

## End of life care public engagement session

- **Date:** 22 November 2018
- **Time:** 1-3pm
- **Location:** NHS Vale of York CCG, West Offices, Station Rise, York

The session was hosted by NHS Vale of York Clinical Commissioning Group and we had 11 attendees and three presenters.

### Presenters

- **Dr Dan Cottingham**, GP and Lead for end of life care and cancer NHS Vale of York CCG
- **Victoria Hirst**, Head of Engagement, cancer NHS Vale of York CCG
- **Dr Victoria Turner**, Public Health Consultant on placement with NHS Vale of York CCG

### Session format

A presentation was given by Dan and Victoria covering

- **Purpose of the session:** To invite members of the public to session to create an end of life care strategy and Citizen's Charter that aims to improve and further develop end of life care and support services.
- **Engagement so far:** To ensure that we reflect the needs and views of the Vale of York community we recently asked local patients and members of the public to share their experiences. We shared some of this feedback with the group.
- **Open session:** To gather feedback and views from attendees on end of life care services
- **Next steps:** Strategy and action plan

## We asked people why they were attending the session

- Interested in increasing awareness and conversations around death and dying
- Concerned with ageing without the support of children and improving resilience
- Increasing awareness of dementia as a life-limiting illness and to look at how we can support people better with dementia care
- To voice views on behalf of the community
- Attendees were already supporting people in the community at end of life
- Personal interest, volunteers, advocates
- Dignity in dying and raising the profile
- Interested in research

## Attendee feedback – verbatim comments

During the session we gave attendees the opportunity to ask questions, talk about what they thought worked well and where there may be gaps in provision of care when people are in the last years of their life. The feedback has been collated into themes, and contains verbatim comments from the day.

### Caring for the whole family

- ‘Families need support when crisis happens.’
- ‘We must involve all family.’
- ‘Can feel very isolated and alone.’

### 24 hour access/telephone number

- ‘Need the confidence and support at 2am in morning when you are at home and don’t know what to do.’

### Single point of contact/coordination

- ‘Members of the family take on the co-ordinating role and it can be difficult with so many services.’
- ‘Knowing who is in charge in a stressful situation is important.’
- ‘Airedale model is good.’

### Continuity of care and coordination

- ‘Less easy to access GP these days.’
- ‘Continuity of care is a real issue.’
- ‘York integrated care team has seen an increase of 30% of people dying where they want to due to integration of care.’
- ‘Health and social care still working independently – not connecting.’

### **Open discussions about death and dying**

- 'Increase public awareness about the topic.'
- 'Needs to be discussed early otherwise people are suddenly being told they have six weeks to live.'
- 'People are appalling at having the difficult conversations.'
- 'Should not be called a 'difficult' conversation. It should be an important conversation.'

### **Language**

- 'Phraseology and language are really important.'
- '*You are very ill*, does not mean the same as *you are going to die*.'
- 'My mother died recently and no one said to her that you are in the last years of your life.'
- 'Important that staff use the correct language, and tell people they are dying.'

### **Equipment**

- 'Cannot wait weeks for equipment at end of life.'
- 'People aren't thinking ahead about what they need.'

### **Dementia and other long-term conditions**

- 'Cancer often has all the focus – e.g. money placed into MacMillan nurses, however dementia is a terminal illness and needs more support.'
- 'Need to start having conversations with those who have dementia early to talk about planning for death'
- 'Focus of the money is too much on cancer and not enough on the other long term illnesses and life limiting conditions.'
- 'There is only one admiral nurse that covers the whole of North Yorkshire. There is more support that could be offered with the right funding. Need to open it up more'
- 'Massive gap at the moment in support for dementia care.'
- 'Dementia Forward is happy to get involved.'

### **Advanced care planning**

- 'We should all be thinking about care planning.'
- 'We need a 'death plan' just like a 'birth plan'.'
- 'Talk about the first point of preference.'
- 'Need to have a clear pathway. Some people will want lots of information.'
- 'Plan with the family. Carers are being traumatised with a sudden mention of do not resuscitate.'

**Choice of where to die**

- 'It's important that people can die in their chosen place of death.'
- 'We should have an aspiration that we can support people to die at home if they wish.'
- 'It's so important the timing of when people are asked about where they want to die.'
- 'Preference can change at different stages of illness – it may be at home when you are better, and then you may want to go into a hospital or hospice towards the end of your illness. We can all change our minds.'
- 'It has become an expected fact that dying at home is the gold standard – but it might not always be appropriate or the wish of the patient. Carer left at home – difficult to deal with due to memories.'
- 'People need more information about the options and the support you will get in your preferred choice for place of death.'
- 'Hospice at home gives people the choice.'

**Post death**

- 'Carer left at home – difficult to deal with due to memories.'
- 'Dying at home can have lasting and difficult memories of nursing someone.'
- 'Bereavement support is needed.'

**Seldom heard communities**

- 'LGBT voice.'
- 'Dementia care.'

**Other information shared**

- 'It is important that we ask patients about their experience and if they are having a coordinated service.'
- 'Need to embrace all diagnoses in end of life care.'
- 'Look at other areas – eg Cumbria, Airedale (Goldline)'
- 'Need more information on figures and funding. How are we going to fund any development in services?'
- 'Treating pain in the community leaves a lot to be desired.'
- 'Too many people only getting pain relief in the last weeks of their life.'
- 'I want to create a good death.'
- 'Nutrition and the right sort of nutrition is important – low GI diet.'

## Next steps

- The audience wanted to know the next steps and time frame
- People were pleased to see that the strategy is intended to inform an action plan
- Facts and figures asked for:
  - Figures around places where people are dying in the Vale of York – e.g. in hospital or at home?
  - Funding for St Leonard's Hospice – how is it funded and how much does the CCG fund?
  - How are we going to fund the improvements in care?
  - How much does the CCG fund for hospice at home?
- Look at producing a plain English summary of the strategy
- Action plan is so important