What is Palliative Care?

Day 1

Learning Outcomes

- Describe the origins of palliative care and its multi-disciplinary team-working approach.
- Discuss the four dimensions of palliative care and the needs of the person, family and carers.
- Understand who could benefit from a palliative care approach.
- Recognise the range of tools to support you.

Origins…

- 1842 first recognised hospice solely for care of the dying in France
- Modern day hospice movement pioneered in Great Britain by Dame Cicely Saunders
- Founded St Christopher's Hospice in London in 1967
- Recognised as a Medical Speciality in 1987

Definitions

- Palliative care
- End of Life
- Care Around Dying

Is she palliative?

When is someone dying?

He's not palliative yet. I'm giving him IV antibiotics

Does that mean I'm terminal?

Are they on 'end of life'?

Palliative Care (1)…

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

(*World Health Organisation 2020*)

Palliative Care (2)…

- Palliative care is holistic care of a person of any age living with life shortening conditions and their family and carers that focuses on what matters to them.
- It can start from around the time of diagnosis and includes care when someone is dying.

Palliative Care Matters For All

(Palliative care strategy 2025- 2030)

End of Life

- *“People are considered to be approaching the end of life when they are likely to die within the next 12 months, although this is not always possible to predict.”* (NHS England) https://www.nhs.uk/
- *“The term ‘end of life’ usually refers to the last year of life, although for some people this will be significantly shorter.”* (Royal College of Nursing UK) https://www.rcn.org.uk.

Care Around Dying

This refers to the holistic care of a person of any age who is dying and in the last hours, days or few weeks of their life, that focuses on comfort and includes people close to them who are supported into bereavement.

We now use this term ‘care around dying’ instead of ‘end of life care’ because the older wording causes confusion with palliative care which can be important long before someone is dying.

Palliative Care Matters For All

(Palliative care strategy 2025-2030)

The Philosophy of Palliative Care

- Person-centred approach
- Partnership
- Holistic approach
- Respect
- Promotion of comfort and dignity

The Philosophy of Nursing

- Patient centred approach
- Partnership
- Holistic approach
- Respect
- Promotion of comfort and dignity

4 Dimensions of Palliative Care

Who needs Palliative Care?

Anyone living with a life-shortening illness

- Heart failure
- Respiratory failure
- Liver failure
- Dementia
- Certain neurological conditions
- Irreversible sepsis
- Ischaemia (eg. CLTI Chronic Limb –threatening ischaemia)

The Stats…

Most people who live in **care homes** for older people are in their **last 18 months of life.**

1 in 3 hospital beds are occupied by people in the **last year of their life.**

Over **30,000 frail older people** receive **care at home** each week.

Over 90% of people who die in Scotland each year have health conditions that could benefit from Palliative Care

Who provides Palliative Care?

A multidisciplinary team of health and social care professionals including:

- GPs
- Community/District Nurses
- Specialist Palliative Care Teams
- Hospice Teams
- Hospital Staff
- Prison Nurses
- Care Home Staff
- Social Carers
- Social Workers
- Charity Support Organisations
- Families /persons support network

The role of the Family

In groups, discuss the potential role of the family as part of the care team in:

1. Caregiving
2. Decision making
3. Advocacy
3. Providing and receiving Emotional & Social Support
4. Communication

How do you access specialist palliative care ?

- In hospitals
- In the community
- In care homes
- In Prison
- If you are homeless

Where is Palliative Care provided ?

Care & support is offered in:

- Homes
- Care Homes
- Hospitals
- Hospices
- Prisons
- Day centres

How do we identify palliative care needs

&

When should a palliative care approach start?

Things that can help…

Clinical Frailty Scale

1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 Well – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

3 Managing Well – People whose medical problems are well controlled, but are not regularly active beyond routine walking.

4 Vulnerable – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being "slowed up", and/or being tired during the day.

5 Mildly Frail – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 Moderately Frail – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

7 Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9 Terminally Ill – Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia,** recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia,** they cannot do personal care without help.

Electronic frailty index

Disease State

Symptoms / Signs

Disability

Abnormal Lab Value

The SPICT

SPICT

SUPPORTIVE AND PALLIATIVE CARE INDICATORS TOOL

Press here to begin

Ways to use SPICT-App

THE UNIVERSITY OF EDINBURGH

Usher Institute

Population Health Sciences & Informatics

Palliative Performance Scale (PPSv2)

PPS Level	Ambulation	Activity Level & Evidence of Disease	Self -care	Intake	Conscious level
PPS 100%	Full	Normal activity & work **No evidence** of disease	Full	Normal	Full
PPS 90%	Full	Normal activity & work **Some evidence** of disease	Full	Normal	Full
PPS 80%	Full	Normal activity & work *with* effort Some evidence of disease	Full	Normal or reduced	Full
PPS 70%	Reduced	Unable normal activity & work **Significant** disease	Full	Normal or reduced	Full
PPS 60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance	Normal or reduced	Full or confusion
PPS 50%	Mainly sit/lie	Unable to do any work **Extensive** disease	Considerable assistance	Normal or reduced	Full or drowsy or confusion
PPS 40%	Mainly in bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy +/- confusion
PPS 30%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Reduced	Full or drowsy +/- confusion
PPS 20%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Minimal sips	Full or drowsy +/- confusion
PPS 10%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Mouth care only	Drowsy or coma
PPS 0%	Dead	-	-	-	-

Instructions: PPS level is determined by reading left to right to find a 'best horizontal fit.' Begin at left column reading downwards until current ambulation is determined, then, read across to next and downwards until each column is determined. Thus, 'leftward' columns take precedence over 'rightward' columns. Also, see 'definitions of terms' below.

The Surprise Question

- For patients with advanced disease, or progressive life shortening conditions, **would you be surprised if the patient were to die in the next years, months, weeks, days?**
- The answer to the question should be an intuitive one, putting together a range of clinical, social & other factors that give a whole picture of deterioration.
- **If you would not be surprised, then what measures might be taken to improve the patient's QOL and in preparation for possible further decline?**

(ref: Gold Standards Framework)

MORE than the LAST BREATH
The SPECTRUM of PALLIATIVE CARE

FOCUSSING on HOLISTIC NEEDS and LIFE QUALITY

SHARED with PATIENT and FAMILY

LIVING with LIFE LIMITING CONDITIONS (INCLUDING ADVANCED FRAILTY +/- DEMENTIA)

CHECK we KNOW...

What MATTERS to ME...

Start FUTURE CARE PLANNING

Are PRESCRIBED DRUGS still needed? STOP unnecessary or harmful medication

Are patient and family aware FOCUS is on GOOD PALLIATIVE CARE?

Consider RESUSCITATION STATUS

POWER of ATTORNEY - in place and DOCUMENTED?

PERIOD of DECLINE and INDICATORS of DECLINE*

Can be HOURS, DAYS, MONTHS or YEARS

DECREASING
- Activity
- Mobility
- Function

INCREASING need for carer support

Choice of no further active treatment

Low mood

fatigue

increasing confusion or delirium

incontinence

recurrent infections

stage 3/4 pressure sores

↑ ADVERSE EVENTS? eg. fall or hospital admission

INCREASING SYMPTOMS or COMPLICATIONS of underlying illnesses

MEDICAL/NURSING REVIEW to look for reversible causes of decline

Review FUTURE CARE PLAN with patient + family

Request JUST in CASE medication

LIAISE with GP or nurse

MEDICINES BETTER CRUSHED? (where allowed) or other form

Resuscitation DISCUSSED and RECORDED

loose?

DECREASING ORAL INTAKE and WEIGHT LOSS

* Gold standards Framework 2011

LAST DAYS or HOURS

STOP monitoring/medicines

Has 'just in case' drugs

Family supported and updated?

GP or nurse courtesy call

DNACPR In place?

Doing what matters

Recognise possible SIGNS of ACTIVE DYING

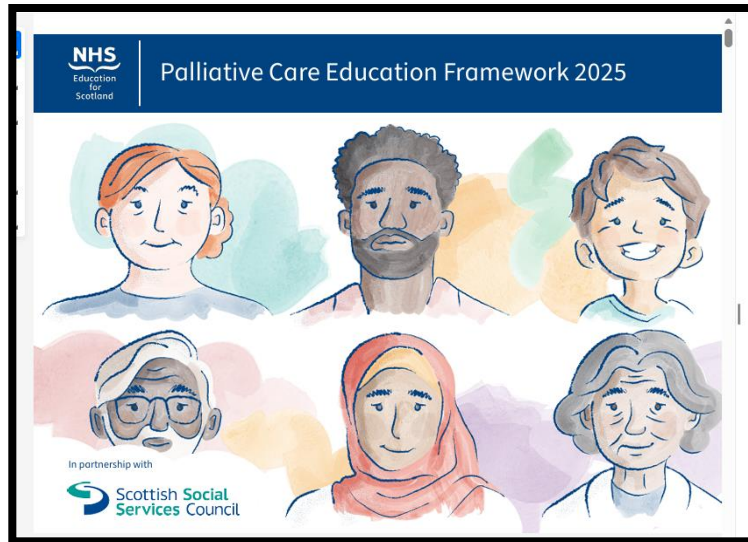
LETHARGY - weak, bed-bound, increasingly sleepy
ALTERED MENTAL STATE - confused, restless, agitated
SKIN CHANGES - pale, blue, mottled, cold hands or feet
TABLETS and oral intake diminished or stopped
BREATHING CHANGES - rattly, rapid, intermittent

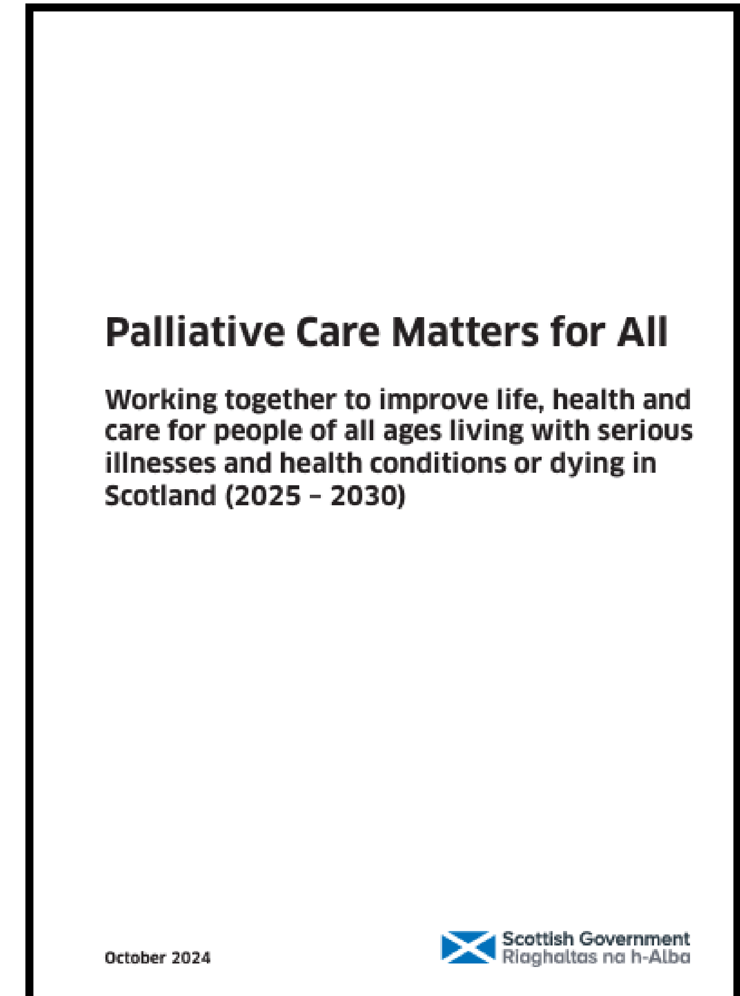
This poster and plain text version

Plain text version available: https://nhsforthvalley.com/palliative-care-poster

Green RV, Ward A, Miller S, NHS Forth Valley, January 2024

National & Local Policies & Frameworks to improve living & dying well





Video: Palliative Care improves the quality of life of patients (WHO)

Link: https://www.youtube.com/watch?v=ZnGXV8SCMo0 (2:19 mins)