

# Our new end of life care strategy 2019-24

## Engagement report 2019

### Background

NHS Vale of York Clinical Commissioning Group (CCG) and local organisations have developed a new strategy to ensure that patients receive tailored and coordinated care when approaching the end of life.

The 2019-2024 End of Life Care strategy details the collective ambitions for palliative and end of life care in the Vale of York which have been guided by feedback from local communities and NHS England recommendations.

We used the six ambitions for palliative and end of life care to benchmark where we are as a system

- **Each person is seen as an individual**
- **Each person gets fair access to care**
- **Maximising comfort and wellbeing**
- **Care is coordinated**
- **All staff are prepared to care**
- **Each community is prepared to care**

Maximising the comfort and wellbeing of a patient approaching the end of life, taking account of their preferred place of death and ensuring each person gets fair access to care are all detailed within the strategy and explain how health and social care staff and communities will put these into practice.

### Who we have spoken to:

To ensure that we reflect the needs and views of the Vale of York community in 2018 and 2019 we asked local patients and members of the public to share their experiences through a survey. This was sent out through a press release in the local newspaper, stakeholder and voluntary groups, carers.

As part of our commitment to involving our patients and public, we held a number of focus groups and open sessions to share the feedback we have already received and ask for your involvement in creating a set of principles to support the care that is provided to individuals at the end of life.

### Surveys

- Patient & carers groups



## Key themes

- **Availability and quality of carers**
- **Seven day working not fully supported**
- **Out of hours support** for carers and care home managers
- **Respite care:** more needed for carers - especially when there can be long waits for care packages
- **Mental Health support needed**
- **Increase capacity for community support:** Joined up health & social care approach, Death Cafes, Dead Good Festival
- **Improve communication with clinicians:** needs to be easy to understand and respectful
- **Treated as an individual,** respect and dignity
- **Caring for the whole family**
- **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'
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- **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. Should not be called a 'difficult' conversation. It should be an important conversation.
- **Equipment:** Cannot wait weeks for equipment at end of life. Need to think ahead about what they need
- **Dementia and other long term conditions:** Cancer often has all the focus – eg money placed into MacMillan nurses, however dementia is a terminal illness and needs more support, Focus of the money is too much on cancer and not enough on the other long term illnesses and life limiting conditions.
- Massive gap at the moment in support for dementia care
- **Advanced care planning**
- We should all be thinking about care planning. We need a 'death plan' just like a 'birth plan'.
- **Language:** Phraseology and language are really important. You are very ill, does not mean the same as you are going to die
- **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 more well, and then you may want to go into a hospital or hospice towards the end of your illness.
- People need more information about the options and the support you will get in your preferred choice for place of death.

- **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 and Dementia care

## The product of your conversations...

### Our end of life care strategy

End of life care is the total care of a person with an advanced, progressive or incurable illness. End of life care can last a few days, months or years, continuing for however long it is needed. Our vision is for everyone who needs end of life care to have access to high quality, responsive services that meet their needs, at the time and place where they are needed.

[Click here to read our end of life care strategy](#)

### Our citizen's charter

This charter was created in collaboration with our patients, community and their families and local professionals to represent what is most important to you for end of life care.

The citizen's charter sets out for members of the public what they can expect from end of life care in Vale of York in a brief, easy to read document. The charter shows how Vale of York allows them to meet the ideal set out in **Every moment counts – a narrative for person centred coordinated care for people near the end of life.**

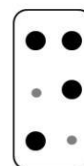
[Click here to read your citizen's charter for end of life care.](#)

## Thank you to all those involved!

### Alternative formats of documents and information

To request information in a different language or format, or for any more information please contact us:

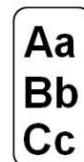
- Phone: 01904 555 870
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