KEYNOTE PRESENTATION:

NAVIGATING THE UNKNOWN: IDENTIFICATION, COMMUNICATION AND MANAGEMENT OF UNCERTAINTY.

Clare Fuller

Navigating the unknown:

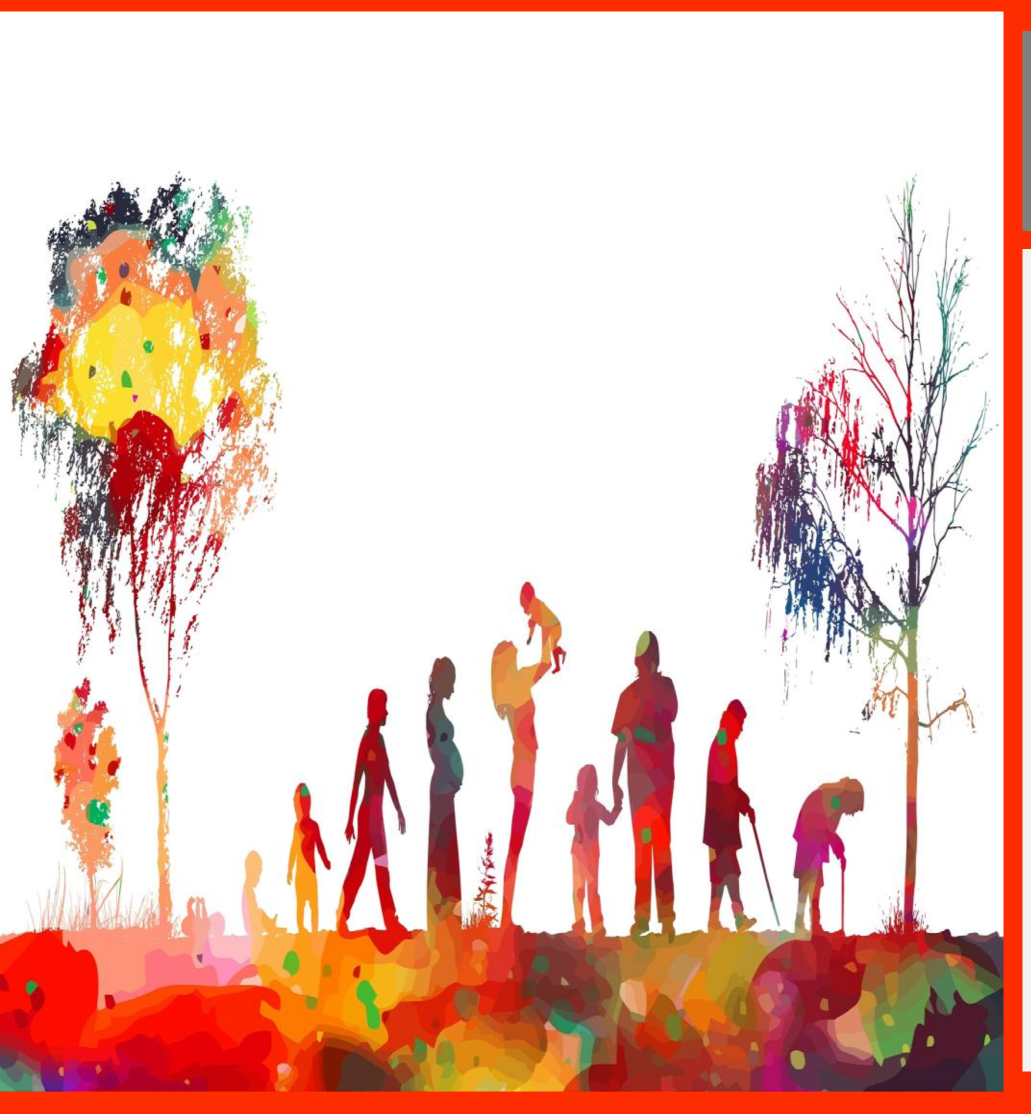
Identification, communication & management of uncertainty

What we will cover

1. Reality of uncertainty
2. Illness trajectories
3. Identification
4. Communication
5. Advance Care Planning

Speak
For
Me

Speak
For
Me



1

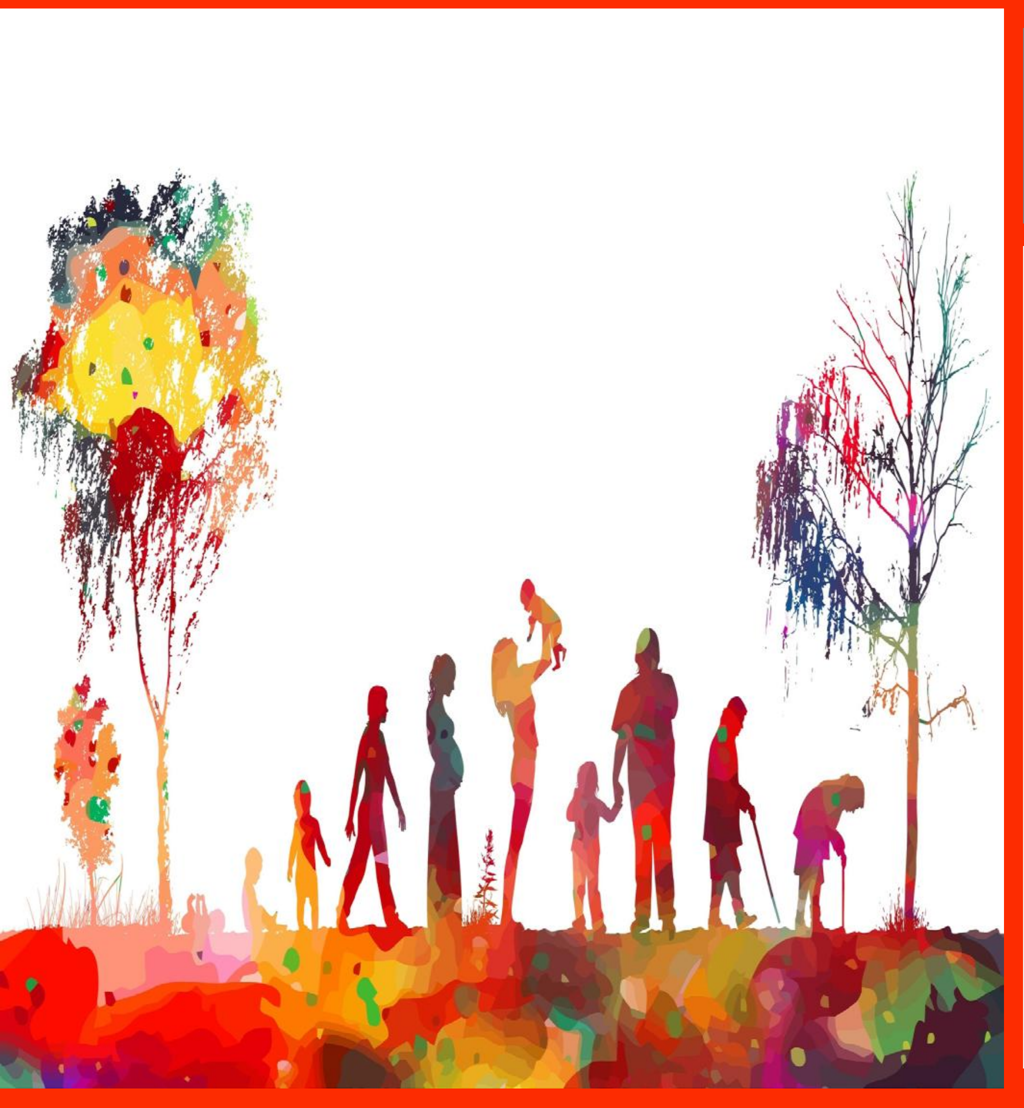
PALLIATIVE CARE IS NOT JUST ABOUT END OF LIFE CARE

Not enough patients had access to early palliative care alongside existing treatments to improve symptoms and quality of life

135/439 (30.8%) patients had parallel planning.

During the final admission, the specialist palliative care team were involved in the care of 230/446 (51.6%) patients.

Where a parallel planning approach was not taken, this linked to room for improved clinical care for 58/140 (41.4%) patients.



2

NORMALISE CONVERSATIONS ABOUT DEATH AND DYING

Death and dying was not discussed as often as it could have been. More people need to have their end of life care wishes recorded.

169/233 (72.5%) patients did not have their preferences for care at the end of their life recorded.

Communication was an area for improvement and of good practice. This included how patients and their families were included in decisions about care being provided, and advance care plans.

Almost a third of respondents reported that health and care professionals had not discussed with them the fact that their relative might die.

Recognition of palliative care needs was often considered too late

One in eight people who died spent more than 30 days in hospital in their last three months of life

https://www.mariecurie.org.uk/document/experiences-at-the-end-of-life-in-england-and-wales

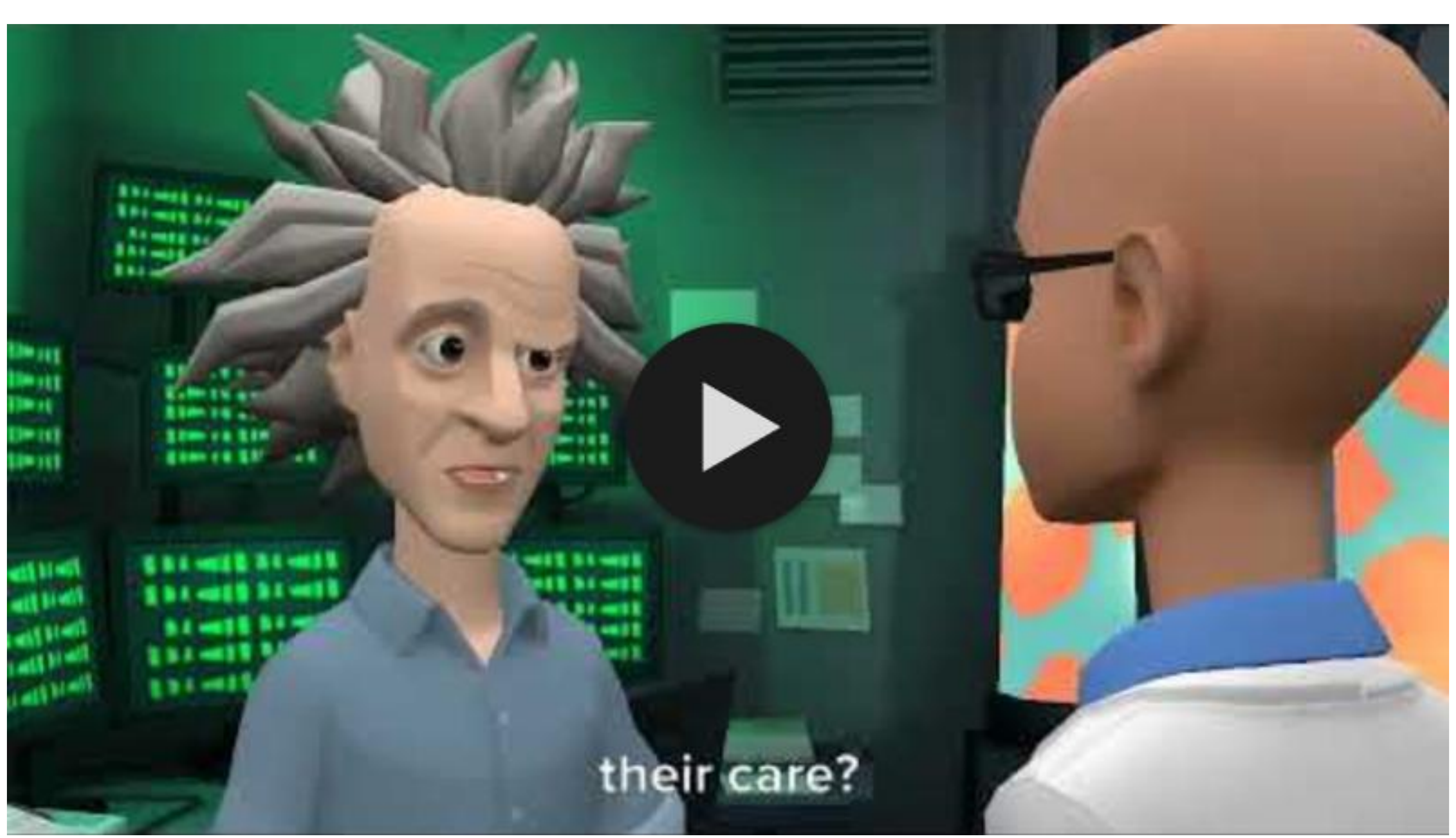
Better End of Life 2024

Time to care in England

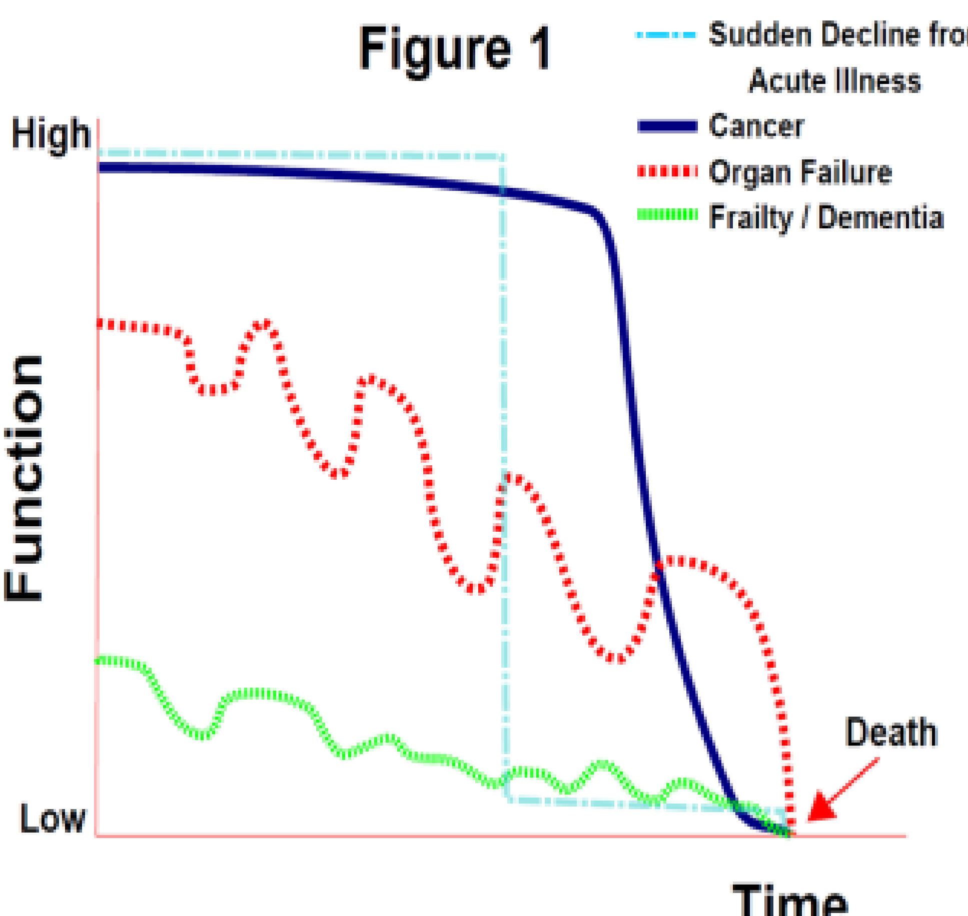
Implications for England of 'Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales'

Policy summary
September 2024

their care?


their care?

Illness trajectories



https://www.mypcnow.org/fast-fact/illness-trajectories-description-and-clinical-use/

Using illness trajectories to inform person centred, advance care planning

https://www.youtube.com/watch?v=0SsWb6m-AS4

Identification

General
Medical
Council

Patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

a. advanced, progressive, incurable conditions
b. general frailty and co-existing conditions that mean they are expected to die within 12 months
c. existing conditions if they are at risk of dying from a sudden acute crisis in their condition
d. life-threatening acute conditions caused by sudden catastrophic events.

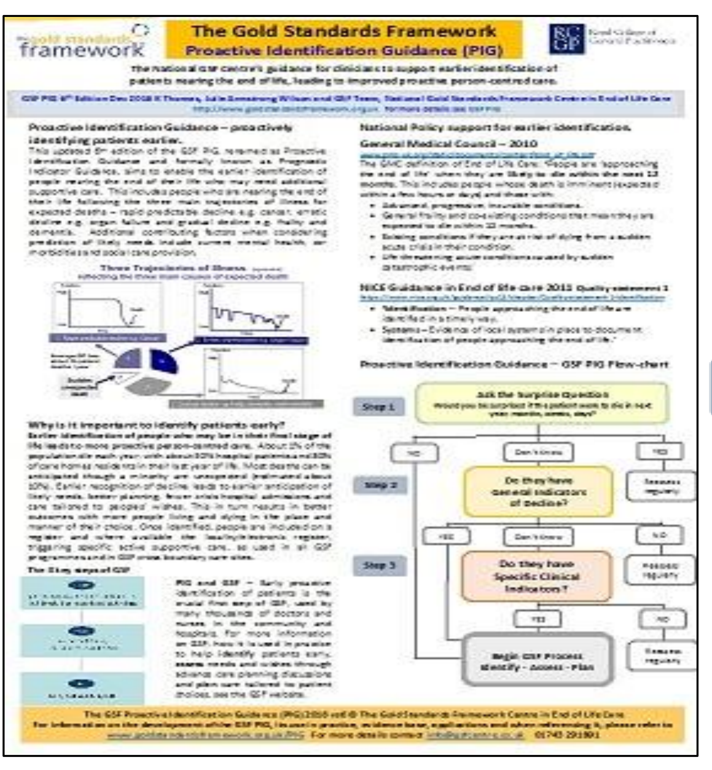
https://www.gmc-uk.org/cdn/documents/treatment-and-care-towards-the-end-of-life---english-1015_pdf-48902105.pdf

NICE Guidance
End of life care for adults: service delivery NG42

1.1.1 People managing and delivering services should develop systems to identify adults who are likely to be approaching the end of their life

[End of Life Care for adults: service delivery NICE guideline [NG 142]]

Identifying End of Life Care Patients


The Gold Standards Framework
Proactive Identification Guidance (PIG)

Step 1

Ask the Surprise Question
Would you be surprised if the patient were to die in next year, months, weeks, days?

https://www.goldstandardsframework.org.uk/cd-content/uploads/files/PIG/NEW%20PIG%20-%20%20%2020.1.17%20KT%20vs17.pdf

General Indicators of decline & increasing needs

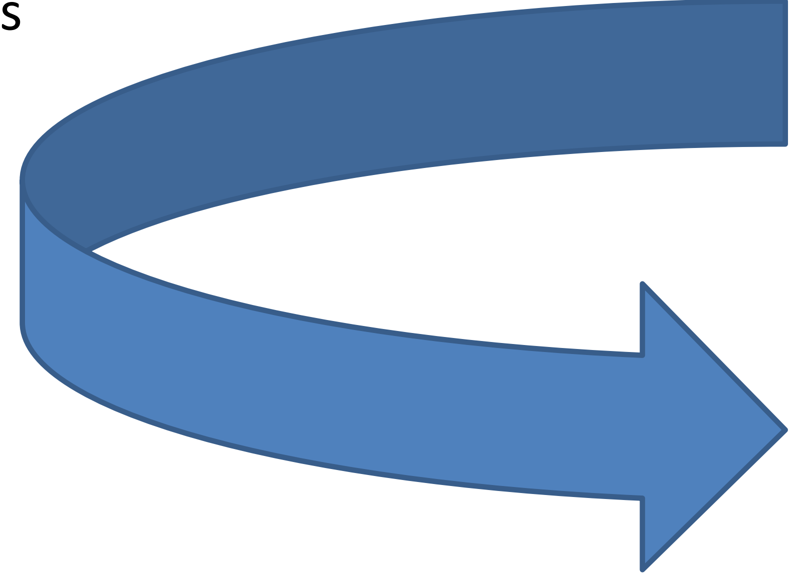
STEP 2: General indicators of decline and increasing needs
• General physical decline, increasing dependence and need for support
• Repeated unplanned hospital admissions or acute crises at home
• Advanced disease - unstable, deteriorating, complex symptom burden
• Presence of significant multi-morbidities
• Decreasing activity – functional performance status declining (e.g., Barthel or Karnofsky Performance score, Rockwood) limited self-care, in bed or chair 50% of day and increasing dependence in activities of daily living
• Decreasing response to treatments, decreasing reversibility
• Patient choice for no further active treatment, focus on quality of life
• Progressive weight loss (>10%) in past six months
• Sentinel Event e.g., serious fall, carer distress, bereavement, transfer to nursing home, etc

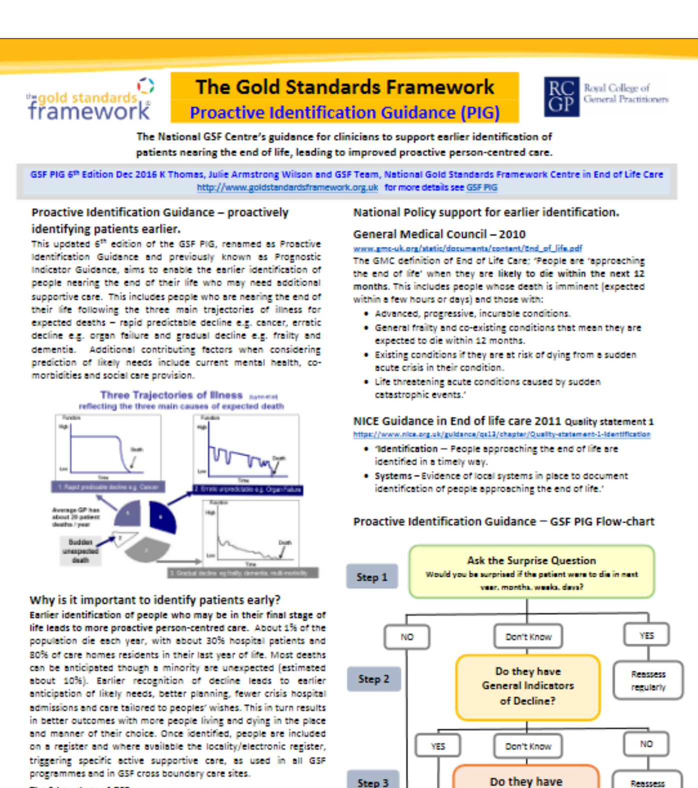
Specific indicators related to a single/multiple organ failure

CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

- Severe disease (e.g., FEV1 <30% predicted), persistent symptoms e.g., breathlessness despite optimal therapy, causing distress
- Recurrent hospital admissions (at least 3 in last year due to COPD)
- Hypoxia/fulfilling long term oxygen therapy criteria (PaO2<7.3kPa)
- Too unwell for surgery or pulmonary rehabilitation
- MRC grade 4/5 – shortness of breath after 100 metres on level surface
- Required ITU/NIV during admission or ventilation contraindicated
- Other factors e.g., right heart failure, anorexia, cachexia, >6 weeks steroids in preceding 6 months, despite specialist review/treatment optimisation, requires palliative medication for breathlessness.

[Download](#) the GSF Proactive Identification Guidance for full details





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.

GSF PIG 6th Edition Dec 2016 K Thomas, Julie Armstrong Wilson and GSF Team, National Gold Standards Framework Centre in End of Life Care
http://www.goldstandardsframework.org.uk for more details see GSF PIG

Proactive Identification Guidance – proactively identifying patients earlier.

This updated 6th edition of the GSF PIG, renamed as Proactive Identification Guidance and previously known as Prognostic Indicator Guidance, aims to enable the earlier identification of people nearing the end of their life who may need additional supportive care. This includes people who are nearing the end of their life following the three main trajectories of illness for expected deaths – rapid predictable decline e.g. cancer, erratic decline e.g. organ failure and gradual decline e.g. frailty and dementia. Additional contributing factors when considering prediction of likely needs include current mental health, co-morbidities and social care provision.

Why is it important to identify patients early?

Earlier identification of people who may be in their final stage of life leads to more proactive person-centred care. About 1% of the population die each year, with about 30% hospital patients and 80% of care homes residents in their last year of life. Most deaths can be anticipated though a minority are unexpected (estimated about 10%). Earlier recognition of decline leads to earlier anticipation of likely needs, better planning, fewer crisis hospital admissions and care tailored to peoples' wishes. This in turn results in better outcomes with more people living and dying in the place and manner of their choice. Once identified, people are included on a register and where available the locality/electronic register, triggering specific active supportive care, as used in all GSF programmes and in GSF cross boundary care sites.

The 3 key steps of GSF

PIG and GSF – Early proactive identification of patients is the crucial first step of GSF, used by many thousands of doctors and nurses in the community and hospitals. For more information on GSF, how it is used in practice to help **identify** patients early, **assess** needs and wishes through advance care planning discussions and **plan** care tailored to patient choices, see the GSF website.

National Policy support for earlier identification.

General Medical Council – 2010
www.gmc-uk.org/static/documents/content/End_of_life.pdf

The GMC definition of End of Life Care; 'People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions.
- General frailty and co-existing conditions that mean they are expected to die within 12 months.
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- Life threatening acute conditions caused by sudden catastrophic events.'

NICE Guidance in End of life care 2011 Quality statement 1
https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-1-identification

- 'Identification – People approaching the end of life are identified in a timely way.
- Systems – Evidence of local systems in place to document identification of people approaching the end of life.'

Proactive Identification Guidance – GSF PIG Flow-chart

The GSF Proactive Identification Guidance (PIG) 2016 vs6 © The Gold Standards Framework Centre in End of Life Care
For information on the development of the GSF PIG, its use in practice, evidence base, applications and when referencing it, please refer to www.goldstandardsframework.org.uk/PIG For more details contact info@gsfcentre.co.uk 01743 291891

https://www.goldstandardsframework.org.uk/PIG

The Supportive & Palliative Care Indicators Tool (SPICT™)

SPICT™

SUPPORTIVE AND PALLIATIVE CARE INDICATORS TOOL

THE UNIVERSITY of EDINBURGH

Home | The SPICT™ | Using SPICT™ | SPICT-4ALL™ | SPICT-LIS™ | Partners | Publications | Resources | Contact

Using SPICT during COVID-19

Supportive & Palliative Care Indicators Tool (SPICT™)

SPICT™ helps identify people with deteriorating health due to advanced conditions or a serious illness, and prompts holistic assessment and future care planning. SPICT™ is available in multiple translations. SPICT-4ALL™ uses non-medical language.

Download SPICT™

Identify
Coordinate
Talk
Assess
Plan

Using SPICT

SPICT™

SPICT-4ALL™

https://www.spict.org.uk/

SPICT

The SPICT is used to help identify people whose health is deteriorating. Review unmet palliative care needs. Plan current and future care with them.

Look for any general indicators of poor or deteriorating health

- Urgent or emergency hospital admission(s) or visits.
- Functional ability is poor or deteriorating, with limited reversibility. (The person often stays in bed or in a chair for more than half the day.)
- Depends on others more for care due to increasing physical and/or mental health problems. Person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of health 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.

https://www.spict.org.uk/the-spict/e-spict/

Look for clinical indicators of life shortening conditions

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptoms.

Dementia or fraility

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 illnesses or infections; aspiration pneumonia.

Heart or vascular disease

Heart failure or extensive, untreatable coronary artery disease; breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

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.

Ongoing disability with worsening physical and/or mental health after a major stroke or multiple strokes.

Respiratory disease

Severe, long term lung disease; breathless 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 shortening conditions or treatments.

Stopping or not starting kidney dialysis.

Liver disease

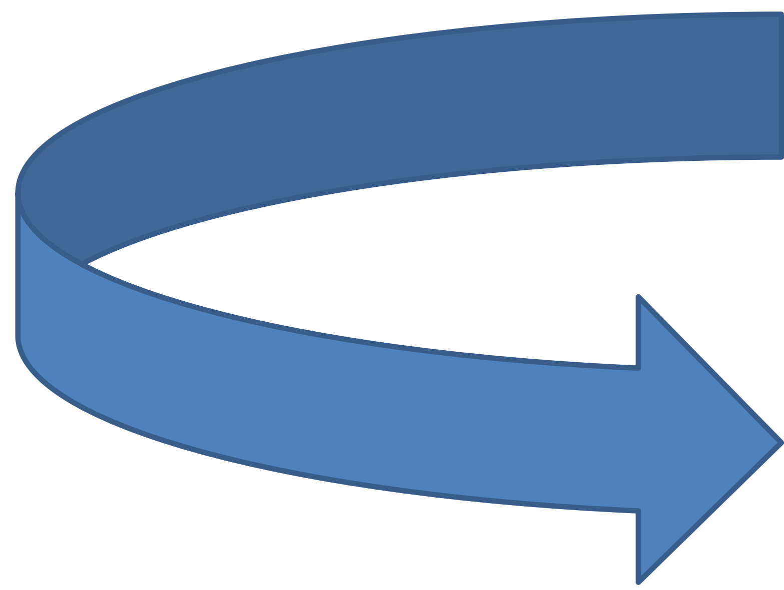
Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

https://www.spict.org.uk/the-spict/e-spict/

Download the full SPICT™ guidance



Why use the SPICT™?

The SPICT™ helps professionals identify people with general indicators of poor or deteriorating health and clinical signs of life-limiting conditions for assessment and care planning.

What will happen to each person and when is often uncertain. SPICT™ looks at health status not a prognostic time frame. Identifying people with deteriorating health earlier improves care.

Using SPICT™ to assess people's needs and plan care.

- After an **unplanned hospital admission** or a **decline in health status**: review current care, treatment and medication; discuss future options; plan for managing further deterioration.
- For people with **poorly controlled symptoms**: review and optimise treatment of underlying conditions, stop medicines not of benefit; use effective symptom control measures.
- Identify people who are **increasingly dependent on others** due to deteriorating function, general frailty and/or mental health problems for additional care and support.
- Identify people (and caregivers) with **complex symptoms or other needs**; consider assessment by a specialist palliative care service or another appropriate specialist or service.
- Assess **decision-making capacity**. Record details of close family/ friends and any POA or proxy for decision-making and involve them if the person's capacity is impaired.
- Identify people who need proactive, **coordinated care in the community** from the primary care team and/or other community staff and services.
- Agree, record and share an **Advance/ Anticipatory Care Plan;** include plans for emergency care and treatment if the person's health (or care at home) deteriorates rapidly or unexpectedly.

Talking about future care planning

- Ask:
  - What do you know about your health problems and what might happen in the future?
  - *'What matters'* to you? What are you worried about? What could help with those things?
  - Who should be contacted and how urgently if your health deteriorates?
- Talk about:
  - The outcomes of hospital admission and treatments such as: IV antibiotics; surgery; interventions for stroke, vascular or cardiac disease; tube or IV feeding; ventilation.
  - Treatments that will not work or have a poor outcome for this person. (eg. CPR)
  - POA or proxy for decision-making in case the person loses capacity in the future.
  - Help and support for family/ informal caregivers.

Tips on starting conversations about deteriorating health

- ***I wish*** *we had a treatment for...., but could we talk about what we can do if that's not possible?*
- *I am glad you feel better and* ***I hope*** *you will stay well, but* ***I am worried*** *that you could get ill again...*
- ***Can we talk*** *about how we might manage with not knowing exactly what will happen and when?*
- ***If you*** *were to get less well in the future, what would be important for us to think about?*
- ***Some people*** *want to talk about whether to go to hospital or be cared for at home....*

www.spict.org.uk April 2019

https://www.spict.org.uk/

Severe Frailty CFS 7-9

Think about supportive care versus cure, advance care planning, recognition that enhanced supportive care is an active intervention in itself offering improved quality of life and, sometimes quantity of life.

Comprehensive Geriatric Assessment must be completed.

https://apps.nhslothian.scot/files/sites/2/Clinical-Frailty-Score.pdf

Mrs Jones

87 year old female

Breast Ca

Alzheimer's

AF

NoF

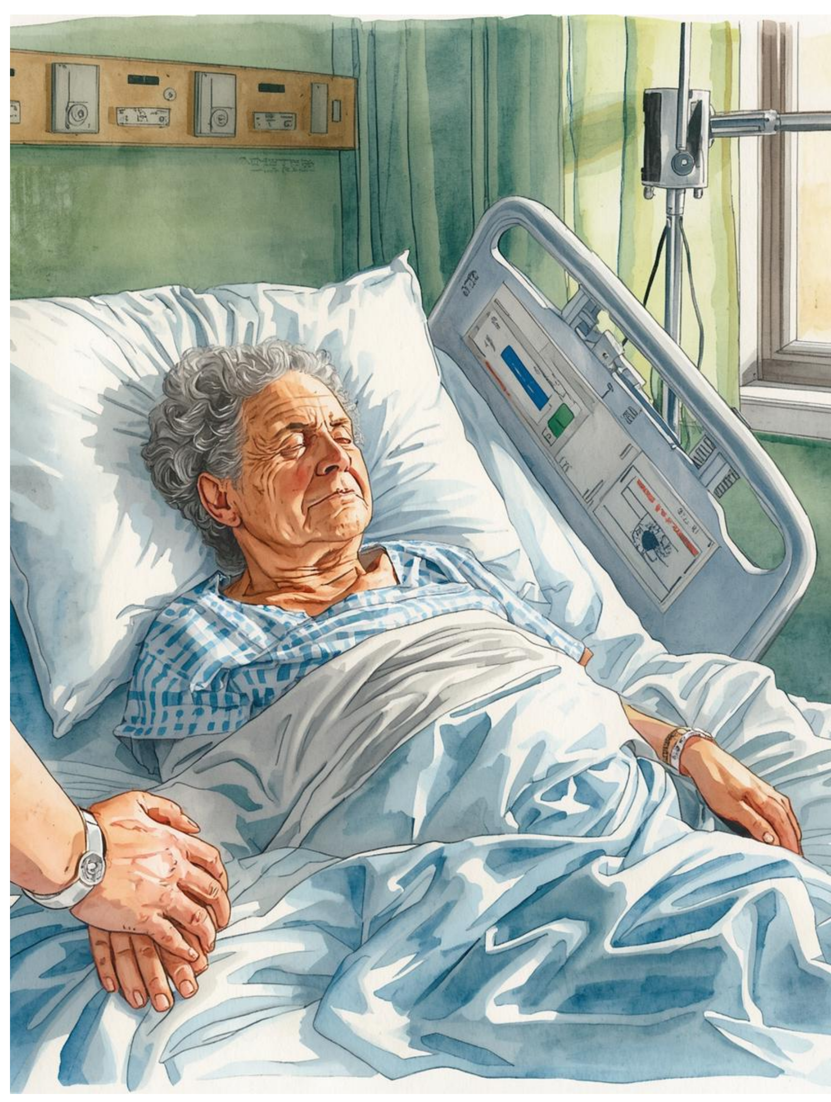
Mrs Jones

Admission to hospital

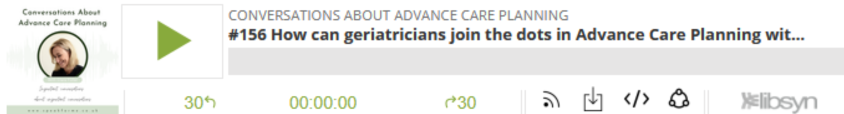
Discharge to care home

Assessment in care home

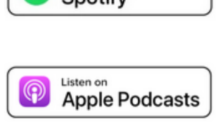
Readmission to ED



#156 How can geriatricians join the dots in Advance Care Planning with Professor Jugdeep Dhesi



#156 How can geriatricians join the dots in Advance Care Planning with Professor Jugdeep Dhesi 06.04.26 I am delighted to open the new season with Professor Jugdeep Dhesi, geriatrician and President of the British Geriatrics Society. Listen in as we explore the changing demographics of dying and the vital role geriatricians play in joining the dots in Advance Care Planning.



https://speakforme.co.uk/podcast-episode-33

Policy paper

Neighbourhood health framework

Published 17 March 2026

Goal 1 objectives and metrics (compared with 2025 to 2026 baseline)
We have 4 core objectives and corresponding metrics for this goal. We will:

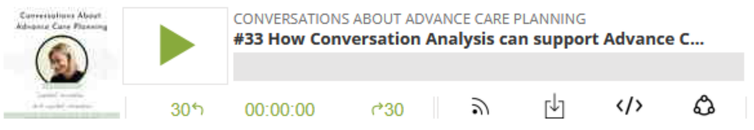
- better identify people coming to the end of life and improve access to services so people can die in a place of their choosing. By March 2029, we aim to: increase the number of people identified as approaching end of life by 10%

- reduce non-elective admissions and bed days of one day or over for people in the end of life cohort by 10%

https://www.gov.uk/government/publications/neighbourhood-health-framework/neighbourhood-health-framework

Communication

#33 Conversation Analysis with Professor Ruth Parry and how we can use in Advance Care Planning.



10.10.2022

#33 How Conversation Analysis can support Advance Care Planning with Professor Ruth Parry

https://speakforme.co.uk/podcast-episode-33

Story sharing

Body posture

Active listening

Silence

Empathic behaviour

Conversation dance

Summarising

Step by step questions

Hypothesis

Cues

Speak
For
Me

"We continue to frame conversations around 'cure' or 'control', rather than using the more honest language of progression, deterioration and limits to treatment. In doing so, we delay difficult but necessary conversations."

Dr Kathryn Mannix

Future Healthcare Journal 31/03/2026

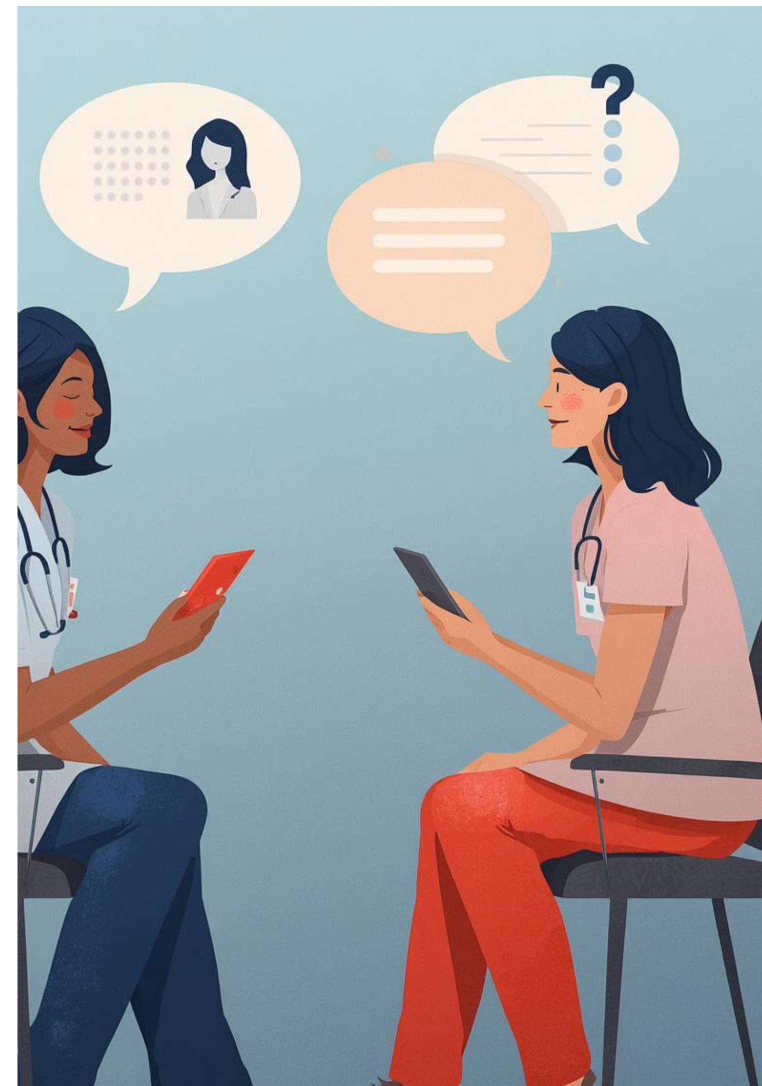
https://www.rcp.ac.uk/news-and-media/news-and-opinion/why-physicians-need-to-talk-about-dying/

https://inews.co.uk/culture/the-story-of-a-heart-by-rachel-clarke-review-3242358

“There is nothing more we can do”

“We are stopping care.”

“We are withdrawing treatment”



#149 Care doesn't stop, it simply changes focus.

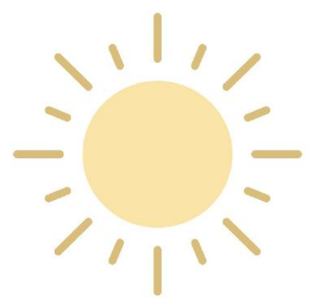
In discussion with Dani & Clare

26.01.26

#149 Care doesn't stop, it simply changes focus. In discussion with Dani & Clare

https://speakforme.co.uk/podcast-episode-149

Advance Care Planning



Advance Care Planning

What You DO Want

End of Life Care

What You DON'T Want

Who Would Speak For You?

Your Legacy

What Matters Most To You?

©Clare Fuller

What Matters Most to You?

Remember, you don't have to be an expert and have all the answers

There may be something you can sort or maybe something you can't, but that's okay.

Often just the listening and connection is enough.

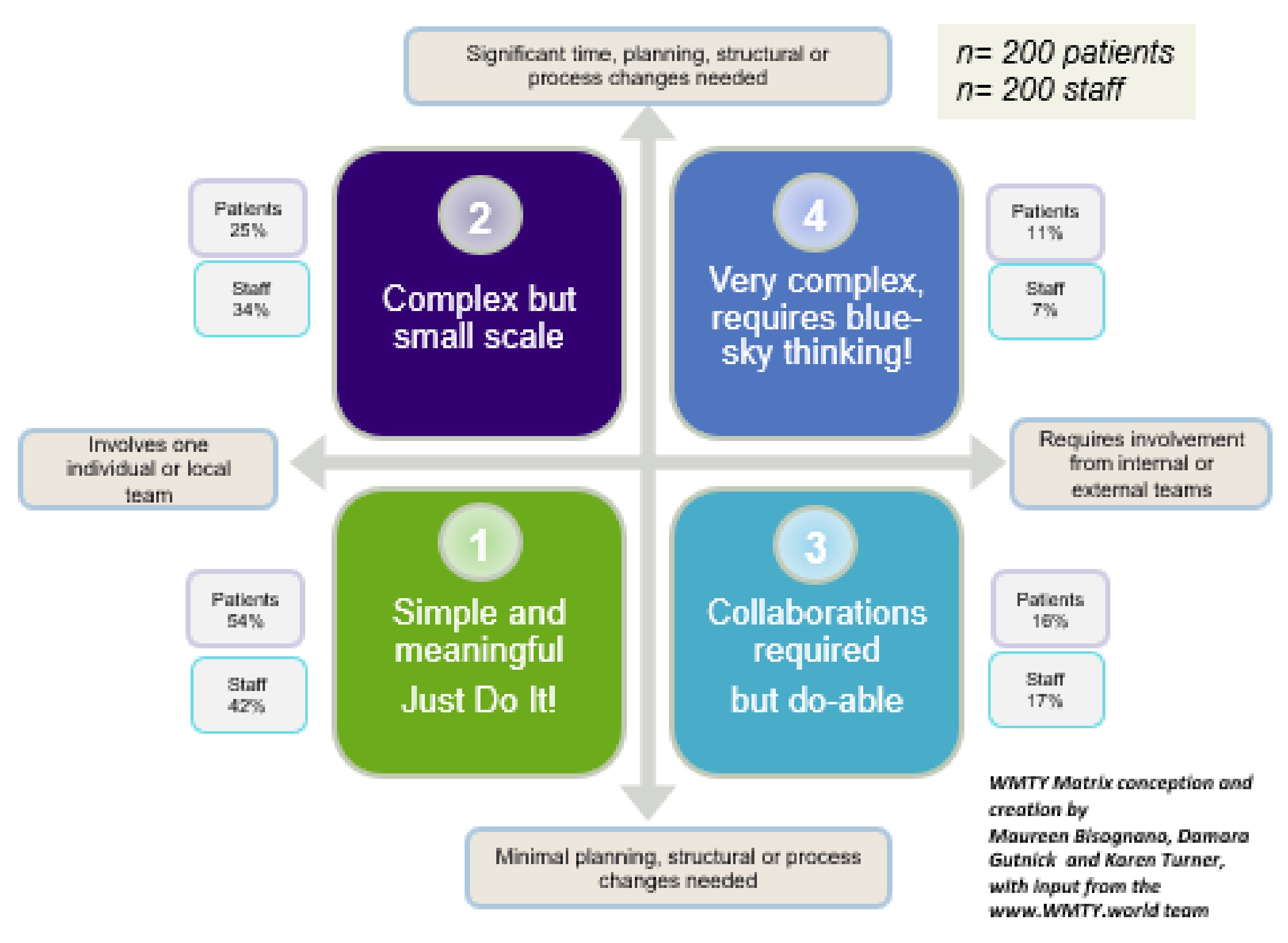
No time to have a conversation?

Think about how much time you'd waste doing what's not important if you don't

Make the time to find out 'what matters' and 'what's important'

Check our website for more information and resources

What Matters to You with Karen Turner


Significant time, planning, structural or process changes needed
n= 200 patients
n= 200 staff
Patients 25%
Staff 34%
2
Complex but small scale
4
Very complex, requires blue-sky thinking!
Patients 11%
Staff 7%
Involves one individual or local team
Requires involvement from internal or external teams
Patients 54%
Staff 42%
1
Simple and meaningful
Just Do It!
3
Collaborations required
but do-able
Patients 16%
Staff 17%
WMTY Matrix conception and creation by
Maureen Bisognano, Damara Gutnick and Karen Turner, with input from the www.WMTY.world team
Minimal planning, structural or process changes needed

"What matters to you?" Day – 2 June 2026

"What matters to you?" Day is an annual celebration of putting people at the heart of their care or support.

What you do want

A statement of wishes & preferences

Joy List

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Advance Care Planning

Advance Care Planning

Planning for Your Future Care

Information to help in preparing for the future and assisting with practical arrangements

Please note that completing the sections in this booklet is optional and you may choose not to complete all of it. It is not designed to be completed all at once and can be filled in over a period of time, as and when you feel comfortable to do so.

Adapted from the Weston Hospice care Advance Care Plan and National Preferred Priorities for Care Guidelines

My Future Care

Handbook

Plan for tomorrow,
live for today

https://myfuturecare.org/

What you don’t want

Advance
Decision to
Refuse
Treatment

Cardio-
pulmonary
resuscitation

©Clare Fuller 2023

Advance Decision to Refuse Treatment

"An advance decision (sometimes known as an advance decision to refuse treatment, an ADRT, or a living will) is a decision you can make now to refuse a specific type of treatment at some time in the future."

https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/

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.
- **Information for GPs**
  A one page cover sheet for you to give to your GP along with your form.
- **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.

You can contact us to order a wallet-sized '**Notice of Advance Decision**' card. This explains that you have made an Advance Decision and where a copy can be found.

To order a card contact us on:
0800 999 2434
info@compassionindying.org.uk

https://compassionindying.org.uk/

An advance decision is valid if:

- you're 18 years old or over & had the capacity to make the decision
- you specify clearly which treatments you wish to refuse
- you explain the circumstances in which you wish to refuse them
- it's signed & witnessed
- you have made the advance decision of your own accord
- you have not said or done anything that would contradict the advance decision

https://www.nhs.uk/conditions/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment/

Speak
For
Me

Promoting Open Justice in the Court of Protection

https://openjusticecourtofprotection.org/

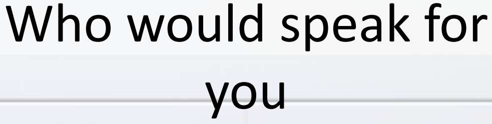
NEWS

'I never thought I'd reach 84… or see my buds bloom'

Esther Rantzen, who has terminal lung cancer, says a 'miracle drug' has given her more time. But she is adamant she should be able to choose how she ends her life

and Joshua. She saw her husband, mother and rescue mongrel Marmite die in relatively short succession, and it was Marmite's death, painless at home after two breakfasts and a walk, that Rantzen "envied". When Wilcox died of a heart attack in 2000, doctors kept trying to save him when there was really nothing they could do – and Rantzen wished she could have held him instead.

Read the blog: [Assisted Dying – an open letter to Esther Rantzen]



Who would speak for you

Lasting Power of Attorney: Health & Welfare

Lasting Power of Attorney: Property & Finance

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LASTING POWER OF ATTORNEY

A legal document that enables you to nominate a person or people to support you to make decisions or make decisions in your best interests in you lose capacity.

Health & Wellbeing

Property & Finance

77% of people

think an LPA can be set up when needed

https://press.which.co.uk/whichpressreleases/creaking-power-of-attorney-system-in-desperate-need-of-improvement-which-warns/

Power of attorney fears

Alarm bells have been sounded that families are at risk of failing to set up a power of attorney in time, with more than three quarters of people mistakenly believing they can be set up at any point in life.

A lasting power of attorney (LPA), a legal document that gives someone you trust the power to make decisions on your behalf should you lose the capacity to do so yourself, can be registered only while you still have "mental capacity", defined as the ability to make your own choices.

The consumer website Which? polled 2,000 people and found that 77 per cent thought it could be set up whenever. About 70 per cent said th were healthy so did not need one.

Of those who had registered LPA 60 per cent raised concerns about a lac of knowledge among staff, while com plexities in the process and delays wer also flagged as problems.

Some 31 per cent said banks were th most difficult to deal with, reportin that many lost documents, failed to explain the process and required them to make unnecessary trips to a branch.

Last year the Office of the Public Guardian launched a consultation to modernise LPAs. The results are expected in the coming months.

Imogen Tew

"77% thought an LPA could be set up whenever"

https://press.which.co.uk/whichpressreleases/creaking-power-of-attorney-system-in-desperate-need-of-improvement-which-warns/

How many people think they don’t need an LPA because they have a next of kin?

https://powerofattorney.campaign.gov.uk/

72% of people think

Think that your next of kin always gets the final say in treatment decisions at hospital, if you can't make them yourself.

This is untrue.

Medical decisions need the specific, agreed consent of the person involved, before a next of kin can make treatment or welfare choices on someone else's behalf.

https://powerofattorney.campaign.gov.uk/

how many of us think we don’t need an LPA for Property & Finance because we have a joint back account?

https://powerofattorney.campaign.gov.uk/

73% of people

Think that if a couple have a joint bank account and one person can't make decisions for themselves, their partner can legally make decisions for them both.

This is untrue.

An LPA will however give you consent to access joint funds to pay and monitor financial aspects of a joint account.

https://powerofattorney.campaign.gov.uk/

Don't assume

If you're married or in a civil partnership, you may have assumed that your spouse would automatically be able to deal with your bank account and pensions, and make decisions about your healthcare, if you lose the ability to do so. This is not the case. Without an LPA, they won't have the authority.

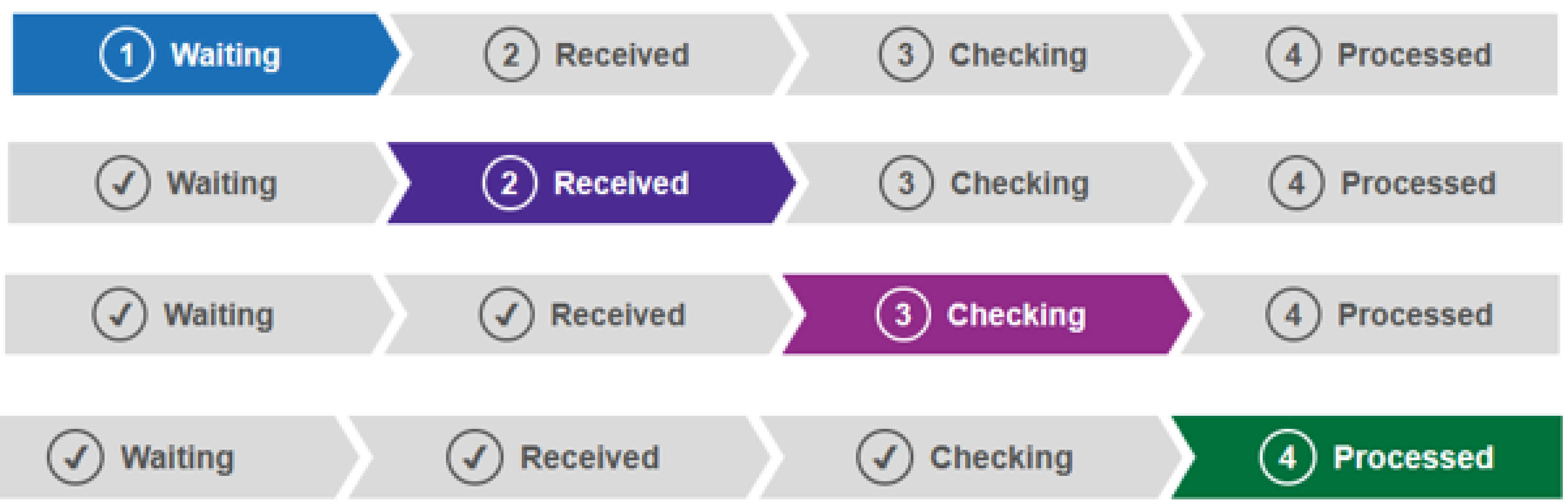
https://www.ageuk.org.uk/information-advice/money-legal/legal-issues/power-of-attorney/

Do it yourself

Go to a solicitor

LPA Consultant

The LPA timeline = 10 weeks



MyWishes
171 subscribers
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'Lasting Power of Attorney: What every healthcare professional needs to know' - Clare Fuller

Clare Fuller (RGN MSc)

Advance Care Planning Advocate,
Educator & Coach, Speak For Me LPA

Title of talk:

**'Lasting Power of Attorney:
What every healthcare professional needs to know'**

www.AdvanceCarePlanDay.org

Heard of power of attorney but think it's something for when you get older?

Your legacy

How you want to be remembered

Digital legacy

Will

Making memories

Funeral/charity

Donation of body for medical education

Your legacy

Share beautiful stories and greeting cards brought to life with the magic of your own voice

[Featherbed Tales and the power of voice with Caroline England.]

[How to start your Digital Legacy with James Norris]

[Making Memories with Karen Pardoe]

[Choice is meaningless unless you know all the options with Holly Lyon Hawke holistic funeral director]

https://www.youtube.com/watch?v=Fl-_ed513RY

[The power of Memorial Jewellery with Ros Wood]

End of Life Care

Last days of life

Last months of life

Last years of life

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Advance Care Planning

Progressive disease	Deteriorating	Last days of life
LPA/Will/Legacy/Organ Donation	**All identified in green plus:**	**All identified in green & yellow plus:**
Advance Decision to Refuse Treatment	Update plans	Crisis medications and chart
Memory Making	Assess family and carer risk factors for bereavement	Last Days of Life Care Plan
ReSPECT/Treatment Escalation Plan/Consider DNACPR	Rationalise investigations, treatment, medication	Use Priorities for Care of the Dying Person
Preferred place of care/death Advance Care Pan	Act upon agreed care plans	COMMUNICATE: Ordinary Dying
Anticipate future care needs: e.g. ICD, respiratory support, dialysis	Fast Track Continuing Health Care	
Assess family and carers needs: signpost	Consider crisis medication	
Check patient is on GP Palliative Care Register	COMMUNICATE: Illness trajectory	
Consider CHC application		

Advance Care Planning Explained

Advance Care Plan Day 2026

Provided with love and care by...

You can hear Sammy & Hsien talk about why they created the 7 keys:
https://www.youtube.com/watch?v=tfS8pYeRk0M&list=PLa1_77g2uuw1ffwoBtLmb7Wb8wPFNgo2Z&index=1

www.waitingroomrevolution.com

Walk Two Roads

Zoom Out

Connect the Dots

Invite Yourself

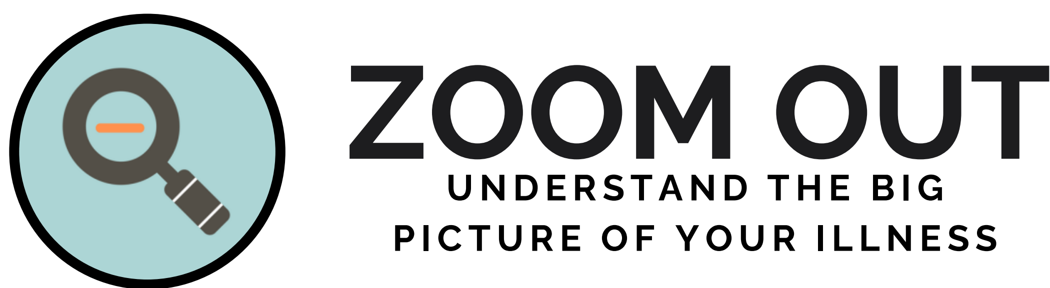
Know Your Style

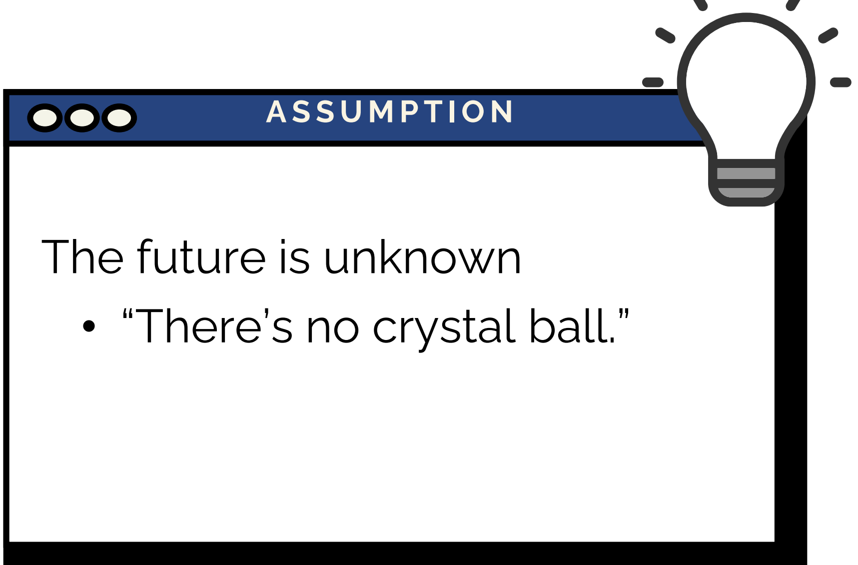
Customize Your Order

Anticipate Ripple Effects

Putting it All Together

When Time is Running Out


ZOOM OUT
UNDERSTAND THE BIG
PICTURE OF YOUR ILLNESS


ASSUMPTION
The future is unknown
• "There's no crystal ball."

The Waiting Room
REVOLUTION

ASSUMPTION

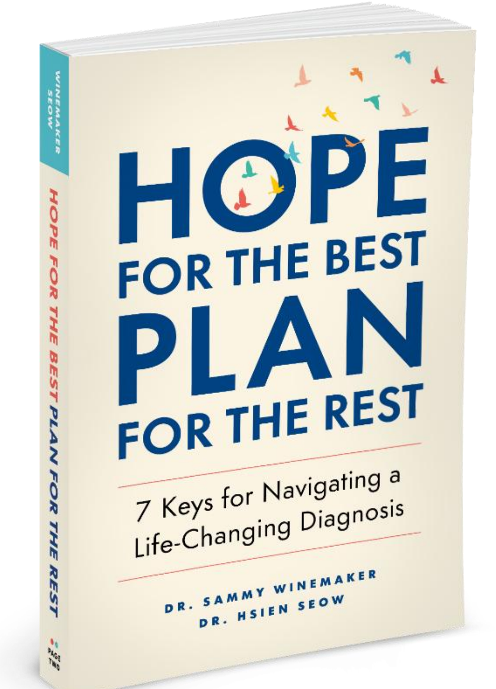
The future is unknown

- "There's no crystal ball."

REALITY

Every illness has a well-known pattern

- The storyline can be known


WINEMAKER SEOW
HOPE FOR THE BEST PLAN FOR THE REST
HOPE
FOR THE BEST
PLAN
FOR THE REST
7 Keys for Navigating a
Life-Changing Diagnosis
DR. SAMMY WINEMAKER
DR. HSIEN SEOW
PAGE TWO

Key takeaways

1

It's OK to share an uncertain future

Key takeaways

1

It's OK to share an uncertain future

2

Illness trajectories are recognisable

Key takeaways

1

It's OK to share an uncertain future

2

Illness trajectories are recognisable

3

Every story is unique, but patterns of illness are the same

Key takeaways

1

It's OK to share an uncertain future

2

Illness trajectories are recognisable

3

Discuss Lasting Power of Attorney at key points

4

Hope for the best & plan for the rest - parallel planning

Key takeaways

1

It's OK to share an uncertain future

2

Illness trajectories are recognisable

3

Every story is unique, but patterns of illness are the same

4

Hope for the best & plan for the rest - parallel planning

5

Planning ahead is everyone's business

THANK YOU

Clare Fuller

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www.speakforme.co.uk

@ClareFullerclare-fuller-acp7

Resource 1 of 2

Advance Care Planning
Speak For Me website https://speakforme.co.uk/
ACP Explained: https://speakforme.co.uk/advance-care-planning-explained
Podcasts: https://speakforme.co.uk/podcast-2
Blogs: https://speakforme.co.uk/blog

Awareness Days
What Matters to You Day
https://www.whatmatterstoyou.scot/what-matters-to-you-day-6-june-2024/
Power of Attorney Day 2026
https://www.powerofattorneyday.org.uk/
Advance Care Plan Day
https://advancecareplanday.org/get-involved/

Identification Tools
Gold Standards Framework
https://www.goldstandardsframework.org.uk/PIG
Supportive & Palliative Care Indicators Tool
https://www.spict.org.uk/the-spict/
Clinical Frailty Scale
https://apps.nhslothian.scot/files/sites/2/Clinical-Frailty-Score.pdf

Resource 2 of 2

Research
National Confidential Enquiry into Patient Outcome & Death: End of life care
https://www.ncepod.org.uk/2024eolc.html
Better End of Life Care Report 2024
https://www.mariecurie.org.uk/research-and-policy/policy/better-end-life-report
Specialist palliative care improves patient experience, reduces bed days and saves money: An economic modelling study of home- and hospital-based care
https://journals.sagepub.com/doi/10.1177/02692163261423755

Video resource
Jared Rubenstein YouTube: https://www.youtube.com/@DrJRubenstein
Back in Time Jared Rubenstein: https://www.youtube.com/watch?v=kT5I3ZtZ7YY
Using Illness trajectories to inform person centred, advance care planning: https://www.youtube.com/watch?v=0SsWb6m-AS4

Open Justice Court of Protection Project
Open Justice Court oof Protection Project: https://openjusticecourtofprotection.org/
Reflecting on Re MW and Advance Planning: Legal frameworks and why they matter:
https://openjusticecourtofprotection.org/2022/01/04/reflecting-on-re-mw-and-advance-planning-legal-frameworks-and-why-they-matter/

Waiting Room Revolution
https://www.waitingroomrevolution.com/