An introduction to palliative and end of life care

An interactive look at palliative and EoL care

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Click the Button below to continue

continue

Aims

- Explore the terms “palliative” and “end of life” care
- Consider the meaning of holistic care
- Introduce advance care planning
- Identify when someone is approaching the end of life
- Reflect on the care needs of the dying patient
- Reflect on how to support families, colleagues and self

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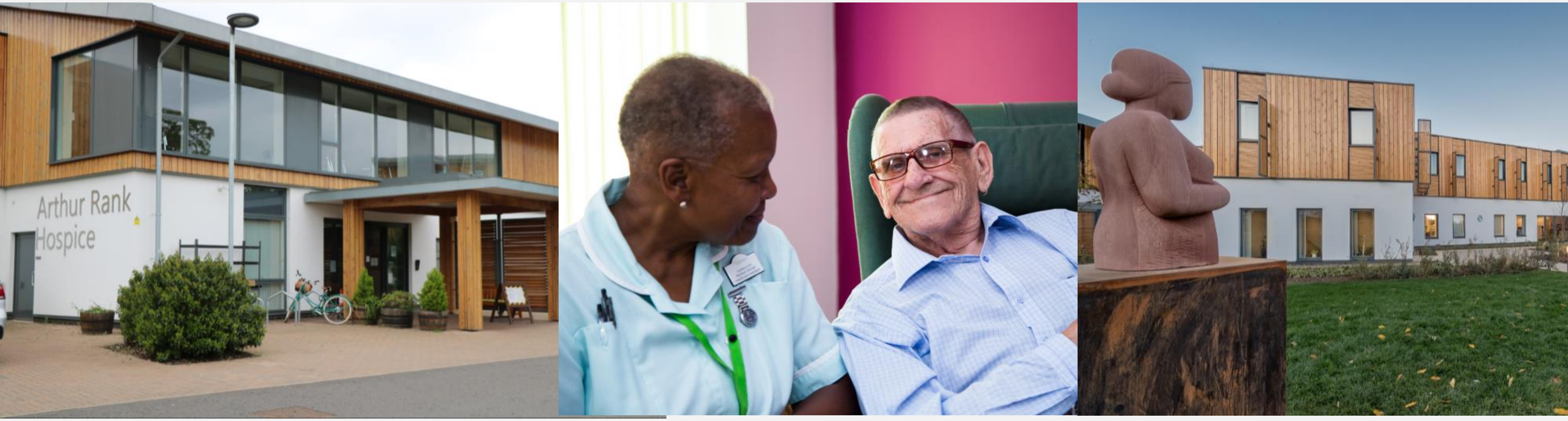
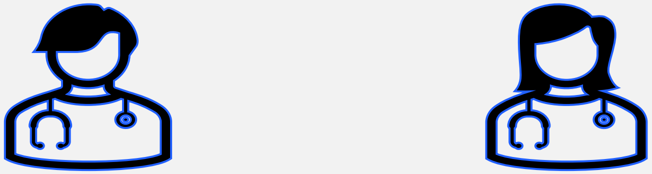


A gentle health warning

- Emotive subject but… dying does affect everyone and we all meet patients who have life limiting illness
- Reflections should focus on professional rather than personal experiences
- Take time out if you need to, but please come back ☺



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What do you know about palliative and end of life care?

- Spend some time thinking about what you already know about this subject and what you would like to learn

2 min

continue

Main Menu

End of life care facts

End of Life Care for Adults (NICE)

What is palliative care

Hospice movement

Caring for you

- Click on an object to learn more about end of life and palliative care.
- When you have completed all the content areas click on "EXIT" in the bottom left to finish

You tube video How to live and die well

Holistic Care

You tube **Dying is not as** bad as you think!

ONE
CHANCE
TO GET
IT RIGHT

Improving people's experience of care in the last few days and hours of life.

Published June 2014 by the
Leadership Alliance for the Care of Dying People

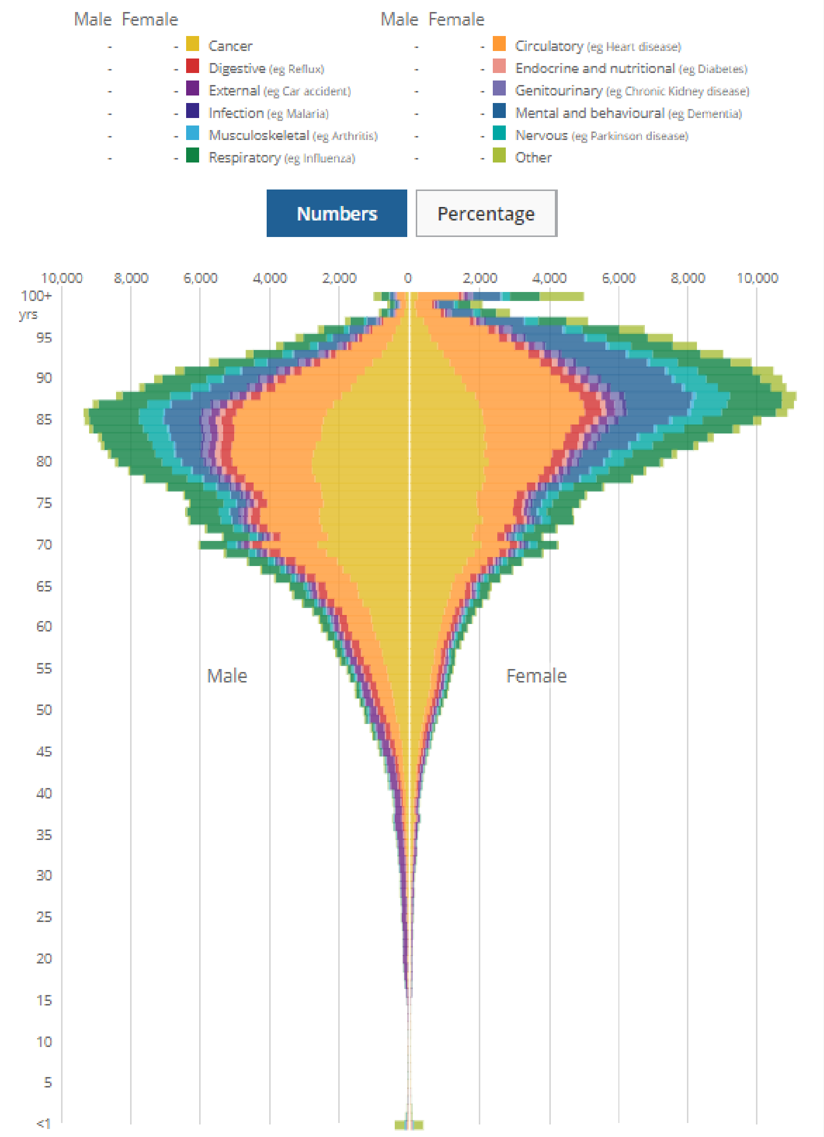
Publications Gateway Reference 01509

LINK to symptom management learning

End

Figure 4: Broad causes of death by sex and single year of age

England and Wales, 2017



Source: Death registrations in England and Wales, summary tables: 2017

About $^{1}/_{2}$ million people die in England and Wales each year

- $^{2}/_{3}$ are over 75
- Most die of chronic diseases

- 58% die in hospital
- 18% die at home
- 17% die in a care home
- 4% in a hospice
- 3% elsewhere

- (pre-covid figures)

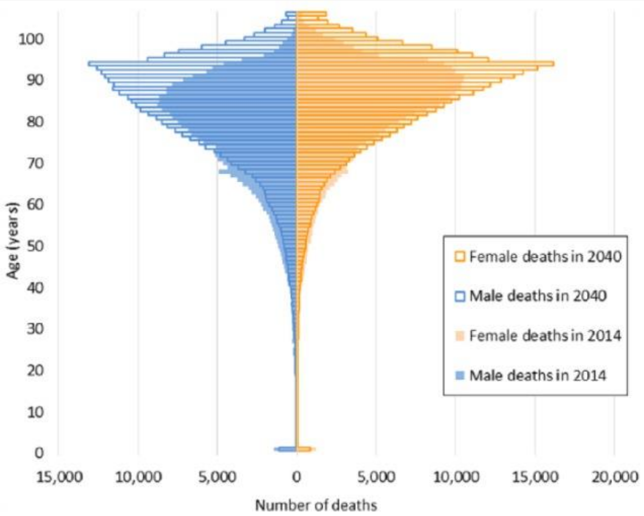
Mortality 2017

continue

In the future?

An increasingly aging population means that there will be:

- An extra 4000 deaths annually by 2020-25
- An extra 8000 deaths annually by 2030-35
- 54% deaths will be aged ≥85 years by 2040



Bone et al, Palliative Medicine, 2017

We also live differently:

In 1961 12 % of households in England were single person, by 2040 it is projected to be 40%.

We are more likely to see more very elderly dying patients with:

- Increased need for palliative care especially for complex and very elderly patients
- Multi-morbidity
- Elderly carers looking after each other
- People living alone and needing care

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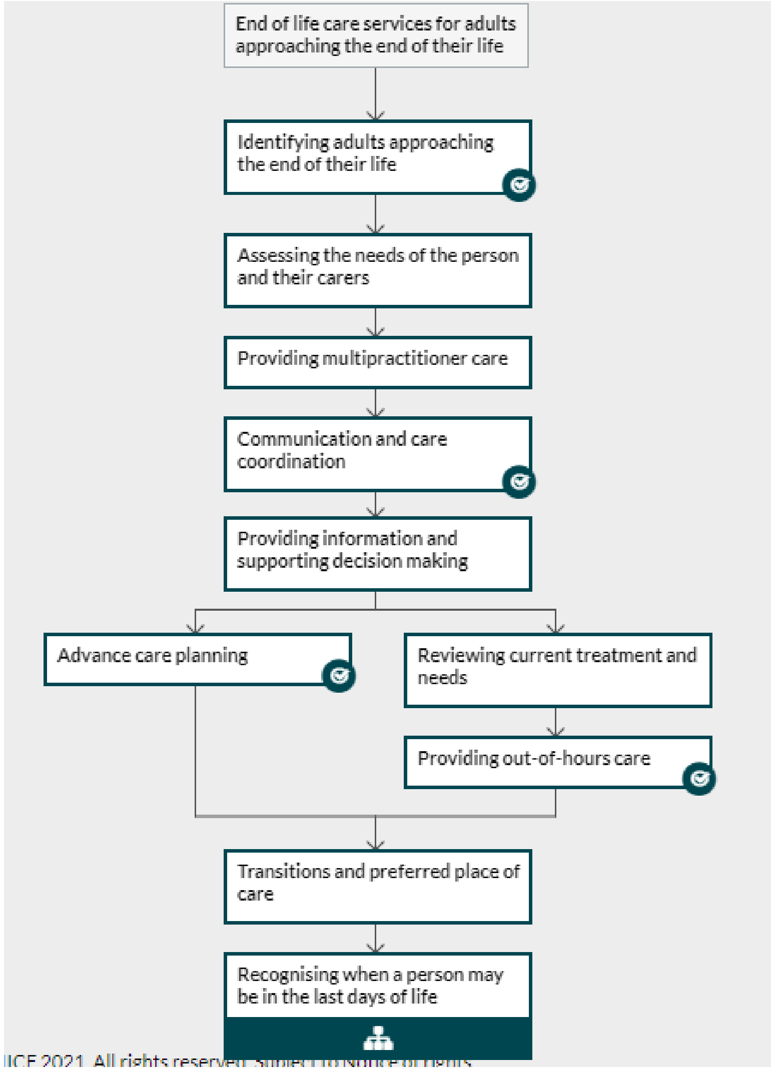
End of Life Care for Adults (NICE)

End of life is when a person is assessed as having a long term or life limiting condition.

This can be the last year of life or longer, during which they may receive palliative care.



End of life care services for adults approaching the end of their life

Identifying adults approaching the end of their life

Assessing the needs of the person and their carers

Providing multipractitioner care

Communication and care coordination

Providing information and supporting decision making

Advance care planning

Reviewing current treatment and needs

Providing out-of-hours care

Transitions and preferred place of care

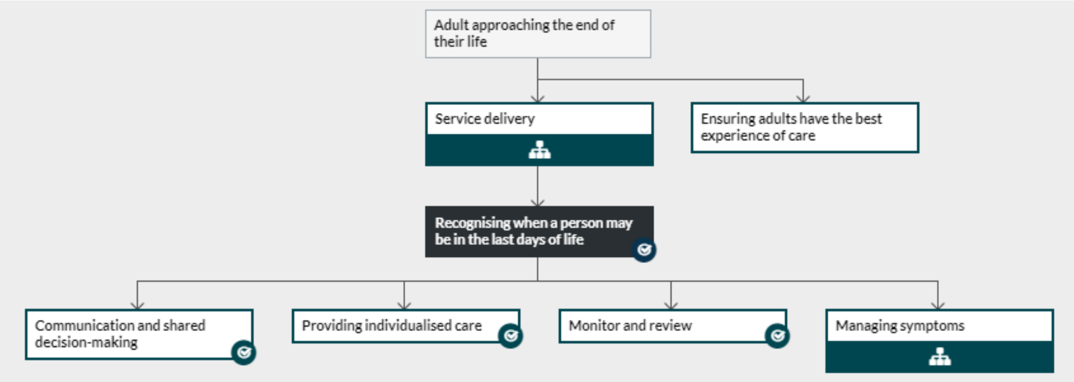
Recognising when a person may be in the last days of life

continue

Caring for an adult at end of life (NICE)

Terminal care is only one stage of palliative care, and usually refers to the last few days or weeks of life from a point at which it becomes clear that the patient is in a progressive state of decline

NICE PATHWAY



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Definitions of Palliative Care

Link
to
NICE

Care towards the end of life that aims to provide relief from pain and other distressing symptoms, integrate the psychological and spiritual aspects of the person’s care and provide a support system that allows people to live as actively as possible until their death.

NICE (2019)

World Health Organization

Link to full definition

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.

WHO: Consensus-Based Definition of Palliative Care (2019)

continue

Term	Definition
Supportive care	Care that helps the person and people important to them to cope with life-limiting illness and its treatment – from before diagnosis, through diagnosis and treatment, to cure or continuing illness, or death and bereavement.
Palliative care	Care towards the end of life that aims to provide relief from pain and other distressing symptoms, integrates the psychological and spiritual aspects of the person's care, and provide a support system that allows people to live as actively as possible until their death.
Non-specialist palliative care	Palliative care provided by healthcare professionals within their normal duties, and without specialist knowledge, skills and competence in palliative care.
Specialist palliative care	Palliative care provided at the expert level, by a trained multi-professional team (including, for example, consultants in palliative medicine and clinical nurse specialists in palliative care), who must continually update their skills and knowledge, in order to manage persisting and more complex problems and to provide specialised educational and practical resources to other non-specialised members of the primary or secondary care teams problems and to provide specialised educational and practical resources to other non-specialised members of the primary or secondary care teams.
Terminal Care	Usually refers to the last few days or weeks of life from a point at which it becomes clear that the patient is in a progressive state of decline.

Which of these is available in your place of work? How are they accessed?

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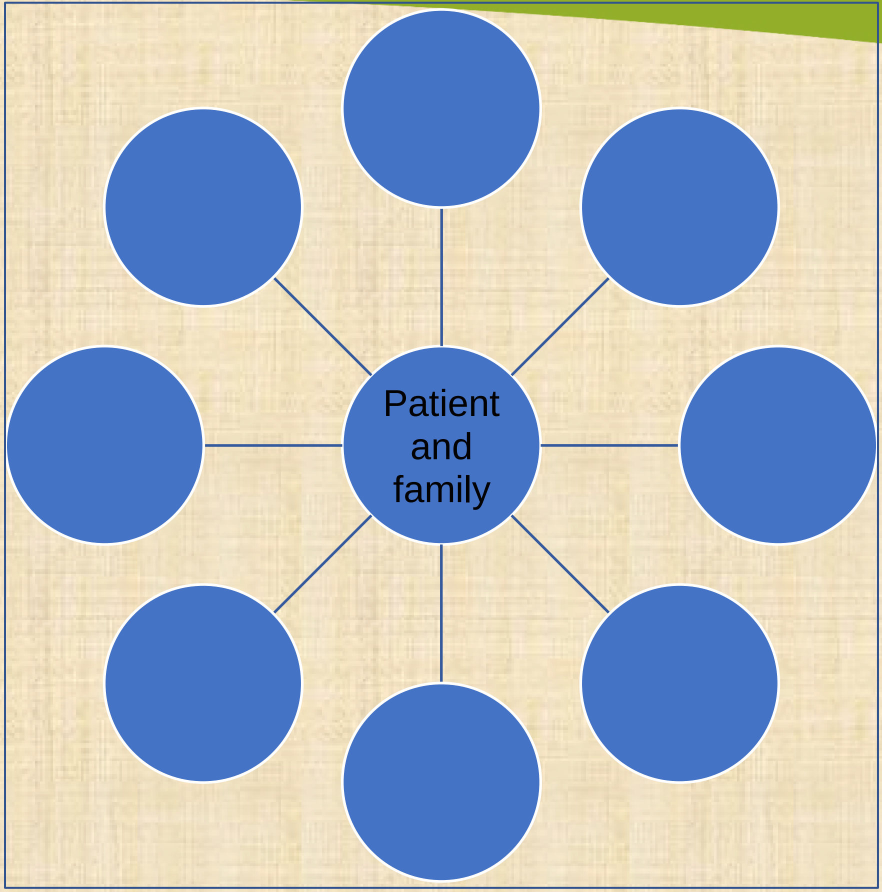

Multidisciplinary Team

Putting your resident or patient at the centre of care: what services and professionals are available to support them at end of life?

Do you know how to access them or make a referral?

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Palliative Care and the Hospice Movement

In 1967, Dame Cicely Saunders founded St Christopher's Hospice in London. This led to the development of the modern hospice movement and recognition of palliative care as a distinct medical speciality.

Dame Cecily believed in holistic care, treating the whole person. She developed the concept of total pain as an approach to meeting the holistic distress which may be expressed at by the dying.

Today palliative care takes place in all care settings, community, care homes, acute hospitals and there are more than 220 hospice services in the UK.

Dame Cicely Saunders

"You matter because you are you, and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also live until you die".

Total Pain

Biography Link

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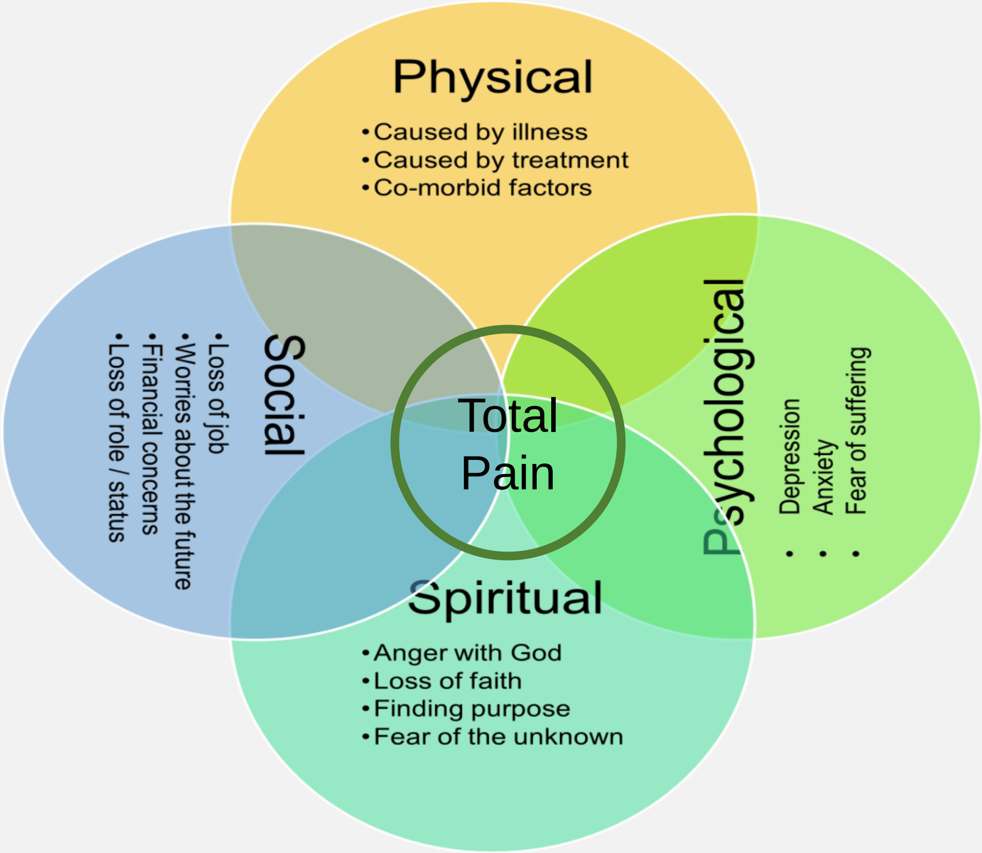
Total pain



Physical
- Caused by illness
- Caused by treatment
- Co-morbid factors

Social
- Loss of job
- Worries about the future
- Financial concerns
- Loss of role / status

Psychological
- Depression
- Anxiety
- Fear of suffering

Spiritual
- Anger with God
- Loss of faith
- Finding purpose
- Fear of the unknown

Total Pain

Dame Cicely Saunders, described ‘total pain’, as ‘the division of a whole experience into physical, emotional, social and spiritual components’ (Saunders and Sykes, 1993)

Total pain describes the holistic nature of palliative care; and recognises that there can be many features that affect patients experiences of pain. Physical, social, psychological and spiritual concerns need to be heard and considered.

When we listen to peoples concerns we can learn about and understand what is happening to them and how to help

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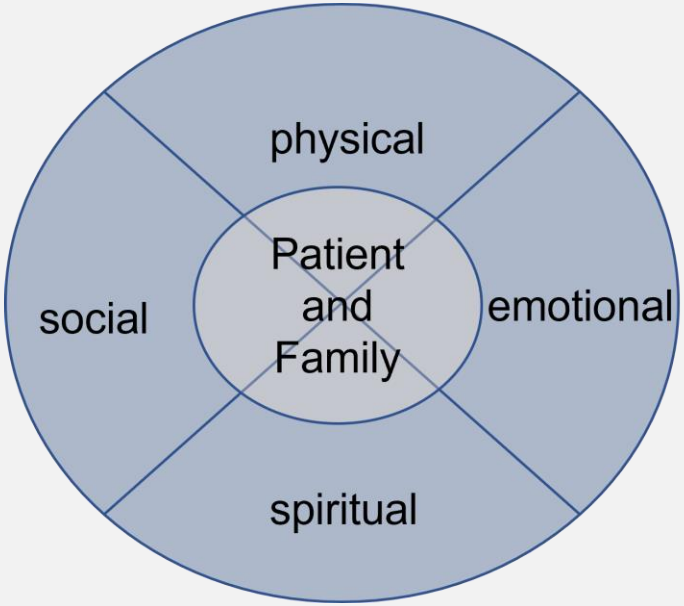
Using a Holistic Approach

- Specialist Palliative Care teams are multi-professional and each profession works together to make a personal care plan with the patient and their family. Palliative treatment can include medication, surgery, chemotherapy or radiotherapy, as well as physiotherapy, occupational therapy and palliative rehabilitation. In addition many patients benefit from accessing alternative therapies.
- Palliative care follows holistic principles and each person will have a holistic assessment of needs. Physical, emotional, social and spiritual aspects are addressed.
- A holistic approach to care treats the whole person rather than individual symptoms. This involves the patient, their family and significant others and people and services you identified in the previous exercise.
- Think about a person you have cared for who is nearing the end of life and make some notes about their needs in each aspect, physical, emotional, social, spiritual. How were you able to address their needs?



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Assessing and managing symptoms

A holistic approach helps to identify how symptoms and concerns are interconnected and the impact for the patient. Using good communication skills like active listening and sensitive questioning help to elicit concerns.

Some areas that are helpful to explore include:

- Assessing physical symptoms
  - Frequency – how often the symptom occurs
  - Severity – an assessment tool may be used to record this
  - Affect on patient – including body image and psychological distress
  - Medication they are taking or have tried
  - Things that make it better/worse
- Symptom impact and other patient identified concerns
  - How is patient function affected by the symptom? (for example, pain and dyspnoea can be very disabling)
  - Any activity it stops them doing
  - Check any concerns about family, social, spiritual, financial issues
- Impact on quality of life
  - How does it affect the persons quality of life and do they want to change it?
  - Is the symptom stopping the person enjoying and participating in normal activities or affecting their ability to enjoy and participate in life as they would wish to – how would they want that to change.
  - How acceptable is the burden of treatment for them against the benefits and what ideas do they have about potential treatment?

Holistic Needs Assessment

- Contributes to a better understanding and identification of a person’s concerns
- Involves patients and families in the assessment process so that they can make informed decisions
- Enables early intervention and diagnosis of side effects or consequences of treatment
- Explores individual beliefs, expectations and understanding of the situation
- Helps to agree an individual plan of care

continue

Commons symptoms experienced by patients in the last year of life

vomiting

fatigue

Dyspnoea

Dry mouth

Dysphasia

Pressure sores

LINK to symptom management learning

Pain

Anxiety

Constipation

Faecal Incontinence

confusion

nausea

Anorexia

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Urinary incontinence

How to live and die well Film (4.37)

https://www.youtube.com/watch?v=iXiK9eBPs9Y

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What is ACP

“All people approaching the end of life need to have their needs assessed and their wishes and preferences discussed”.

Department of Health. *End of Life Care Strategy: promoting high quality care for all adults at the end of life*, July 2008)

“Advance Care Planning (ACP) is a voluntary process of discussion between an individual and their care providers. It is to make clear a person's wishes in anticipation of a deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others”.

(National End of Life Care Programme, *Advance Care Planning: a guide for health and social care staff*. February 2007)

“The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants”.

(Leadership Alliance for Care of Dying People: *One Chance to Get it Right: Improving people’s experience of care in the last few days and hours of life*, June 2014)

continue

Advance Care Planning discussions can lead to decisions that are:

- **Legal**
- **Personal**
- **Clinical**

continue

Legal planning may include:

Wills

- Legal documents, dealing with inheritance, may be of primary importance to the patient.
- Usually drawn up by a solicitor. Must be signed and witnessed.

Lasting power of attorney (LPA)

- An LPA is a legally binding document that allows the person to appoint one or more people (known as ‘attorneys’) to help make decisions or fully make decisions on their behalf if they lack mental capacity.
- This gives the person more control over what happens if they become unable to make decisions, as the attorneys are there to speak for them.
- There are two types of LPA
  - LPA – for property and financial affairs decisions

    LPA - for health and welfare decisions – this is the LPA which allows the attorney to be involved in planning with the health care team. There should be evidence such as a copy of the document provided.

  https://www.gov.uk/power-of-attorney

continue

Personal planning may include:

Advance statement/wishes

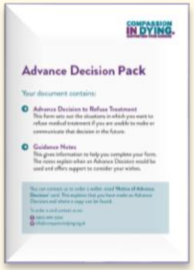

Preferred Priorities for Care

Sets out a patients wishes and preferences for their future care

- May explain feelings, beliefs and values
- Can be medical or non-medical issues
- Not legally binding but used to guide in best interest
- Can be written or spoken – should be recorded in notes

Advance decisions to refuse treatment/living will

An ADRT is a legally binding document that allows someone to refuse a treatment that may be offered in the future. To be valid a person:


COMPASSION IN DYING

Advance Decision Pack

Your document contains:

- Advance Decision to Refuse Treatment
  This form sets out the situations in which you want to refuse medical treatment if you are unable to make or communicate that decision in the future.
- Guidance Notes
  This gives information to help you complete your form. The notes explain when an Advance Decision would be used and offers support to consider your wishes.

- Must be aged 18 or over and have the capacity to make, understand and communicate their decision
- They must specify clearly which treatments they wish to refuse
- Must explain the circumstances in which they wish to refuse
- Not contradict the decision or be harassed into making it
- It's signed and by them and a witness if they want to refuse life-sustaining treatment

continue

Clinical planning may include

DNACPR - do not attempt cardio-pulmonary resuscitation

- If someone's heart stops CPR needs to be started immediately to give the person the best chance of survival. The BMA, RCN and Resuscitation Council state that - where no explicit decision about CPR is recorded there should be an initial presumption in favour of CPR
- But this should not mean that CPR is applied where it will be of no benefit and is not in a persons best interests. E.g. when a natural death has occurred
- DNACPR discussions are a small but important element of end of life care and any clinical decisions are based on individual needs. DNACPR relates to CPR only and all other treatment and care continues.
- DNACPR decisions have been associated with negative patient and public perceptions, negative clinicians' perceptions, complaints, litigation, and negative media reports which have led to legal challenges which have changed the law. The judgement in the Tracey Case, which came to the Court of Appeal in 2014, set out that when decisions about DNACPR are considered, there should be a presumption in favour of involving the patient.
- Compassionated communication is key when discussing DNACPR with patients and families as they need to have relevant information to understand the decision.

Resuscitation Council UK

continue

Clinical planning may include ReSPECT

(Recommended Summary Plan for Emergency Care and Treatment)

The ReSPECT process is being introduced for patients in many areas.

Anyone can make a ReSPECT plan and it is especially useful for people with particular needs, including long term conditions, or who may be approaching end of life and want to record their preferences.

Using the ReSPECT process requires discussion between the person and health care professionals about what should happen to them in a future emergency where the person does not have capacity to make decisions. A recommended personalised plan is then agreed and documented.

Recommendations are focussed towards life-sustaining or towards prioritising comfort care; discussions are not limited to death or cardiac arrest but to any anticipated future healthcare crisis or emergency.

Emergencies may occur in any healthcare setting including at home, in an ambulance, in a care home or acute hospital and each setting agrees to use the ReSPECT process when caring for patients.

The process respects patient preference with clinical judgement to reach a shared decision about whether CPR and other specific treatments are provided and in what circumstances. So that in an emergency clinicians can make rapid decisions about what to do to meet the persons wishes.

continue

A completed **ReSPECT** form can:

- recommend **all life sustaining treatments INCLUDING CPR**

- recommend **life sustaining treatment** (including transfer to hospital) but **not for attempted CPR**

- recommend **comfort care and no attempt at CPR** with guidance on when/if to go to hospital

The form stays with the patient as they move from setting to setting and is updated as changes occur, or if the patient requests it

If you would like to learn more about ReSPECT watch the film below or click **here**

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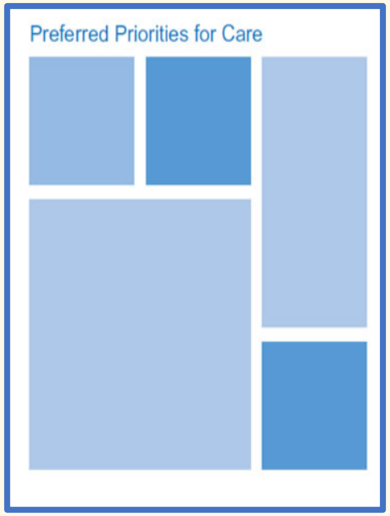
Example: Advance Wishes - Preferred Priorities of Care (PPC)

In relation to your health, what has been happening to you?	I have cancer and it has spread
	I know I am dying, but I feel that things are ok
	I am frightened when I can't breathe
What are your preferences and priorities for your future care?	I am worried that my children may find me if I die
	It is important that I don’t have a post-mortem
	I don't want any more treatment or to go to hospital
What is important to know about where you would like to be cared for or where you would like to die?	I want to stay in my own home
	I would like to be in the hospital where I know the staff
	I'd prefer to die in a hospice
What matters most to you at this time?	I want to make the decisions even if when I am dying
	I don't know but I want you to keep on asking me.
	I want to talk about this with my family and decide together


Preferred Priorities for Care

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One Chance to Get it Right (2014)

ONE
CHANCE
TO GET
IT RIGHT

Improving people's experience of care
in the last few days and hours of life.

Published June 2014 by the
Leadership Alliance for the Care of Dying People

Publications Gateway Reference 01509

- Produced in response to public concern about end of life care
- By the Leadership Alliance for the Care of Dying People
- Reviewed practice and established Five Priorities of Care for dying

continue

Priorities of care for the dying person

- **Active dying is recognised and communicated clearly**. All decisions take the person’s needs and wishes into account and are reviewed regularly.

- **Sensitive communication takes place** between staff and the dying person, and those identified as important to them.

- The dying person and those identified as important to them, are **involved in decisions** about treatment and care to the exten that the dying person wants.

- **The needs of families** and others identified as important to the dying person are **actively explored, respected and met** as far as possible.

- **An individualised plan of care**, which includes food and drink, symptom control and psychological, social and spiritual support **, is agreed, co-ordinated and delivered with compassion**

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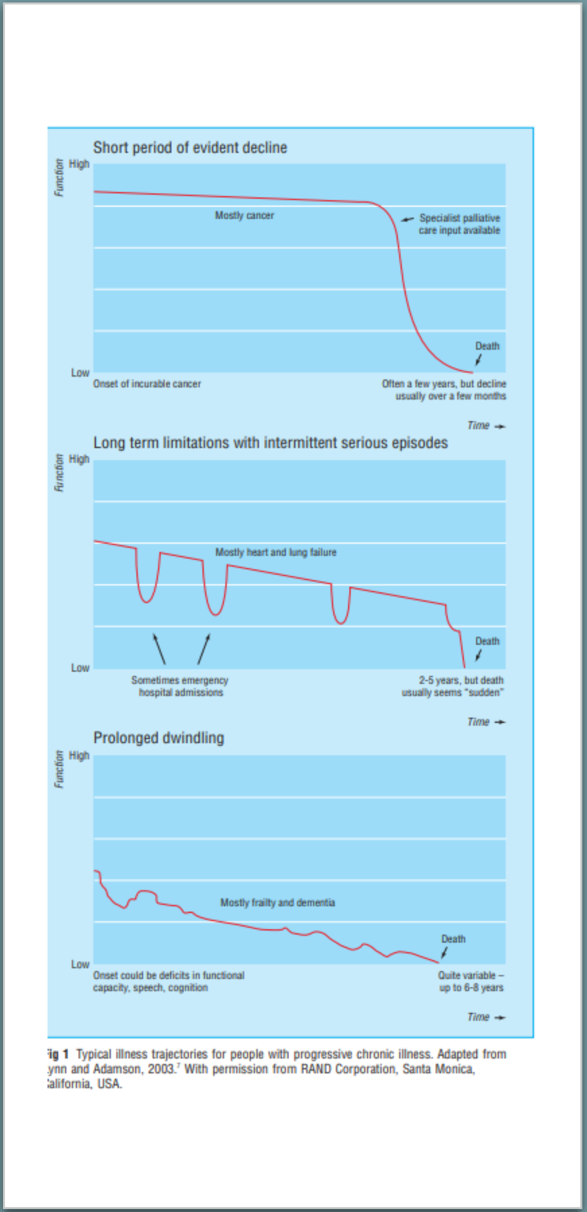

ig 1 Typical illness trajectories for people with progressive chronic illness. Adapted from ynn and Adamson, 2003.[7] With permission from RAND Corporation, Santa Monica, alifornia, USA.

Recognising dying

- As you saw in the film, three typical illness trajectories have been described for patients with progressive chronic illness: cancer, organ failure, and the frail elderly or dementia trajectory
- The physical, social, psychological, and spiritual needs of patients and their carers are likely to vary according to the trajectory they are following
- Being aware of these trajectories helps us to recognise when someone is dying
- Recognising when someone is dying enables us to make plans with them, and provide care to meet their needs
- Illness trajectories and palliative care Scott A Murray, Marilyn Kendall, Kirsty Boyd, Aziz Sheikh. BMJ 2005

continue

Recognising dying

General indicators that someone is in the last weeks of life	General indicators that someone is in the last few days of life
Decreased activity, greater need for help, increasing periods asleep	Likely to be bedbound
Less alert, vague, becoming detached/disinterested, may become listless/confused	Diminishing consciousness; sleeping most of time, progressing to semi-conscious, then comatose
Decreased oral intake +/- dysphagia	Unable to swallow oral medication/fluids
May express weariness or “have had enough”	Speech may be limited to short phrases, single words; may be incomprehensible
Voice becoming weaker, drifts off mid- sentence	Circulatory changes: tachycardia, high/low temperature, peripheral shutdown, pale, cold, mottled extremities
May have heightened anxiety or become peaceful	Changes in breathing: shallow, fast, slow, irregular, Cheyne-Stokes, noisy
Dreaming, hallucinating	“Pinched nose”, dull eyes, altered facial expression
May/may not have increased symptoms	Decreased urine output

Although it can be difficult to recognise when someone will die, we can recognise some common signs that death is near that help us to support patient and families.

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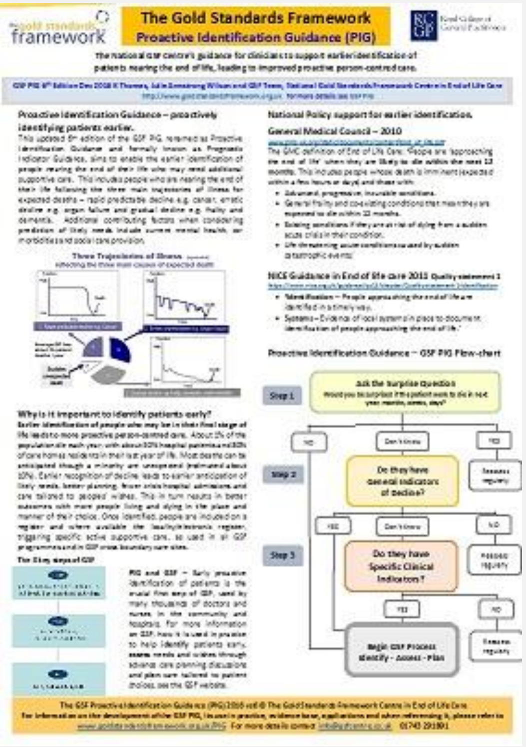
Tools that help with prognosis

- **Gold Standards Framework** uses the surprise question and disease related indicators – click image for link



The Gold Standards Framework
Proactive Identification Guidance (PIG)

The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life, leading to improved proactive person-centred care.

SPICT has a tool for health care professionals and one for public - click images for links

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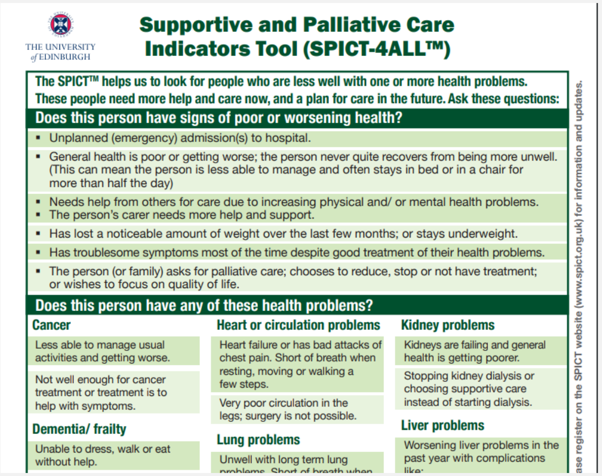
Supportive and Palliative Care Indicators Tool (SPICT™)

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).



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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.

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

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

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

continue

Promoting comfort and wellbeing

When dying approaches - the goals of care and treatment focus on ensuring the person's comfort and wellbeing and supporting them and their family and carers.

Regular mouthcare can prevent a dry and painful mouth if the patient is no longer eating and drinking

Eye care, personal care and other hygiene care is important for dignity and comfort

Pressure area care will help to prevent skin breaking down causing pain and distress

Supporting the family can help them to remain present and may help them in bereavement.

Treatment should start or continue if it is providing comfort and/or reducing distressing symptoms:

- treating infected ulcers may help to reduce pain and odour
- treating pneumonia may help to reduce sputum
- treating UTIs may reduce pain and agitation

But if no benefit is seen after 24-48 hours of treatment, it may be advisable to stop for the patients comfort

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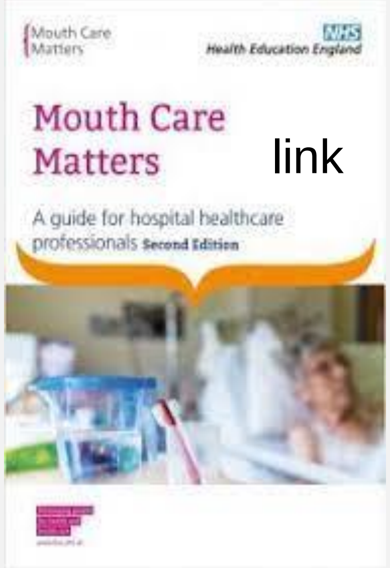
Mouth care at end of life

https://www.youtube.com/watch?v=6KB4UkZ-YVM&t=6s


Mouth Care Matters

NHS Health Education England

Mouth Care Matters

A guide for hospital healthcare professionals **Second Edition**

link

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Kathryn Mannix, (2019) ‘Dying is not as bad as you think’ film.

https://www.youtube.com/watch?v=CruBRZh8quc

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Care for yourself and check in with colleagues

- It is ok, **and necessary**, to care for yourself when you are caring for others
- Ask for support – talk things through
- Spend time with people who make you feel good
- Identify your stress triggers – is there anything you can do to lessen or remove them
- Use reflective practice
- Make use of support services – counselling, phone lines, self-help groups

The expectation that we can be immersed in suffering and loss daily, and not be touched by it, is as unrealistic as expecting to be able to walk through water without getting wet
(Remen, 2002).

continue

1. Talk to your colleagues before leaving work.
2. Try to switch off and divert your mind to other things. Take breaks.
3. Do the ordinary things you enjoy at home.
4. Eat well, try to sleep, exercise and get fresh air when you can.
5. Be kind to yourself. You deserve it.

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Summary

- Palliative care and end-of-life care are approaches to caring for patients with a range of advanced progressive incurable illnesses and aim to improve the patient’s quality of life or to help them to live as well as possible until death
- As well as focusing on the management of physical symptoms, palliative care and end of life care address psychological, social and spiritual care of the patient and includes care of the family
- A holistic assessment is used to identify reversible causes of symptoms, identify the impact of symptoms on the patient and treat them in a way that is acceptable to the patient
- Open and honest communication is needed to allow the patient and family to be involved in decision making and to make informed advance care plans
- It is important to recognise deterioration and the dying process so that patients and families can be supported through the dying process
- Most health care professionals will meet people with palliative disease during their work and it may require us to think differently about some treatment choices. We need to reflect on how this may impact us, carers and colleagues

continue

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- What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death Anna E Bone,[1] Barbara Gomes,[1,2] Simon N Etkind,[1] Julia Verne,[3] Fliss EM Murtagh,[1,4] Catherine J Evans,[1,5] and Irene J Higginson[1]

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