The Conversation Project

NHS
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Lets start the Conversation

Everyone Matters
Working Together
Making a Difference

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Why focus on Conversations?

- 78% of people that die have **at least one admission to hospital** in their last year of life[1]
- A third of all hospital admissions in last year of life **occur in the last 30 days before death**[1]
- Issues related to **communication** are the greatest source of complaints in end of life care
- People who have engaged in Advance Care Planning (ACP) are **less likely to die in hospital**[2]
- Patients who have **engaged in ACP** have better outcomes

1. National end of life care Intelligence May 2012
2. National Council for Palliative Care 2015

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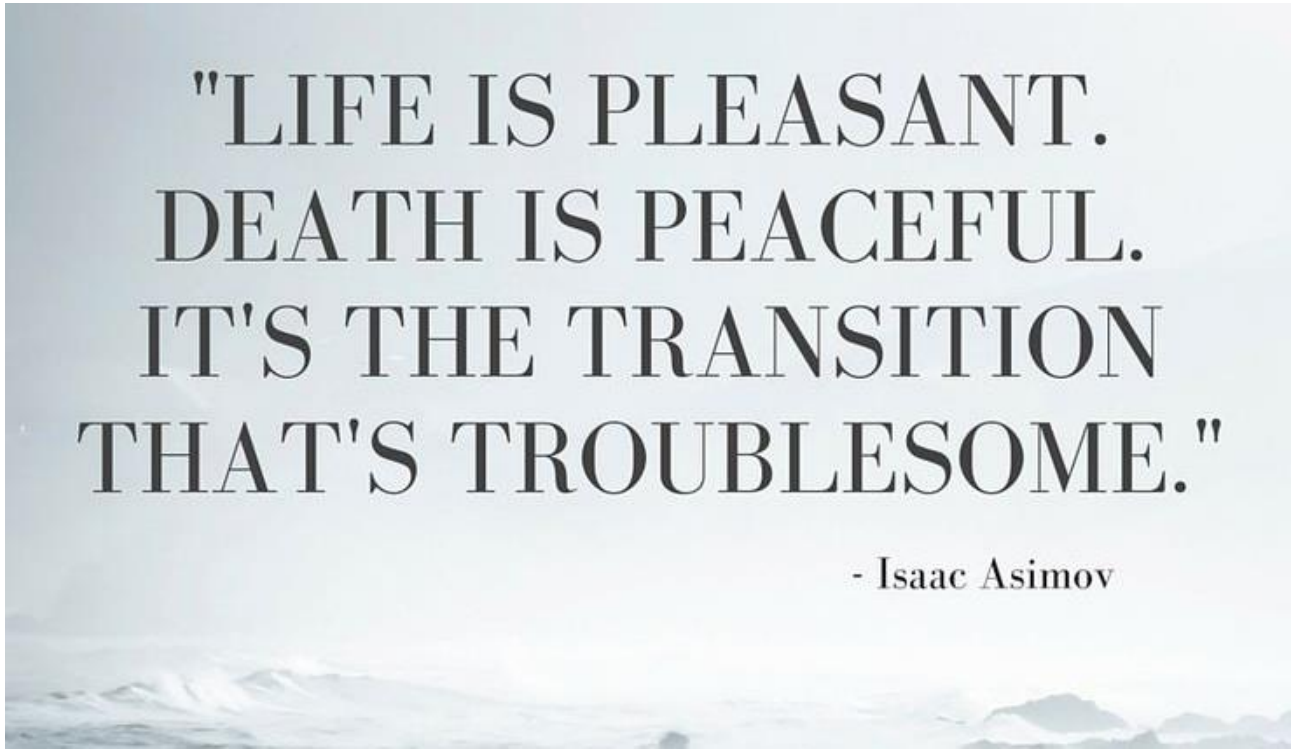

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Facing uncertainty

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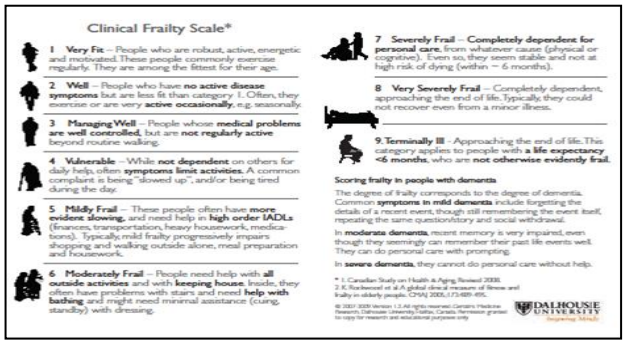
Recognising approaching end of life

Triggers

- Unplanned hospital admissions or repeated admissions
- Disease burden –increase in symptoms
- Frailty, weakness, weight loss
- Family report deterioration, greater level of dependency
- Patient refuses treatment
- Admission from a care home

Tools


Clinical Frailty Scale*

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

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

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

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

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

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

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

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

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

Scoring frailty in people with dementia

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

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

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

* 1. Canadian Study on Health & Aging. Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489–495.

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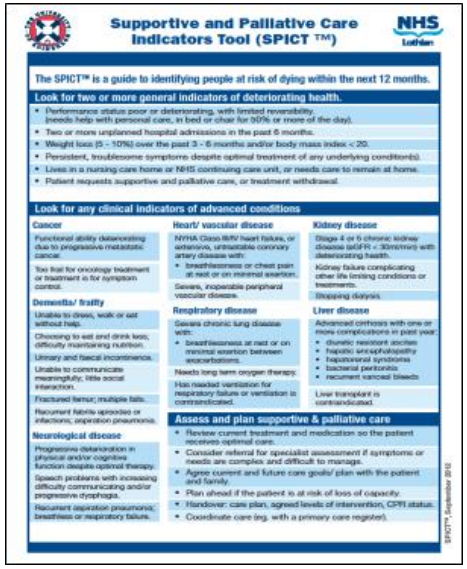
Rockwood Frailty Score


Supportive and Palliative Care Indicators Tool (SPICT ™)

NHS Lothian

The SPICT™ is a guide to identifying people at risk of dying within the next 12 months.

Look for two or more general indicators of deteriorating health.

- Performance status poor or deteriorating, with limited reversibility, (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- Lives in a nursing care home or NHS continuing care unit, or needs care to remain at home.
- Patient requests supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of advanced conditions

Cancer
Functional ability deteriorating due to progressive metastatic cancer.
Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty
Unable to dress, walk or eat without help.
Choosing to eat and drink less; difficulty maintaining nutrition.
Urinary and faecal incontinence.
Unable to communicate meaningfully; little social interaction.
Fractured femur; multiple falls.
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 dysphagia.
Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease
NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:
- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease
Severe chronic lung disease with:
- breathlessness at rest or on minimal exertion between exacerbations.

Needs 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 limiting conditions or treatments.
Stopping dialysis.

Liver disease
Advanced cirrhosis with one or more complications in past year:
- chronic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Assess and plan supportive & palliative care
- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals/ plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Handover: care plan, agreed levels of intervention, CPR status.
- Coordinate care (eg. with a primary care register).

SPICT™ September 2016

Supportive and palliative care indicator tool

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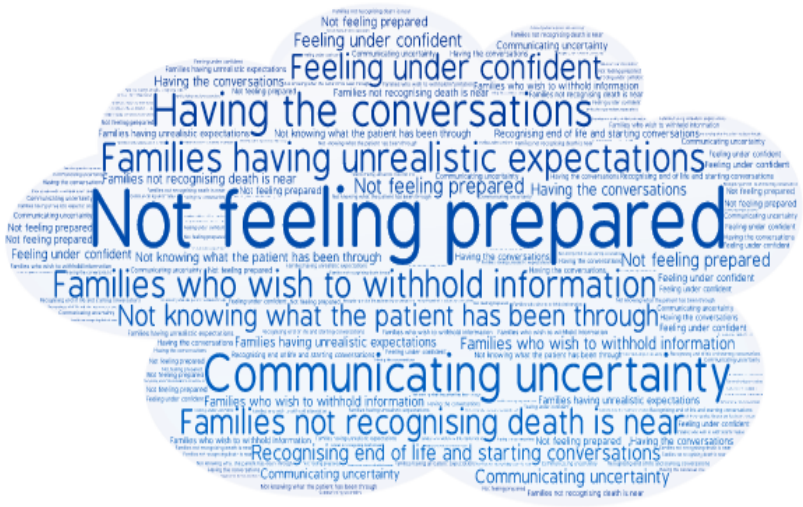
Feedback from staff questionnaire

What are the challenges?



What can we do better?

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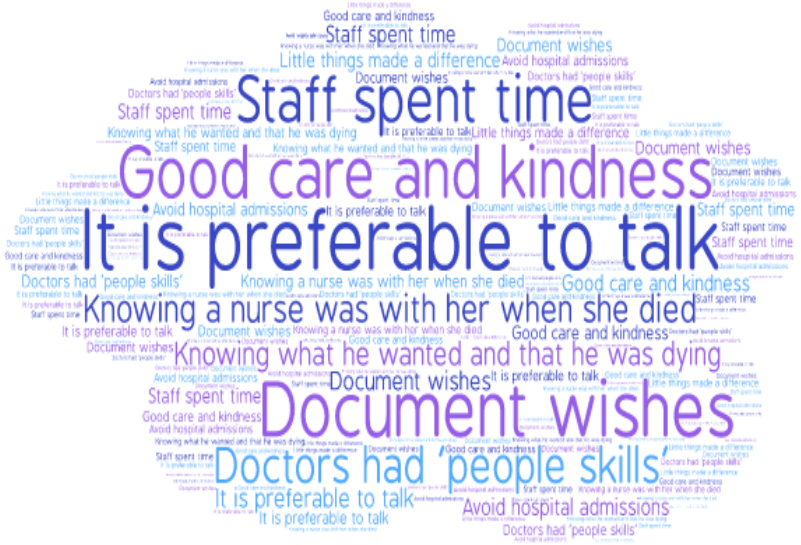
Feedback from telephone interviews with trust members

What was important to you?



What was difficult?

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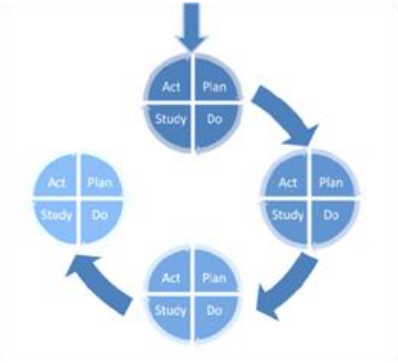
Quality improvement methodology

- PDSA methodology – small cycles of change
- Incorporating patient and family experience throughout
- Promoting staff engagement and developing ward ownership
- Palliative care team and ward Ambassadors for end of life care acting as facilitators
- Developing a culture change, normalising end of life conversations and making it ‘everyone’s business’
- Monitoring outcomes



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The Conversation Project:

What? The Conversation Project is an RUH ward-based initiative that promotes the earlier recognition of those patients whose futures are uncertain or who are approaching the end of their lives.

Why? To create a shared understanding of what matters most to the patient and their family in order to plan appropriately for now and for the future.

How? By using the MDT ward meetings and ward rounds to identify such patients, to then focus on the conversations that may need to take place.

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Where are we now?

- Let's get talking – with patients, families, trust members and staff to develop the Conversation Project
- Adopted SPICT[3] and Rockwood Frailty[4] assessment tools to support identification of patients with EOLC and frailty
- Conversation Key Card for staff, ACP information leaflet and piloting ACP planning ahead document
- Ward based training, induction training and eLearning module, 'essential' training for end of life care which includes principles of the Conversation Project
- Intranet resource for the Conversation Project and ACP

www.spict.org.uk[3]
Rockwood et al CMAJ 2005[4]

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CHAT Bundle

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Consider

Consider whether the patient has an uncertain prognosis or is nearing end of life?

Consider:

- Rockwood Frailty Assessment
- SPICT - Supportive and Palliative Care Indicator Tool
- The 'surprise question'
- The patient's narrative
- Information from the family/carer
- Discuss at white board / MDT meetings
- Conversation Project magnet on the white board to identify patients

Have

Have conversations with the patient & their family to support Advance Care Planning (ACP):

- Think about the environment and your approach
- Check their understanding
- Acknowledge uncertainty of recovery
- Have honest conversations
- Listen compassionately to concerns, wishes and preferences
- Include discussion of TEP
- Offer 'Planning ahead' leaflet

Advise

Advise the MDT following ACP conversations:

- Share information on the patient's wishes & preferences
- Complete TEP
- Include information from ACP discussions in the plan of care
- Document ACP conversations in the MDT records - reverse of TEP and Millennium 'Conversation Project ACP template'

Transfer

Transfer information to support continuity of care:

- Offer use of 'Planning Ahead' leaflet to the patient and family
- Consider community TEP or share information on TEP decisions
- Include 'discussions had and decisions made' in the discharge summary
- Communicate with GP, DN or care home by phone

For information on the Conversation Project:

- Open the intranet and click 'P' for Palliative or 'E' for End of Life Care
- Contact the Palliative Care Team on ext 5587

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What makes end of life conversations challenging

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Challenges

- Not having the right experience/having had a bad experience
- Not knowing what the patient/family knows
- Family/patient expectations
- The environment- finding quiet space or time
- Fear of getting it wrong
- Fearing of getting in out of depth
- End of life care is still a taboo subject!
- Time

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Conversation Starters

- **Fishing questions**- Have you thought about a time when…….you may not be as well as you are now
- **Focusing on key issues**- Can you tell me what is the most important thing for you?
- **Framing difficult matters as universal or general**- Some people like to make their thoughts/wishes known and to make plans……
- **Seeking permission**-Are you the sort of person who likes to know what is going on?
- **Hypothetical questions**- Sometimes it is helpful to think about the what if's

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Communication Techniques

- **Look for cues**, I'm not so well today'…'Can you tell me why you say that?'
- **Actively listen**- think manner, position, eye contact
- **Reflect back** 'So a lot has happened in a short time?'
- **Focus on the emotion**- "Am I right in thinking that you feel scared?'
- **Open questions- 'How** are you today?' not 'Are you ok today?'
- **Use of silence** –Give people time to think
- **Be empathetic-** that living with uncertainty is very difficult

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"The truth will set you free,

but first it will piss you off"

Gloria Steinem

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Outcomes of ACP

Preferred Priorities for Care

- Better understanding of their illness
- Expectations for the future clearer
- Attending to personal wishes- eg. letters for family, key events
- Know what care and support is available
- Preferred place of care
- Who they would like involved in their care
- Preferred place of death

- Treatment Escalation Plan
- Advanced Directive to Refuse Treatment
- Admission avoidance

Help patients to consider:

- Putting financial affairs in order
- Power of Attorney
- Funeral plans
- Power of Attorney
- Writing wills

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Future work and next steps

- Ward accreditation and quality mark for the Conversation Project and end of life care
- Ambassador badge for recognition of quality improvement on the ward and support for the Conversation Project
- The Health Foundation grant continues to October 2018 to support extension of the Conversation Project with community partners, development of resources and shared learning opportunities
- Develop short films to support access to ongoing learning in the Conversation Project and ACP
- Electronic Conversation Project ACP template
- Launch of Conversation Project bundle and Priorities for Care bundle

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It is important to…

- **See the person** in the patient, know what is important to them, understand their wishes and preferences?
- **Be brave** enough to start a conversation that matters
- **Be honest** and adopt a kind and caring manner, this supports those that feel vulnerable
- **Remember the art of listening** as well as being heard is as important in good communication
- **Kindness and compassion** creates trust and lessens suffering
- **Little things** can matter the most

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Martin Luther King