

# 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**
- **End of life care**
- **Terminal**

Is she palliative?

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

When is someone dying?

Are they on 'end of life'?

Does that mean I'm terminal?

# Definition

**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)*

# 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 UK)

<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

We often refer to this as the care given to a person who is living through the dying phase of life, when someone is actively dying.

Previously known as End of Life Care

# Terminal care

Terminal care was an outdated term for End of Life Care and refers to care of the person living through the dying phase of life. This phase could vary between weeks, days or hours, the exact timing often being unpredictable. Changes and deterioration may occur suddenly and unexpectedly.

*(Scottish Government 2018)*



# Why is this important?

- Discuss:

- Why is this important?
- How many people die each year in NHS GG&C?
- What are the leading causes of death?



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

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



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

# 4 Dimensions of Palliative Care

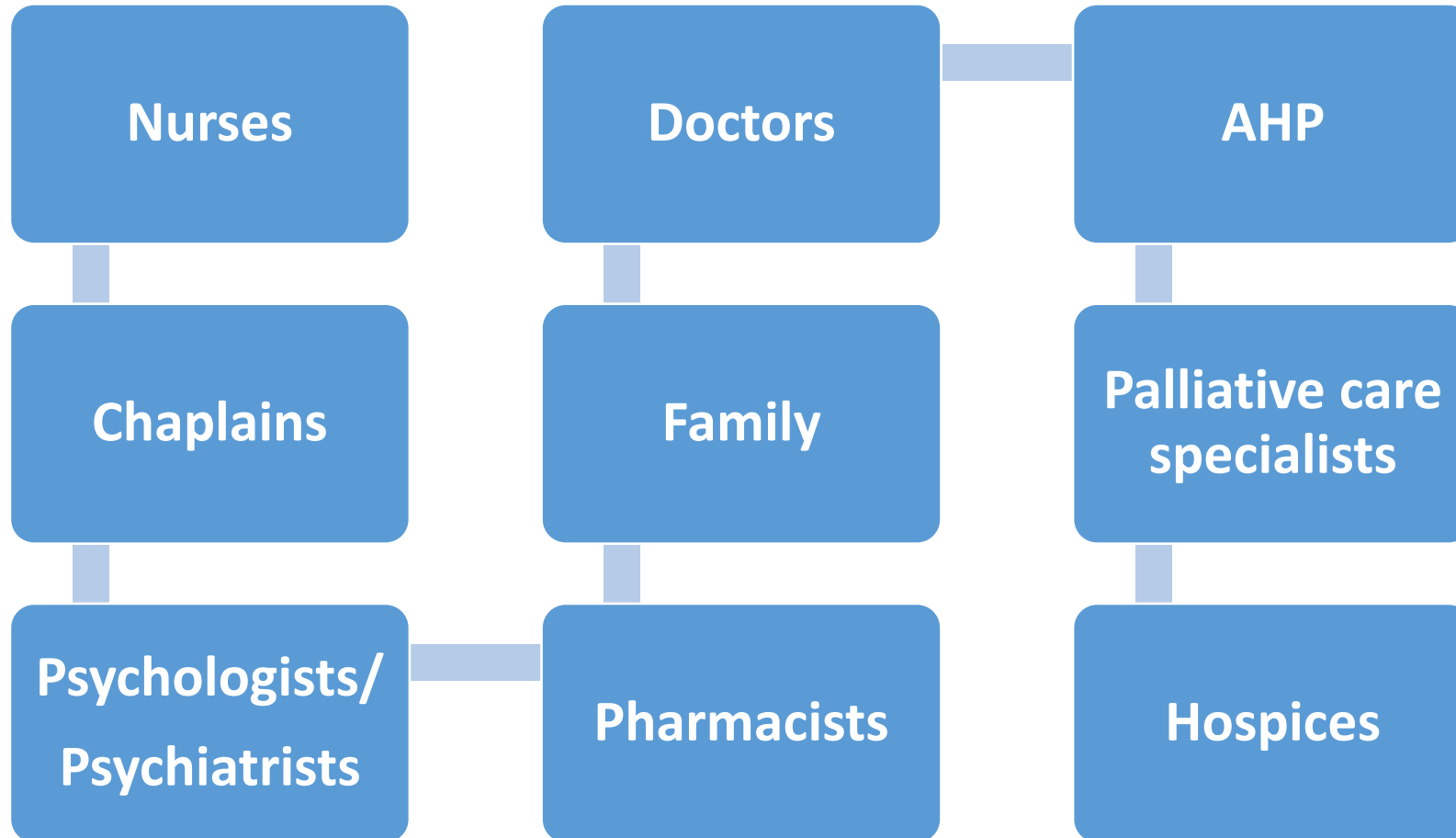


# Who needs Palliative Care?

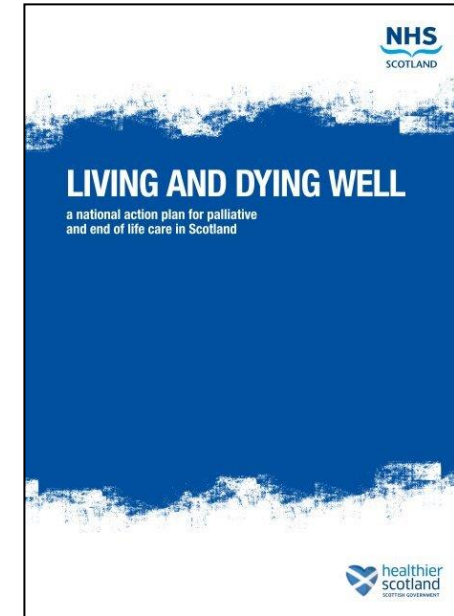
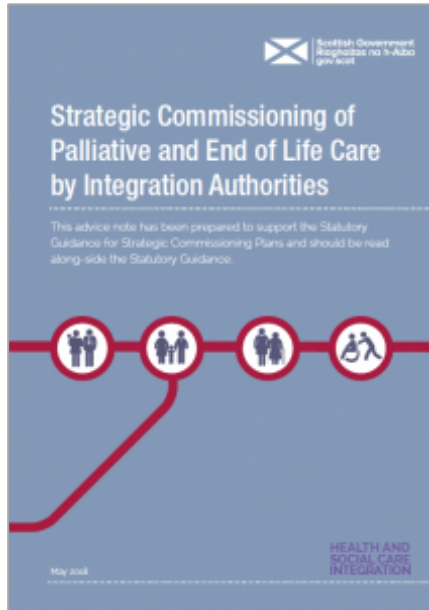
Anyone living with a life-limiting illness

- Heart failure
- Respiratory failure
- Liver failure
- Dementia
- Certain neurological conditions
- Irreversible sepsis/perforation
- Ischaemia

# Who Provides Palliative Care?



# National Policies to improve living & dying well



How to access specialist  
palliative care?

**In hospital -**

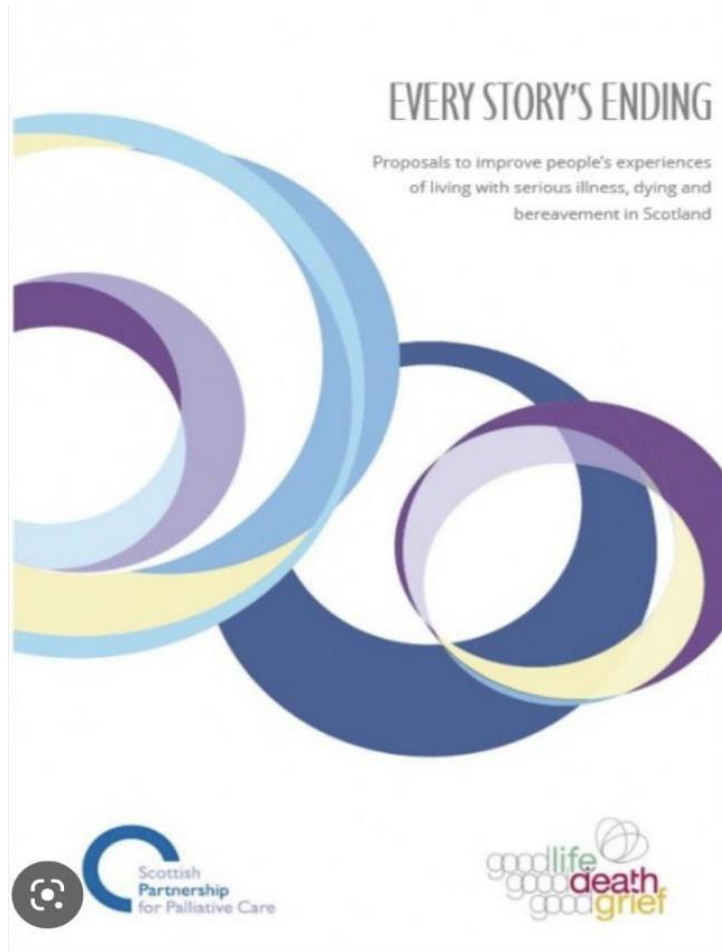
Via TrakCare

**In community –**

Via SCI/email/paper referral



# Why? What matters?



- Support, empathy, information
- Autonomy, opportunity, honesty
- Privacy, individuality, relationships



# When should it start/is needed?

## Look for *general* indicators of deteriorating health

- Unplanned hospital admissions
- PS is poor/deteriorating with limited reversibility
- Increasingly dependent on others for pADLs
- Significant weight loss, or remains underweight
- Persistent symptoms despite optimal treatment of underlying condition(s)
- Person (or family) *asks for palliative care*; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life (QOL)










***Consider referral for specialist assessment if symptoms/problems are complex & difficult to manage***








# Any other tools?

- Rockwood frailty tool
- Electronic frailty index

### Clinical Frailty Scale

|  |  |
|--|--|
|  <p><b>1 Very Fit</b> – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.</p>   |  <p><b>7 Severely Frail</b> – 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).</p>   |
|  <p><b>2 Well</b> – 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.</p>   |  <p><b>8 Very Severely Frail</b> – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.</p>  |
|  <p><b>3 Managing Well</b> – People whose medical problems are well controlled, but are not regularly active beyond routine walking.</p>  |  <p><b>9 Terminally Ill</b> – Approaching the end of life. This category applies to people with a life expectancy &lt;6 months, who are not otherwise evidently frail.</p>  |
|  <p><b>4 Vulnerable</b> – 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.</p>  |  |
|  <p><b>5 Mildly Frail</b> – 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.</p> | <p><b>Scoring frailty in people with dementia</b></p> <p>The degree of frailty corresponds to the degree of dementia. Common <b>symptoms in mild dementia</b> include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.</p> <p>In <b>moderate dementia</b>, recent memory is very impaired, even if their past life ev with prompting.</p> <p>In <b>severe dementia</b>, without help.</p> |
|  <p><b>6 Moderately Frail</b> – 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.</p>  |  |

### Electronic frailty index

| Disease State  | Symptoms / Signs  | Disability   | Abnormal Lab Values  |
|--|---|--|--|
|  Hypertension            |  Diabetes     |  Heart Valve Disease   |  Pulmonary Disease       |
|  Stroke                 |  Thyroid     |  Rheumatoid Arthritis |  Chronic Kidney Disease |
|  Asthma                 |  Depression  |  Parkinson's Disease  |  Liver Disease          |
|  Chronic Kidney Disease |  Sleep Apnea |  Dementia             |  Anemia                 |
|  Chronic Kidney Disease |  Falls       |  Fractures            |  Abnormal Lab Values    |

# GSF-PIG : The Surprise Question

- For patients with advanced disease, or progressive life limiting 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?**

# GSF-PIG: General indicators of decline

- Advanced disease – unstable, ↓ing, complex symptom burden
- Sentinel event e.g. serious fall, bereavement, transfer to nursing home
- Serum albumin <25g/l
- General physical decline, ↑ dependence & need for support
- Decreasing response to treatments, ↓ reversibility
- Considered eligible for DS1500 payment (BASRIS)
- Presence of significant multi-morbidities
- Decreasing activity: functional performance status declining (e.g. Barthel score) ↑dependence in most activities of daily living

Both SPICT & GSF also contain disease specific clinical indicators

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



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