Personalised care approach to cardiovascular medicines in palliative and end of life care

Helena Gregory, NENC ICB – Personalised Care and Palliative Care MO lead

NICE medicines and prescribing associate

June 2024

Join at

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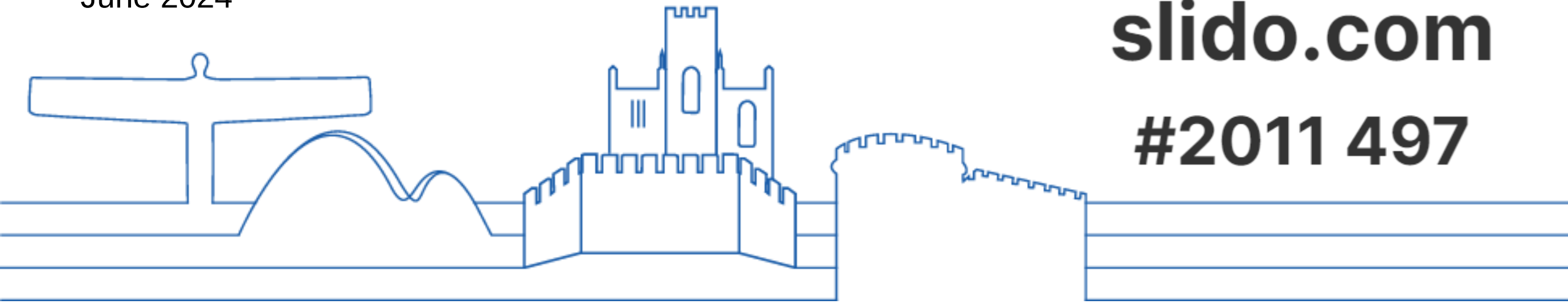

Welfare information

Royal College of Psychiatrists – Bereavement

https://www.rcpsych.ac.uk/mental-health/mental-illnesses-and-mental-health-problems/bereavement

Bereavement Advice Centre

Helpline: 0800 634 9494

Supports bereaved people on a range of practical issues via a single freephone number. It offers advice on all aspects of bereavement from registering the death and finding a funeral director through to probate, tax and benefit queries.

Breathing Space Scotland

Helpline: 0800 83 85 87

Experienced advisors are available to listen and give advice and information to those who are depressed and need to talk.

Child Bereavement UK

Support and information line: 0800 02 888 40

A national charity that helps grieving families and the professionals who care for them.

Cruse Bereavement Care and Cruse Bereavement Care Scotland

Helpline: 0808 808 1677

Helpline (Scotland): 0845 600 2227

Supports people after the death of someone close. Face-to-face and group support delivered by trained bereavement support volunteers across the UK.

Dying Matters

A coalition of 32000 members across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

"You matter because you are you, and you matter to the end of your life.

"We will do all we can not only to help you die peacefully, but also to live until you die."

Dame Cicely Saunders
Founder of the modern hospice movement

#Cicely100

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CVD management journey

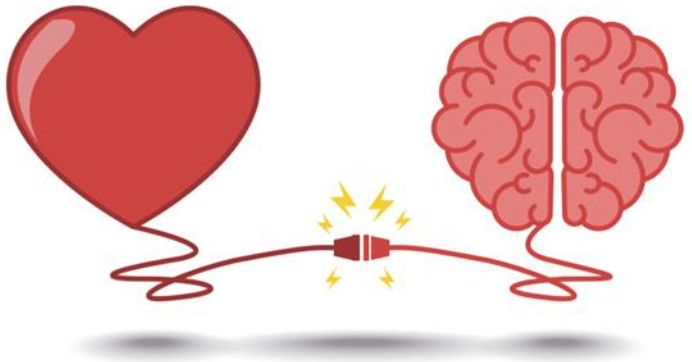
Initial chat after a healthcheck

Health declining

Low risk and active

Following cardiovascular event

Last time



AEC	Dizziness	Drowsiness	Drug
			LISINOPRIL
			LANSOPRAZOLE
			ASPIRIN
			CLOPIDOGREL
			ATORVASTATIN
			FUROSEMIDE
			BISOPROLOL

Practicalities of managing medication at home

- Daily routine
- Ordering and collection
- Reasonab adjustme
- Appointments
- Carers and partners
- Are your medicines working for you?

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What proportion of people die in the place they choose?

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How many crisis admissions does that average person have in their last year of life?

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What proportion of deaths in hospital could have occurred elsewhere?

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Death and dying in the UK

- About 1% of the population die each year, with an estimated 17% increase from 2012.
- About 35% are home deaths (18% home, 17% care home) and 54% die in hospital.
- 40% of deaths in hospital could have occurred elsewhere (National Audit Office 2008).
- 60–70% of people do not die where they choose.
- 75% of deaths are from non-cancer conditions.
- 85% of deaths occur in people over 65.
- On average each patient will have three crisis admissions in the final year of life.

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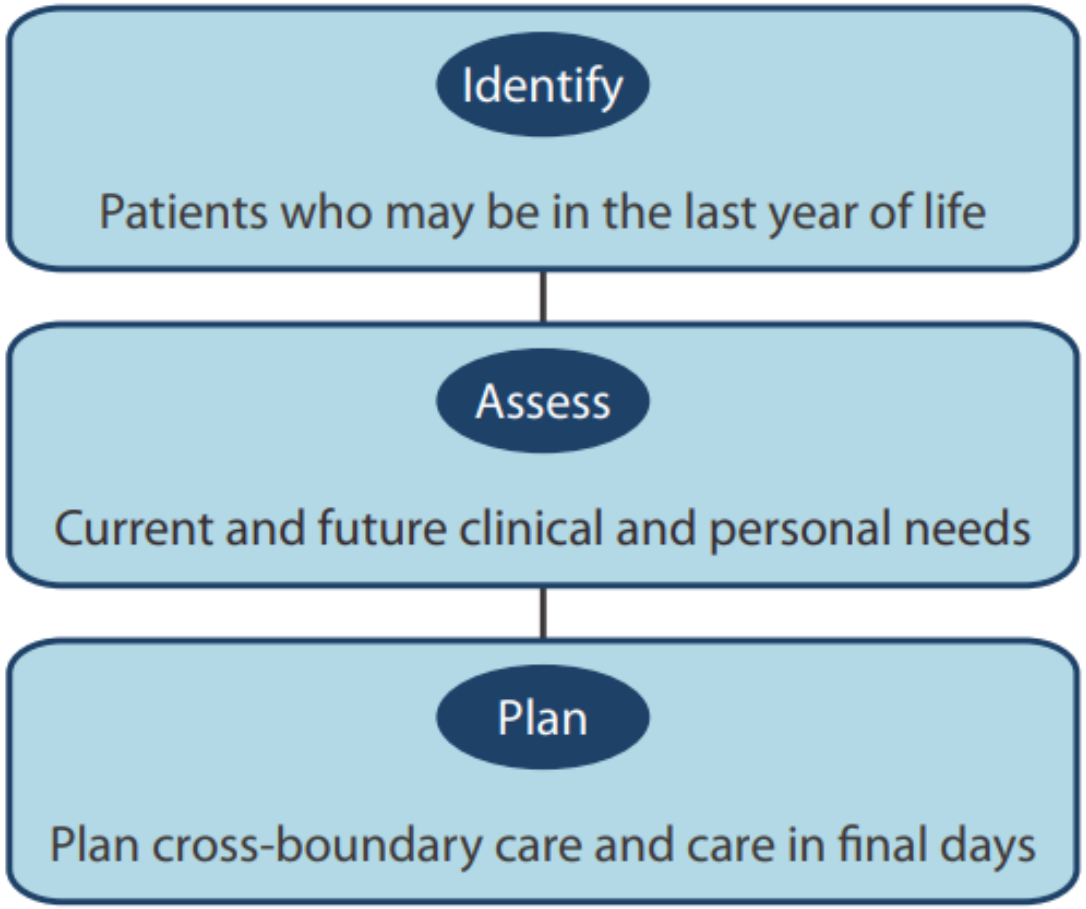
Ambitions of PEoLC



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Reconnect with Jamal

- You’re going to visit Jamal today to talk about his being puffy - breathless.
- Jamal is now in his mid 70s.
- His heart failure has progressed, he appears to have some cognitive decline (no formal diagnosis), hasn’t been participating in his usual activities and has been losing weight recently.

Identifying people to talk to

- General indicators
- Clinical indicators

THE UNIVERSITY of EDINBURGH

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 with other conditions, multiple conditions and/or complications that are not reversible; best available treatment has a poor outcome.

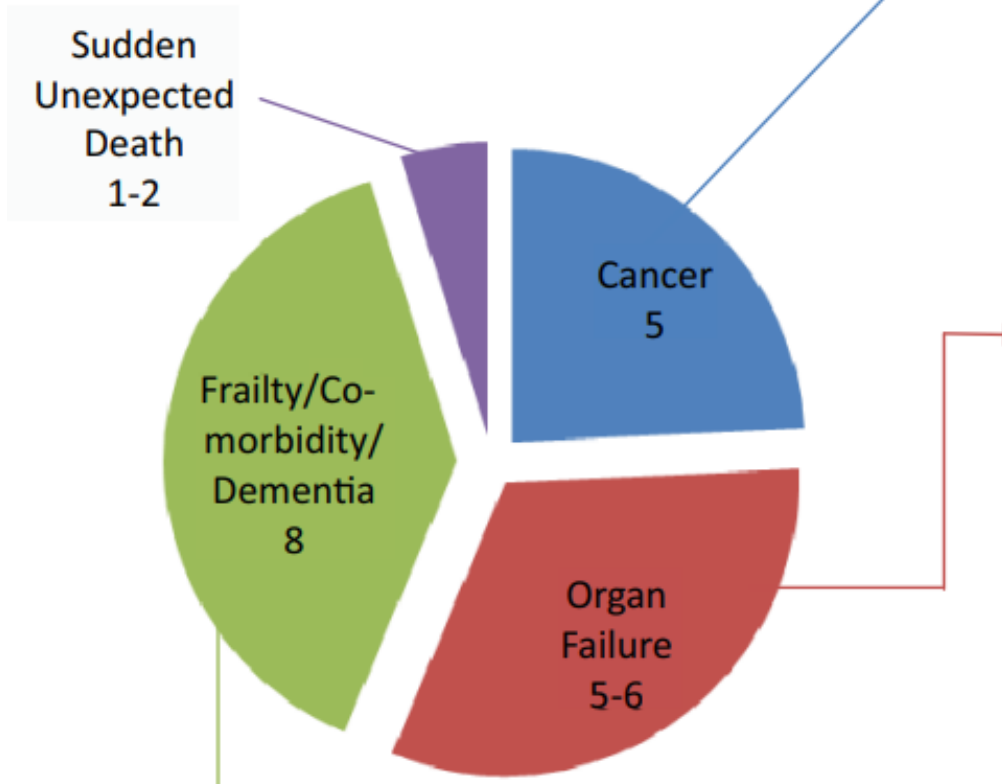
Kidney disease
- Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
- Kidney failure complicating other life limiting conditions or treatments.
- Stopping or not starting dialysis.

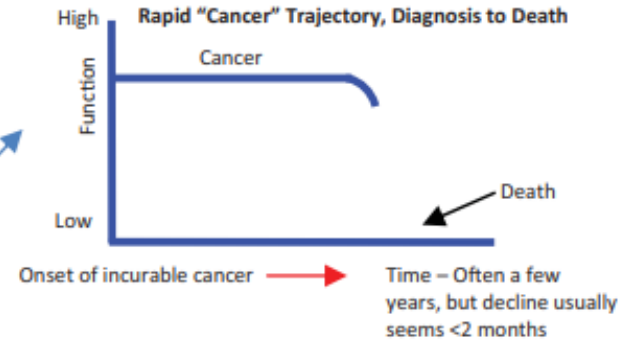
Liver disease
- Cirrhosis with one or more complications in the past year:
  - diuretic resistant ascites
  - hepatic encephalopathy
  - hepatorenal syndrome
  - bacterial peritonitis
  - recurrent variceal bleeds
- Liver transplant is not possible.

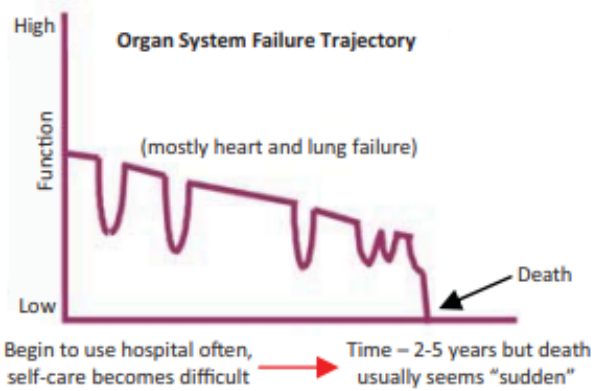
Review current care and care planning.
- Review current treatment and medication to make sure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family/people close to them. Support carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, share, and review care plans.

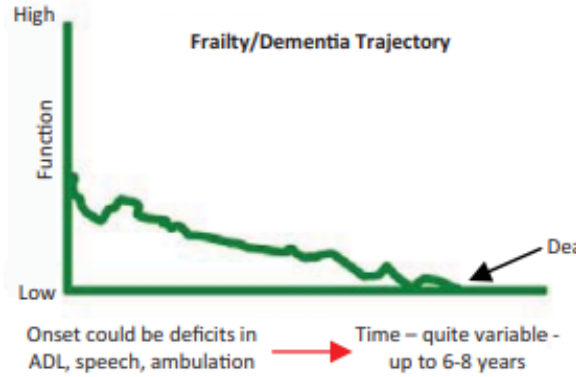
Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™ 2022









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Conversations around death and dying

- Ascertain a patient or family member's perspective before offering your own
- Where possible, mirror the language of the patient or family
- Create opportunities to discuss the future
- Be clear about uncertainty
- Display sensitivity

Talking about Care Planning with REDMAP

Ready	Can we talk about your health and care? Who should be involved?
Expect	What do you **know**? Do you want to tell/ask me about anything? What has changed? Some people think about what might happen if…
Diagnosis	What we **know** is… We **don't know**… We are **not sure** … I **hope** that, but I **am worried** about… It **is possible** that you might…. Do you have questions or worries we can talk about?
Matters	What is **important** to you and your family? What would you like to **be able to do**? How **would you like** to be cared for? Is there anything you **don't want**? What would (*name*) **say** about this situation, if we could ask them? **Why?**
Actions	What we **can do** is… Options that **can help** are…. This **will not help** because…. That **does not work** when…
Plan	Let's **plan ahead** for when/if…. Making some plans in advance helps people get better care.

September 2023

In Practice – Questions and Information

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Can you tell me about your current illness and how you are feeling?

Could you tell me what the most important things are to you at the moment?

Who is the most significant person/ people in your life?

What fears or worries, if any, do you have about the future?

In thinking about the future, have you thought about where you would prefer to be cared for as your illness gets worse?

What would give you the most comfort when your life draws to a close?

'Palliative care means that time is up'

Palliative care is about maximising quality of life when time is limited. It's not just for when a person is close to death; it can be given earlier, even from diagnosis. It can be a change in focus, or exist in parallel with disease-targeted treatments. It can help with symptom control, psychological support and practical issues, and help patients to understand their illness better.

'A ceiling of treatment has an implication on a patient's individual worth'

Setting a ceiling of treatment is not a value judgement on a patient's worth as a person. It is based on the likelihood that the intervention will achieve the intended outcome, that that outcome is acceptable to the patient and the patient feels the burden of treatment is worthwhile. This needs to be discussed sensitively with the patient and their loved ones to avoid misunderstandings. Less treatment at this point should go hand in hand with more care.

'We should avoid mentioning death to acutely unwell patients'

Explaining to a patient and family that the patient is 'sick enough to die' won't make them sicker, but it will enable everyone to understand the gravity of the situation and to respond appropriately.

'People, patients and healthcare professionals do not want to talk about death'

Confronting one's own mortality can be difficult. However, when supported, many people do want to talk about death. Disclosing a diagnosis of a terminal illness could help patients to feel more empowered about care and decision making, rather than diminish their hope.

'Doctors can give precise prognoses when pushed'

If a patient is sick enough to die, you do not have to be sure of a timeframe to initiate the conversation.

Healthcare professionals can only give an indicative range of life expectancies. It is more helpful to give a timeframe of 'many months', 'weeks to months', 'only a few weeks', 'could be as short as days or as long as a couple of weeks', and to avoid numerical answers. A more precise prognosis is almost always wrong, and mistakes can be harmful.

'Every patient who is dying should be made aware'

Everyone will have their own individual preferences. For many people, talking about death remains taboo. Healthcare professionals need to respect this while offering patients the opportunity to discuss their future.

'Clinicians know what patients want without asking them'

Healthcare professionals sometimes assume that a patient will not want further aggressive intervention. However, while clinicians may be better placed than others to judge prognosis, illness trajectory or success rates of possible treatments, they cannot possibly know a patient's individual priorities without asking.

'Plans made in advance are binding'

People can and do change their minds about their priorities, including preferred place of death. Equally, a small but significant proportion of patients who are thought to be dying do improve.

Advance care planning is a process by which future care is negotiated and recorded in anticipation of future loss of mental capacity. As long as the patient has mental capacity, their contemporaneous wishes override any prior wishes they may have stated.

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What have we ascertained for Jamal?

- He knows his heart failure is getting worse.
- He's a bit forgetful sometimes.
- He's 'puffy' whenever he moves.
- He's struggling with daily tasks, including making meals and taking his tablets.
- He's scared he'll die choking on phlegm, unable to catch his breath.
- He'd love to have a shower, visit the mosque and get some fresh air in the park – he hopes these will make him feel better.
- His daughter is often around to help him but he doesn't want to scare her by letting her know how bad he is.

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Breathlessness and Phlegm

- Lifestyle medicine
- Treating causes
- Additional symptom control

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What are some of the options you would suggest for Jamal to consider as part of the Action step?

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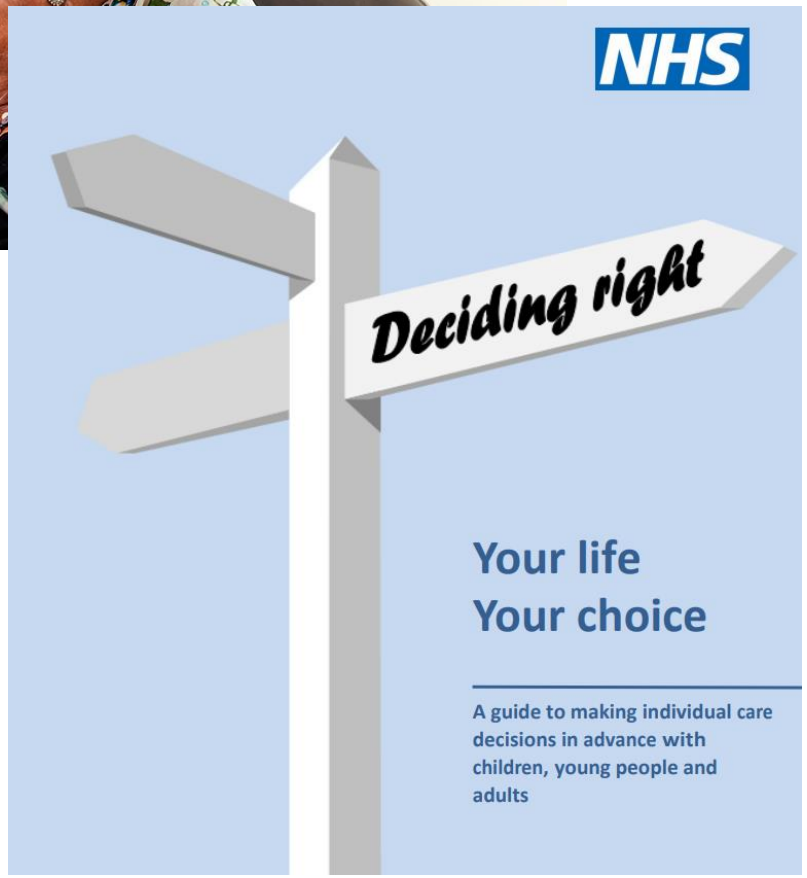
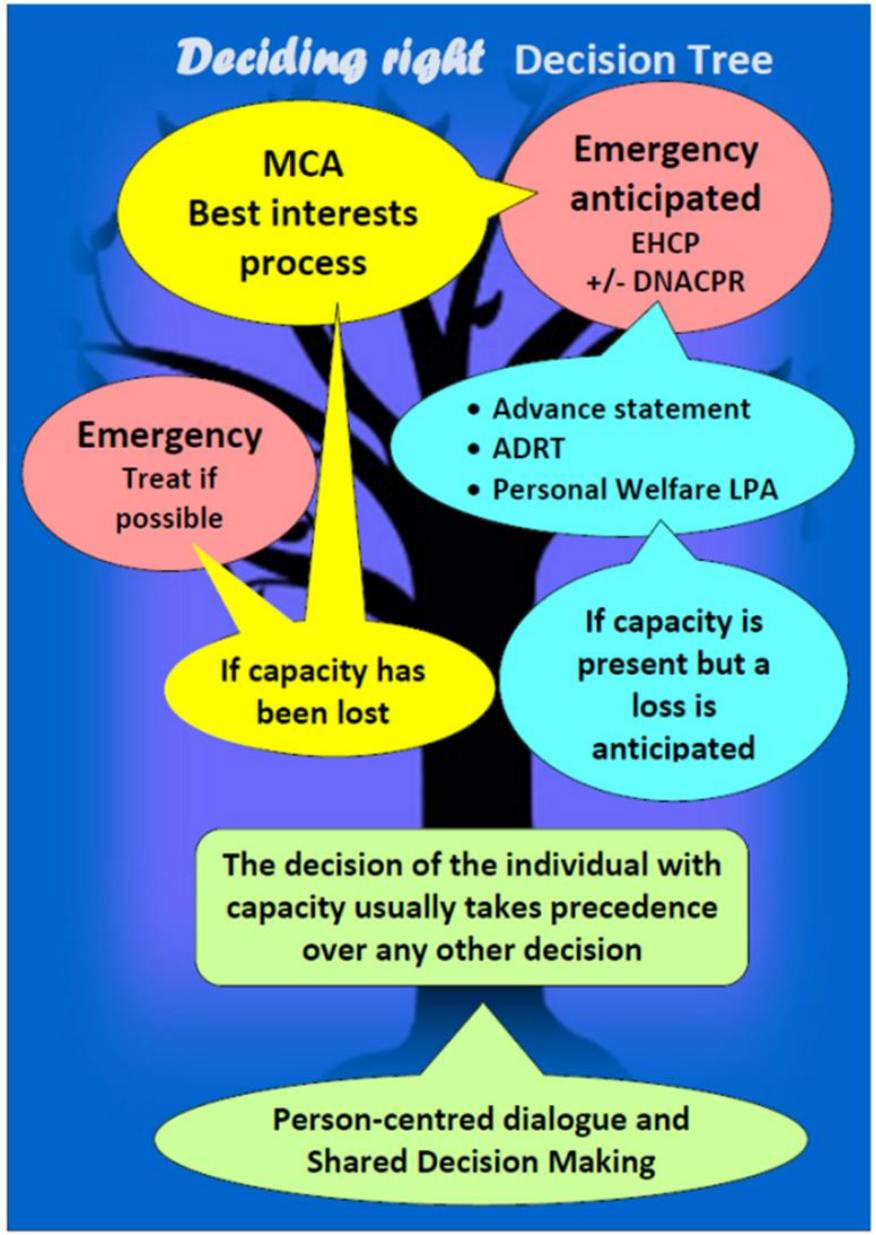
Making Decisions





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Advance care planning and medication

- Medicines can bring real comfort to people to treat symptoms of life limiting conditions e.g. secondary pain from cancer.
- Equally must consider any harm and distress e.g. excessive tablet burden or adverse effects.
- Consider symptom control vs. disease prevention or length vs. quality of life. At what point would preventative medicines e.g. for hypertension or lipids, be stopped?
- What are the consequences of choosing to do nothing?
- Same rules and processes apply for starting, stopping and administering medicines as for other choices e.g. Health and Welfare Power of Attorney, Mental Capacity Act, Best Interests, Refusal of Medical Treatments.

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Comfort and Wellbeing

Recognising distress whatever the cause

It is important to recognise all sources of distress quickly, to acknowledge distress and to work with people to assess its extent, its cause and what might be done.

Addressing all forms of distress

The experience of suffering associated with physical symptoms may be exacerbated, or sometimes caused, by emotional, or psychological anguish, or social or spiritual distress. Addressing this requires professionals to recognise, understand and work to alleviate the causes.

Skilled assessment & symptom management

Attending to physical comfort, pain and symptom management is the primary obligation of clinicians at this time of a person's life and their skills and competence to do so must be assured and kept up to date.

Specialist palliative care

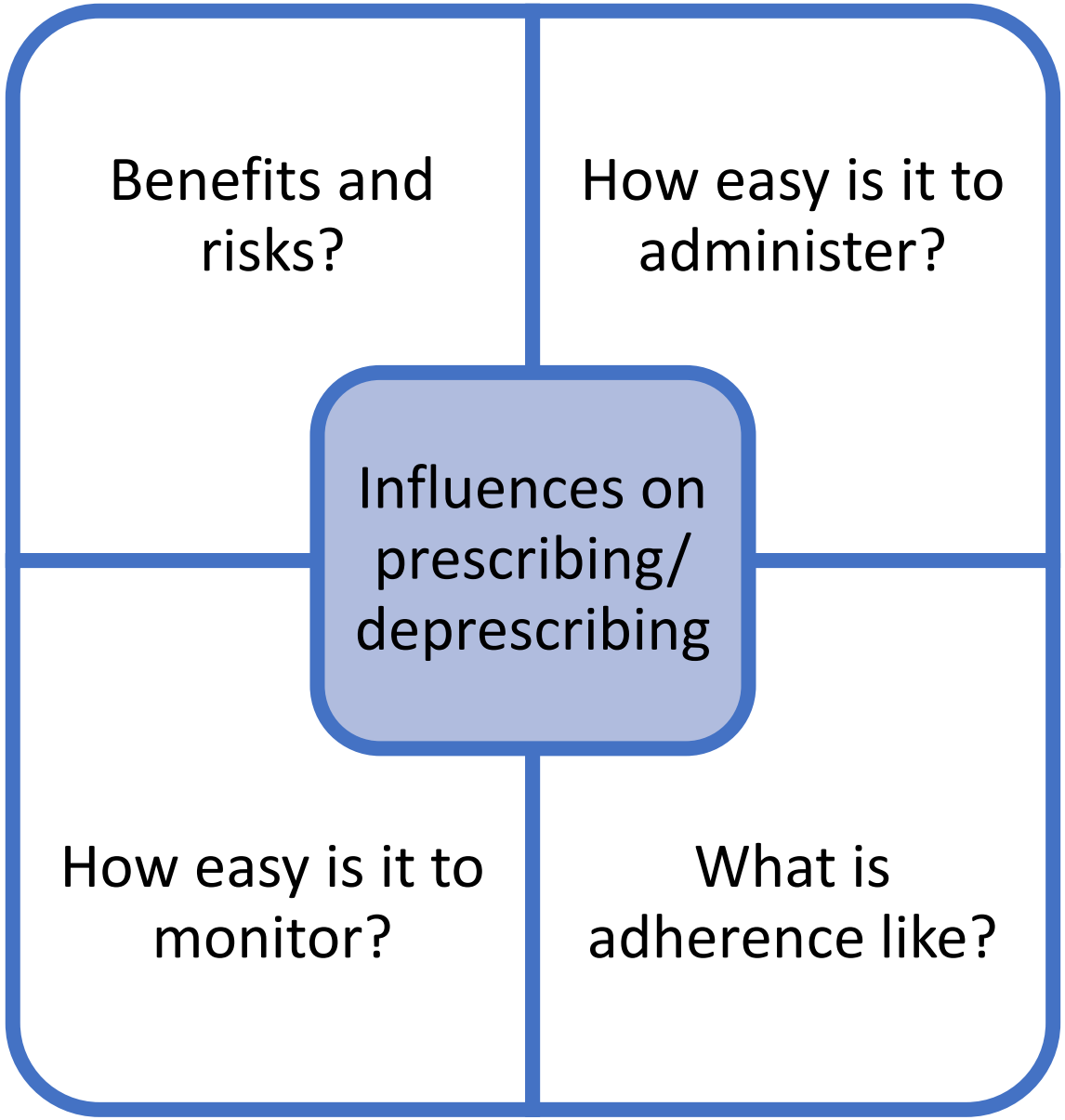
People approaching the end of life should have access to Specialist Palliative Care when this is needed. This should include a clear understanding of how to access medicines and equipment as part of the rapid response to changing needs.

Priorities for care of the dying person

People approaching death should expect local systems to accord with the priorities identified by the Leadership Alliance for the Care of Dying People.

Rehabilitative palliative care

Maximising the person's independence and social participation to the extent that they wish requires professionals to work with, and support, the person in helping them to achieve their personal goals.



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Examples covered in STOPPFrail and OncPal:

- Lipid lowering
- Anti-platelets for primary prevention
- Diabetic oral agents and strict glycaemic control
- Treatment dose PPIs unless recent history
- Osteoporosis medications
- ACE/ARB inhibitors for diabetic nephropathy

Deprescribing statins

For a patient taking a statin, do any of the following apply?

- There is no documented indication or prescribing is not in line with national guidelines.[1]
- Patient is palliative/end of life.[2]
- Statin now contraindicated (see overleaf).
- Patient is non-adherent with statin and does not wish to take a statin after shared decision-making discussion.
- For primary prevention, patients cardiovascular risk is less than 10% over 10 years.[1]

No

Does harm outweigh the benefits?

- Secondary prevention and unable to tolerate statin?
- Adverse drug reaction (ADR) experienced (see ADR list overleaf)?[3-6]
- Patient has general frailty and/or multimorbidity.[7-9]
- Consider the length of time required for benefit and the life expectancy of the patient.[10,11]

Yes

- Consider reducing dose or switching to a lower-intensity statin.[1]
- Does harm still outweigh benefits?

Yes

No

No

Yes

Yes

- Continue prescribing the statin with regular review, to ensure that expected outcome is achieved as per NICE CG181 and no new ADR develops.
- Optimise diet and lifestyle measures. Give patient information leaflet.[12]

- **Consider deprescribing statin.[13]**
- **Document reason for deprescribing.**
- **Re-evaluate risk profile annually if appropriate.**
- **Optimise diet and lifestyle measures. Give patient information leaflet.[12]**

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- Trials show that stopping statin therapy in life limiting illness is safe and may be associated with benefits including improved quality of life.
- No specific studies exist for patients over the age of 80 years for secondary prevention.
- In secondary prevention of cardiovascular disease, NNT = 255 people for one year to prevent one death from all-cause mortality.
- In primary prevention of cardiovascular disease NNT = 595 people for one year to prevent one death from all-cause mortality.
- Statins can usually be stopped without the need for dose-tapering.

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Polypharmacy

- Lisinopril 20mg – one once daily
- Spironolactone 50mg – one once daily
- Aspirin 75mg – one once daily
- Bisoprolol 10mg – one once daily
- Atorvastatin 80mg – one once daily
- Lansoprazole 30mg – one once daily
- Furosemide 40mg – two in the morning and two at lunch

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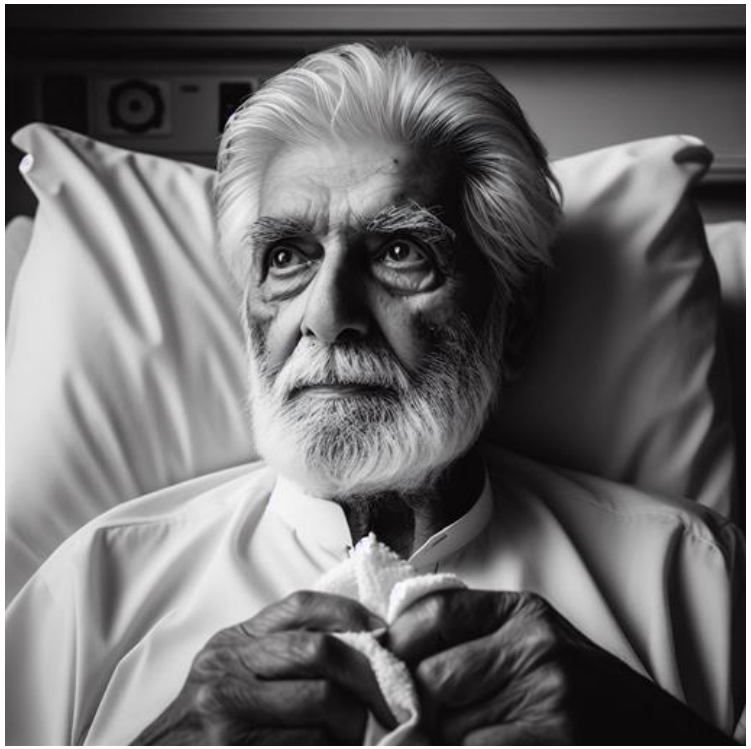
Jamal's daughter

- POA health and welfare – including wishes on preferred place of care, quality vs. length of life.
- Advance care plan available:
  - Care at home
  - Community team support
  - Deprescribing/prescribing
- Is she providing care for her Papa? What support does she need?



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Anticipatory Prescribing

BREATHLESSNESS PRESENT

General measures:
- **Calm environment**
- Reassurance and support.
- Cool room.
- Gentle air flow with fan.
- Give hourly mouth care.
- Oxygen if helpful (only if low saturations).

Patient not already on opioid for pain (for patients with renal impairment, see advice on right and on page 8)
- Give morphine 2.5mg SC stat.
- Also prescribe morphine 2.5mg SC 1-hrly as required.
- Start morphine 10mg SC/24hours by syringe driver.

Patient already on opioid
- Give midazolam 2.5mg SC stat.
- Also prescribe midazolam 2.5mg SC 1-hrly as required.
- Start midazolam 10mg SC/24hrs by syringe driver.

(Midazolam is a useful option in patients with renal impairment if there is doubt about opioid choice).

RISK OF BREATHLESSNESS

Planning ahead

Patient not on opioid: Prescribe morphine 2.5mg SC 1-hrly as required.

Patient on opioid analgesics: Prescribe midazolam 2.5mg SC 1-hrly as required.

Review within 24hours

If 2 or more doses needed, manage as for breathless patient.

Specific situations
Heart failure: consider furosemide by continuous subcutaneous infusion.

Renal impairment: consider replacing morphine with alternative opioid if renal impairment severe e.g. alfentanil 100micrograms SC 1-hrly as required, 1mg SC/24hrs by syringe driver.

NB Diuretics will not help if patient anuric.

SECRETIONS PRESENT

General measures
- Assess if causing distress to patient, and balance with potential side effects of drugs (eg dry mouth, urinary retention).
- Alter position to shift secretions.
- **Give explanation and reassurance to relatives.**
- Give hourly mouth care.

Any potentially reversible causes?

Pulmonary oedema – consider furosemide by SC infusion (seek specialist advice).

Chest infection – consider antibiotics for palliation of symptoms.

Anti-secretory prescribing

Starting dose:
Hyoscine butylbromide 20mg SC **or**
Glycopyrronium 200 micrograms SC **or**
*Hyoscine hydrobromide 400 micrograms SC.

Regular treatment via syringe driver:
Hyoscine butylbromide 60mg/24hrs **or**
Glycopyrronium 600micrograms/24hrs **or**
*Hyoscine hydrobromide 1.2mg/24hrs.

Extra doses: (SC up to 1-hrly as required, maximum 6 doses in 24hrs)
Hyoscine butylbromide 20mg SC **or**
Glycopyrronium 200 micrograms SC **or**
*Hyoscine hydrobromide 400 micrograms SC.

SECRETIONS ABSENT

Pre-emptive discussion with relatives that noisy secretions may occur, but may not distress patient.
Anticipatory prescribing is crucial to allow early and better control of this symptom.

Options:
Hyoscine butylbromide 20mg SC 1-hrly as required **or**
Glycopyrronium 200micrograms SC 1-hrly as required **or**
*Hyoscine hydrobromide 400micrograms SC 1-hrly as required.

Specify maximum 6 doses/24hrs – frequent need should prompt review.

Review within 24hrs
If 2 or more doses required, manage as for 'secretions present'.

Review after 24hours, or sooner if indicated

If extra doses needed, increase 24hr dose:
Hyoscine butylbromide 120mg/24hrs or
Glycopyrronium 1200micrograms/24hrs or
*Hyoscine hydrobromide 2.4mg/24hrs

Consider additional / alternative antisecretory medication SC up to 1-hrly as required, with a maximum daily dose to prompt review.

If symptoms not controlled, seek specialist advice.

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Making a Plan

Do you know who's on your team?

How do you narrow it down to manageable actions?

How would you communicate Jamal's care plan to his family and healthcare teams?

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"We will do all we can not only to help you die peacefully, but also to live until you die."

Dame Cicely Saunders
Founder of the modern hospice movement

#Cicely100

hospice UK

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What are your actions to take away after today's session?

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Thank you

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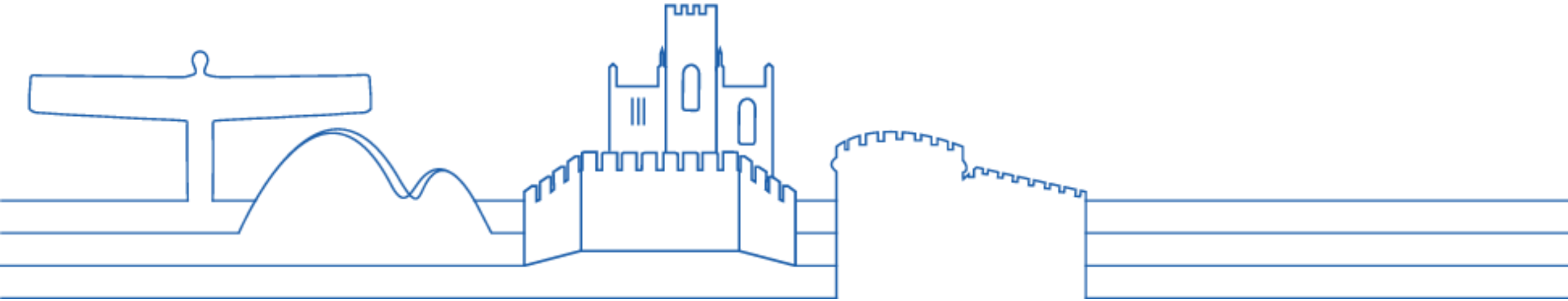
Special thanks to colleagues for their contributions:

Jenny Wilson, Eden Valley Hospice
Dr Kathryn Mannix
Laura Heaton-Sutton, NENC ICB



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References and resources

- Age and Ageing - STOPPFrail
- BHF publications
- BMC Palliative Care - Communicating with patients and families about illness progression and end of life: a review of studies using direct observation of clinical practice
- BMJ Best Practice – Shared Decision Making
- Clinical Medicine – Deprescribing in palliative care
- Cochrane Review - Interventions for interpersonal communication about end of life care between health practitioners and affected people
- CQC Better care in my hands
- Deciding Right
- E-learning for Health – Complex Clinical Reasoning
- E-learning for Health – SDM Hub
- Gold Standards Framework
- GP Evidence
- Heart UK
- Implementing shared decision making in the NHS: lessons from the MAGIC programme | The BMJ
- Life – Deprescribing in palliative cancer care
- NENC Are your medicines working for you?
- NENC PEOLC symptom control guidelines
- NHS Advance decision to refuse treatment
- NHS Power of Attorney
- NHSE Ambitions for Palliative and End of Life Care
- NHSE Personalised Care
- NHSE Service finder
- NHSE Shared Decision Making summary guide
- NHSE Supported Self Management summary guide
- NICE Heart Failure clinical knowledge summary
- Personalised Care Institute e-learning
- Personalised care roles
- RCGP – End of life and palliative care toolkit
- RCGP/RCN – Matters of Life and Death
- ReSPECT
- Royal College of Physicians – Talking about dying
- Sarah Chapman – Talking about dying – Better conversations at end of life
- Validating a self-medication risk assessment instrument | Clinical Effectiveness in Nursing
- What goes wrong with shared decision making