those close to them is key.

HOW?

Assess risk factors for poor bereavement outcome and a 'bad death'.
Refer early if you see a risk.

RISK FACTORS

- Symptom burden?
- High levels of service use relating to their illness?
- Previous negative experiences of death?
- Levels of complexity?
- Self-perceived burden?
- Carer strain related to palliative illness?
- Social isolation/low levels of support?
- Difficult family dynamics?
- Reluctant to engage with advance care planning?
- Limited opportunity for adjustment because of late diagnosis/rapid decline?
- Mismatch of understanding or preferences between patient and carer?

- How often do I think ahead about potential problems and risks?
- Of the deaths I've been involved with, how could I have reduced the risks of a 'bad death' or difficult bereavement?

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FURTHER INFORMATION

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One chance to get it right

Care in the last few days and hours

WHY?

How people die remains in the memory of those who live on and there's only one chance to get it right.

WHEN?

Patient is agreed to be dying, bed bound and taking little by mouth.

WHO?

All staff are prepared to care, and each community should be prepared to help.

HOW?

- Recognise that the patient is deteriorating
- Communicate this to the patient and family
- Involve patient and family in all decisions
- Support the patient and family holistically
- Plan and do

(See reverse for more details)

Notes: See conversation chart. If patient on transdermal patch remember to take that dose into account. If 3 or more doses are administered within 24 hours, refer to the prescriber	Reason for use **PAIN**				DATE			
	Drug **MORPHINE SULPHATE** *Patients already on opiods should have individualised prescription				TIME			
	Dose range **2.5mg to 5mg**	Route **SC**	Frequency **EVERY HOUR**	Start Date **<<SYSTEM_DATE>>**	DOSE			
	Authorised by: **<<REFERRAL_Clinician>>**			Review Date	SIGN			
Notes: If 3 or more doses are administered within 24 hours, refer to the prescriber	Reason for use **NAUSEA AND/OR VOMITING**				DATE			
	Drug **LEVOMEPROMAZINE**				TIME			
	Dose range **6.25mg**	Route **SC**	Frequency **EVERY 4 HOURS**	Start Date **<<SYSTEM_DATE>>**	DOSE			
	Authorised by: **<<REFERRAL_Clinician>>**			Review Date	SIGN			
Notes: If 3 or more doses are administered within 24 hours, refer to the prescriber If patient remains unsettled contact prescriber for further advice.	Reason for use **ANXIETY/SEDATION**				DATE			
	Drug **MIDAZOLAM**				TIME			
	Dose range **2.5mg to 5mg**	Route **SC**	Frequency **EVERY 2 HOURS**	Start Date **<<SYSTEM_DATE>>**	DOSE			
	Authorised by: **<<REFERRAL_Clinician>>**			Review Date	SIGN			
Notes: If 3 or more doses are administered within 24 hours, refer to the prescriber	Reason for use **RESPIRATORY SECRETIONS**				DATE			
	Drug **GLYCOPYRRONIUM** up to 1.2mg in 24hrs				TIME			
	Dose range **400 microgram**	Route **SC**	Frequency **EVERY HOUR**	Start Date **<<SYSTEM_DATE>>**	DOSE			
	Authorised by: **<<REFERRAL_Clinician>>**			Review Date	SIGN			

NOW WHAT?

- Looking back on patients who have died under your care, what can be learnt?
- Am I looking after myself as well as my patients?

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FURTHER INFORMATION

HOW TO CARE IN THE LAST FEW DAYS AND HOURS

Recognise

- Recognise that patient is deteriorating and may potentially die in the next few days/hours
- Exclude reversible causes e.g. hypercalcaemia, AKI, opiate/ drug toxicity, infection
- Does the patient have an advance care plan?
- Does the patient have a DNACPR Form?

Communicate

- Senior clinician to sensitively inform patient/family that the patient is dying or has potential for dying and explain rationale for this.
- Complete record of end of life care conversations form. Put a copy in the notes along side DNACPR
- Document all conversations and management plan in medical notes
- Communicate ongoing aims/ changes in care regularly to patient/family

Involve

- Involve patients and relatives in all decisions regarding care according to their wishes

This should include:

- Resuscitation decision
- Preferred place of death – if Home rapid discharge home to die guide available on the Trust's EOLC we page.
- Need for hydration and nutrition
- Need for medication
- Appropriateness of further tests and investigations

Support

- Identify holistic support needs of family – Patient and family diary to be encouraged for use at the bedside
- Ensure ward contact details given to family
- Explain facilities available i.e. Relatives suites for families on each site, Keys held with SPC team & ITU
- Consider moving patient to single room
- Offer chaplaincy/spiritual support

Plan+Do

- Ensure dignity+compassion in all care given
- Document all decisions and discussions regarding ceilings of care

Medical

- Daily medical assessment of symptoms
- Stop unnecessary investigations, observations and medication
- Prescribe anticipatory medication for pain, agitation, dyspnoea, secretions and nausea to use PRN
- End of life symptom control guidance available via Pilgrims Hospice website and Palliative Care Guidelines plus
- Consider need for CSCI if > 2pm doses used in <24 hours
- If patient is taking regular oral opiates commence CSCI as soon as patient is unable to tolerate oral medication, syringe driver guidance available on the Trust's EOLC web page
- Keep family informed of situation and ongoing changes

Nursing

- Minimum 4-hourly review using end of life care records documentation
- Facilitate eating and drinking if possible

Ensure patient is comfortable by

- Administering anticipatory medication promptly when needed
- Attending to mouth care
- Attending to bowel/bladder care and pressure areas
- Attending to family /carer's distress

Care after death

- Explain care after death and the relative support offices role for documentation
- Follow Trust guidance for care after death
- Inform GP

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Supporting the bereaved

Assess vulnerability and resilience

WHY?

To try and avoid physical and mental illness, higher drug and alcohol use and increased mortality in bereavement.

WHEN?

Early – identify vulnerabilities and resilience before bereavement, so that support can be put in place.

WHO?

All health and social care staff.

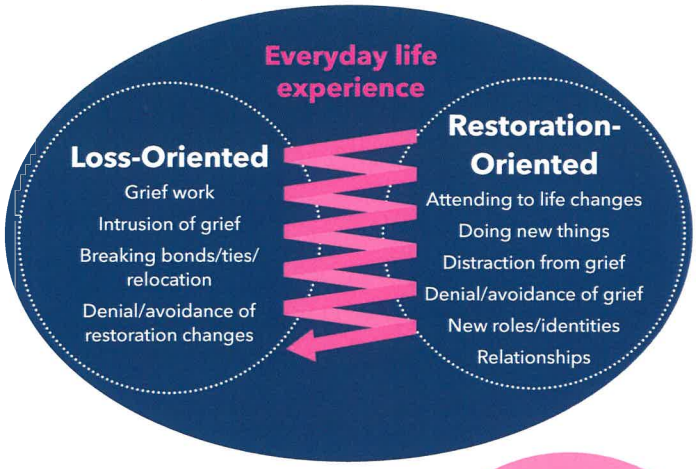
HOW?

Recognise the risks. Listen. Explain. Conduct anticipatory care planning. Offer psychological support through information, support groups and counselling.

Bereavement is a normal part of life and time is a healer, but sometimes more is required. Oscillation between the two sides of the diagram below is normal but getting stuck suggests problems.

DUAL PROCESS MODEL

(Stroebe & Schut 2001)



- How do I know if this bereavement reaction is 'normal'?
- When do I refer to specialist services and what are they?

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FURTHER INFORMATION

FACTORS INFLUENCING BEREAVEMENT:

- Events and circumstances leading to death
  - Untimely death, sudden event, or with difficult symptoms
  - Lack of DNA CPR / need for post mortem
- Meaning of relationship with deceased
  - Ambivalent relationships, disenfranchised family members, extreme feelings of guilt/relief, challenging and abusive relationships.
- Personal vulnerability or coping skills
  - Existing/previous resiliencies and vulnerabilities when faced with distressing and stressful situations
  - Previous losses or loss of "future together" e.g. children or special events
- Concurrent life events e.g. responsible for others, work, financial concerns, housing
- Health history (including smoking, alcohol or drug history)
  - Particularly if person has neglected or delayed addressing their own health issues
- Availability of social support & financial resources

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The Good Grief Trust
www.thegoodgrieftrust.org

Cruse Bereavement Care
www.cruse.org.uk

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Pain is what the patient says it is

Keys to effective symptom control

(Total approach, effective assessment and careful application)

WHY?

Improving symptom control improves prognosis and builds confidence by overcoming fears.

We need to reach a point where the patient is in charge of the symptoms not the other way around.

WHEN?

At all stages of the patient's journey.

WHO?

Common areas of symptom control should be within the remit of all senior health professionals. We should all be able to recognise the 'total' nature of symptoms.

HOW?

- Finding the cause of the symptom makes treating it easier and more effective
- Assessing severity objectively demonstrates improvement
- Look at what goals you can realistically help the patient achieve
- Are the physical symptoms manifestations of psychological, emotional or spiritual issues?
- Don't withhold morphine and other opioids on the basis of misplaced fears (yours or the patients)

- How do you recognise total pain? This applies to all symptoms
- If it's not just about the drugs, who else can help?
- If it is about the drugs, where do I get advice? Telephone: 01233 504133

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Identify your 1%; their care will be better if you do

How to identify patients who may benefit from a palliative care approach?

WHY?

Early palliative input decreases suffering, reduces unnecessary hospital admissions and interventions and improves people's wellbeing.

WHEN?

If a patient meets the SPICT criteria and you would not be surprised if they died in the coming year.

WHO?

Any senior health or social care professional should be able to recognise the triggers and start a discussion about this in the hospital and the community.

HOW?

- Assessing need as well as prognosis is key
- Approximately 1% of patients on a GP's lists will be in need of palliation
- Set up and share an anticipatory care plan
- The SPICT tool on the reverse helps you to identify the people at risk of deteriorating health and death

NOW WHAT?

- How would I rate my skills in identifying these patients and their needs?
- How confident am I in communicating effectively with them?
- How can I improve these skills?
- How well do I know the Pilgrims services that can help meet these needs?

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THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT™)

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.
- The person has had significant weight loss over the last few months, or remains underweight.
- 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.

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.

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.

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.

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SPICT™, April 2017

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Care planning

Dying is inevitable; a bad death is not

WHY?

Patients and families expect healthcare professionals to initiate end of life discussions. They need time to reflect, adapt and talk about their changing circumstances. Whilst we can hope for the best, we need to plan for the worst.

WHEN?

When a patient meets the SPICT tool criteria, especially if at risk of an acute change in condition or a crisis.

WHO?

Any senior health or social care professional should be able to start a discussion about this in the hospital and the community. They should ensure any plan follows the patient and is communicated effectively as part of ongoing care.

HOW?

Prepare some key phrases you feel comfortable using; anticipate questions and potential clinical scenarios in their future illness; listen out for cues in what patients say and use silence effectively. Remember, discussions can be planned or opportunistic.

AVOID CLOSED PHRASES...
"Would you like to be resuscitated?"

TRY INSTEAD... "When your heart and lungs stop, we need to plan how and where you'd like to be cared for."

NOW WHAT?

- How many of the patients dying under my care need an anticipatory care plan?
- What would help to put that plan in place?
- What would prevent a plan being put in place?

Planning end of life care goes beyond the measurable outcomes of resuscitation and preferred place of death. It can be the unique expression of personhood and within lies the possibility of a 'good' death.

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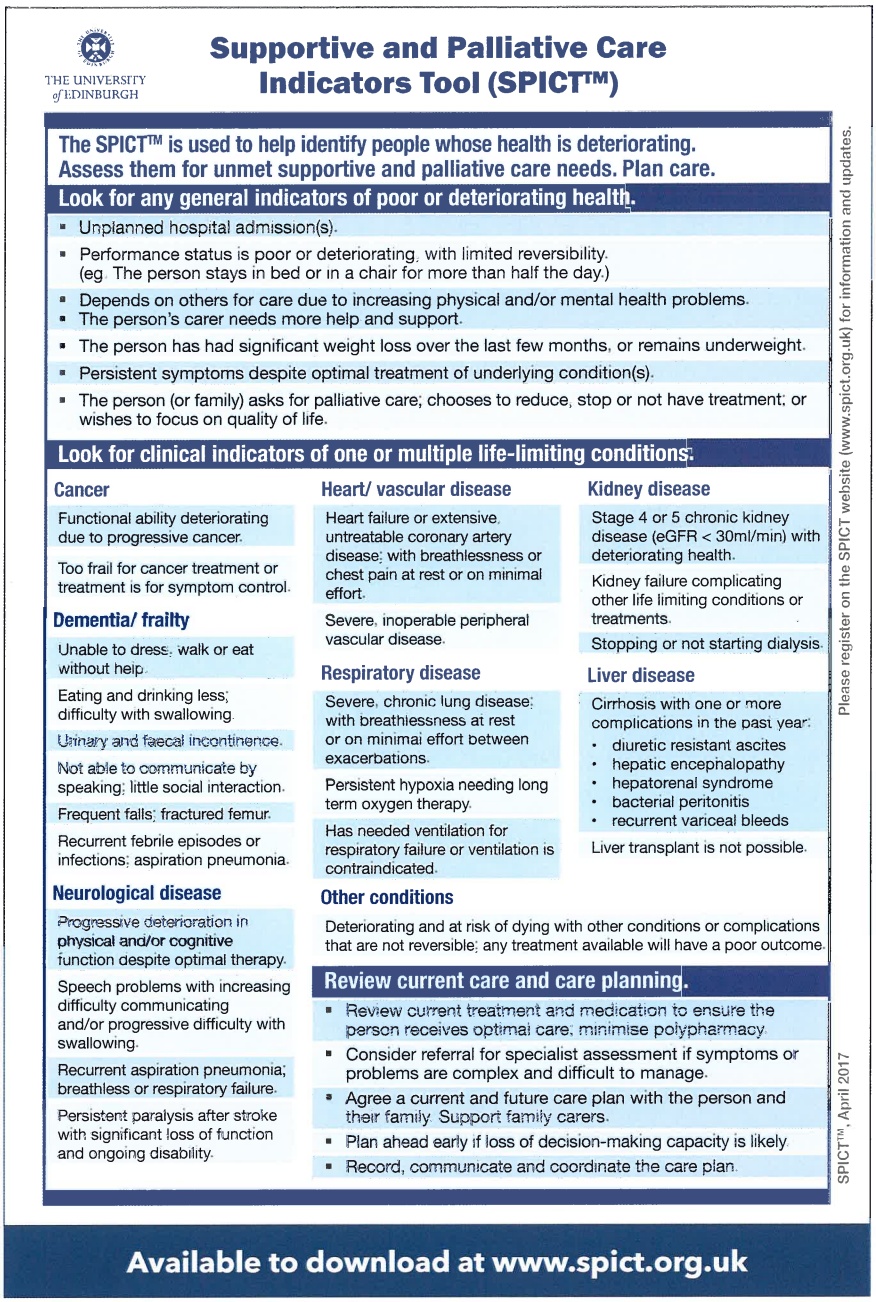

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End of life is for living; not just anticipating dying

Introducing the palliative phase with patients

WHY?

Patients expect to be informed of changes in their condition. Open discussion enables their concerns to be addressed.

Effective communication is therapeutic.

We need to normalise hospice input: Pilgrims should be part of their care and not a sign of giving up.

WHEN?

When a patient is likely to die in the next 12 months or the patient asks or gives a cue they would like to discuss these issues.

WHO?

All health and social care staff.

HOW?

Find a key phrase you are comfortable using to initiate the discussion – 'How do you see the future?' or 'What have you been told about what's happening with your illness?'

Anticipate patients' questions and concerns, listen out for cues, look for 'prognostic awareness', and aim to align their goals with their reality.

- In your experience, what are people's biggest concerns?
- How confident are you when communicating with dying patients?
- Are you looking after your patients' spiritual wellbeing as well as their disease?
- How can you further improve your skills?

Pilgrims Guide to the Key Steps in the last year of life:

H.O.S.P.I.C.E www.pilgrimshospices.org/professionals

FURTHER INFORMATION

GENERAL RESOURCES

Pilgrims Hospices *visit our website* ***www.pilgrimshospices.org/professionals*** *for:*

- Details of hospice services
- Symptom control guidance
- Hospice referral forms
- Sage and Thyme communications course
- Advanced communication skills course
- Advance care planning training

Pilgrims 24-hour advice line: 01233 504133

Email: PH.PilgrimsHospices@nhs.net

Twitter: @PilgrimsHospice

Palliative care guidelines plus
An excellent free symptom control guide including an opioid dose converter
http://book.pallcare.info

Ambitions in end of life care
http://endoflifecareambitions.org.uk

Dying Matters
http://www.dyingmatters.org

E-ELCA
E-learning modules on communication skills and advance care planning
www.e-lfh.org.uk/programmes/end-of-life/

Gold Standards Framework is the UK's leading provider of training in end of life care for generalist frontline staff. Pilgrims delivers this training for care home staff.
www.goldstandardsframework.org.uk

National Institute for Clinical Excellence 2004, Improving supportive and palliative care for adults with cancer. *NICE guideline NG 31: Care of dying adults in the last days of life* (2015) **www.nice.org.uk**

Royal College of General Practitioners, palliative and end of life care
www.rcgp.org.uk/endoflifecare

'SPICT' Supportive and Palliative Care Indicators Tool: a guide to identifying people at risk of deteriorating health and dying.
www.spict.org.uk

Treatment and Care towards the End of Life (GMC)
http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp