Let's start the Conversation

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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

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1. National end of life care Intelligence May 2012
2. National Council for Palliative Care 2015
"LIFE IS PLEASANT. DEATH IS PEACEFUL. IT'S THE TRANSITION THAT'S TROUBLESOME."

- Isaac Asimov
Facing uncertainty

What is going to happen to me?
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
Feedback from staff questionnaire

What are the challenges?

Not feeling prepared
- Families having unrealistic expectations
- Families who wish to withhold information
- Not feeling prepared, having the conversations
- Not feeling prepared, having the conversations
- Communicating uncertainty
- Not recognising death is near

What can we do better?

- Improve decision making
- Education
- Further conversations
- Earlier conversations
- Knowing prior conversations
- Improve confidence and skills
- Improving access to quieter areas
- Documentation of patient wishes
- Making time to talk
- Making time to talk
- Making time to talk
Feedback from telephone interviews with trust members

What was important to you?

What was difficult?
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
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.
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

\(^3\)www.spict.org.uk

\(^4\)Rockwood et al CMAJ 2005
## STARTING THE CONVERSATION

### CHAT Bundle

<table>
<thead>
<tr>
<th>Consider</th>
<th>Have</th>
<th>Advise</th>
<th>Transfer</th>
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<tbody>
<tr>
<td><strong>Consider</strong> whether the patient has an uncertain prognosis or is nearing end of life?</td>
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<tr>
<td><strong>Have</strong> conversations with the patient &amp; their family to support Advance Care Planning (ACP):</td>
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<td><strong>Advise</strong> the MDT following ACP conversations:</td>
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<td><strong>Transfer</strong> information to support continuity of care:</td>
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<td>- Think about the environment and your approach</td>
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<td>- Check their understanding</td>
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<td>- Acknowledge uncertainty of recovery</td>
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<td>- Have honest conversations</td>
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<td>- Listen compassionately to concerns, wishes and preferences</td>
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<td>- Include discussion of TEP</td>
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<td>- Offer ‘Planning ahead’ leaflet</td>
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<td>- Share information on the patient’s wishes &amp; preferences</td>
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<td>- Complete TEP</td>
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<td>- Include information from ACP discussions in the plan of care</td>
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<td>- Document ACP conversations in the MDT records - reverse of TEP and Millennium ‘Conversation Project ACP template’</td>
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<td>- Offer use of ‘Planning Ahead’ leaflet to the patient and family</td>
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<td>- Consider community TEP or share information on TEP decisions</td>
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<td>- Include ‘discussions had and decisions made’ in the discharge summary</td>
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<td>- Communicate with GP, DN or care home by phone</td>
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**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
What makes end of life conversations challenging
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
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
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
“The truth will set you free, but first it will piss you off”

Gloria Steinem
Outcomes of ACP

**Preferred Priorities for Care**

- Better understanding of their illness
- Expectations for the future clearer
- Attending to personal wishes - e.g. 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

**STARTING THE CONVERSATION**

- 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
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
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
You don't have to see the whole Staircase, just take the FIRST STEP

Martin Luther King