

## End of Life across Dudley – Feeding back what people think

### 1. Background

For some time now, partners across Dudley have been working together to develop a strategy for End of Life Care in Dudley. Partners include Dudley CCG, The Dudley Group NHS Foundation Trust, Dudley Council and Mary Stevens Hospice. The vision for Dudley is:

*All people with palliative and end of life care (EOLC) needs, irrespective of their diagnosis, together with those closest to them, are able to express their needs and wishes; and that as far as clinically appropriate and practically possible, these needs and wishes are met.*

We wanted to test out the strategy so the Communications and Engagement team organised a focus group looking at end of life care.

### 2. Focus group

The focus group took place on Wednesday 16<sup>th</sup> May 2018, 10.30am until 12.30pm. We chose the bar area at Brierley Civic Hall as we wanted somewhere that felt quite relaxed and informal. Invites went out through the CCG mailing list and through social media and the website. 16 participants joined us from a range of backgrounds including social workers, care home staff, general public and NHS staff.



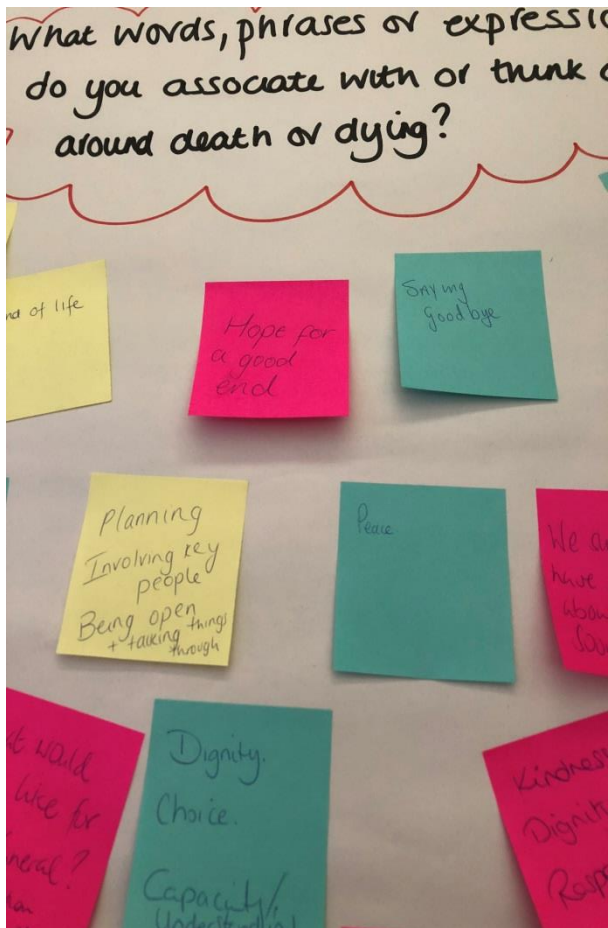
The objectives of the session were:

- To gain an understanding of how EOL works across Dudley and the work/improvements that have taken place so far
- To explore perceptions around death and dying – what words do people use and understand
- To explore perceptions around frequently used terminology

- To develop thoughts around how EOL should be working in Dudley recognising some of the barriers and suggesting solutions and/or innovative ideas

### 3. Activities

On arrival, participants were asked to write down on post it notes any words, phrases or expressions that they associated with death or dying.



How long have I got?  
 Saying goodbye  
 Hope for a good end  
 Loss  
 What matters to me!  
 End of life  
 Death certificate – how many do you need?  
 Peace  
 Last chance  
 Compassion, consideration & concern  
 Kindness, dignity & respect  
 Fright  
 Unfair, inevitable & sad  
 Choice, malignant & final  
 Dignity, choice, capacity & understanding  
 Sadness  
 Challenges  
 Getting things in place  
 Planning and involving key people  
 What would they like for their funeral?  
 Burial/cremation/songs/flowers etc  
 We should have talked about dying sooner  
 Being open and talking things through  
 Peace & sadness

After getting settled into small groups, participants rolled some handmade dice which posed different questions that they had to answer:

- Something that works really well in Dudley
- Why I am here today
- An idea for improving EOL care in Dudley
- What I can bring to today's session
- Something that would surprise others about Dudley
- A challenge for today



Dr Lucy Martin, GP and Cancer & EOL Lead for Dudley CCG then spoke with the group about some of the changes that had taken place across Dudley and the improvements that had been made and the development of the strategy.

#### 4. Postcards - Stories behind the statistics

One of the activities that participants undertook was choosing a postcard from a selection that for them, related to how they felt about or perceived death/dying. The postcards were a really powerful way for participants to express themselves over a complex and emotive question.



'I feel like I am on the scrapheap already but I suppose you could look at it like I'm being recycled.'

'When I die, I want my hair and make up to be perfect and wear fabulous shoes.'

'Playing music helps me get through difficult times and I hope my children learn to play music and that it helps them.'

'I want my dog with me when I die and actually if they (the dog) died, I would be really upset.'

'The peeling paint on the boat means that there are several layers; some great stories and adventures to be told and a legacy left behind. Meanwhile the tide still comes in and out just like life carries on. Sometimes the sea is stormy and sometimes it is tranquil.'

#### 5. Themes

Conversation was really rich and there was plenty of emotion, including tears in the room. Some obvious themes emerged:

**Bereavement** - once the patient had died, it felt like all contact, help and support just stopped 'like being dropped like a hot coal'. Family and relatives were left behind and for some who were left on their own after their loved one had passed away, the sudden lack of contact left a huge and gaping hole. It was perceived by some it was almost better to have a diagnosis of cancer because there were more support mechanisms in place whereas those dying of frailty and other associated illnesses were left a little to get on with it.

**Support** – the value that a sense of community offered was recognised. For example, Muslims have the support of an Imam and that spiritualistic sense of belonging and they believe in their destination. It was felt that spirituality tied in very much with well-being and that improved access to and support from faith groups would be invaluable. There was also conversation around mental health support for both patients and family. Some patients wished to know

how long they had whereas others felt like it was too much responsibility, a burden and affected the ability of people to make the most of their lives. Mental health support was needed for patients and family and there was recognition around peer support groups and what they offered.

**Having conversations earlier** – the group recognised that people needed space to talk about death and it needed to be made 'normal'. It was felt that it was left by many until the very last minute and it wasn't the best time to be talking about details when you're in the middle of coping with dying. Education was also mentioned although there was a balance to be struck. It was felt that parents should talk to children at a young age and there should be support for this. Some, however, felt that targeting children at an age when they were too young could lead to increased anxiety and fear which could be overwhelming

**Relationships and co-ordination of staff** – it was felt that relationships and network between staff could lead to greater co-ordinated care. This would help avoid duplication and a better understanding of what is already in place across Dudley to support staff, patients and families. Training was also mentioned as being essential for staff as the topic was so sensitive. There was a suggestion of using different organisations or groups in the voluntary sector.

**Communication** – the issues around communication underpinned all of the points made. Better communication was needed to improve patient and family experience and help staff too. Some of the terminology used was confusing and misunderstood and sometimes patients and families did not feel able to challenge or query.

## 6. Next steps

Lucy identified that there were some elements missing from the strategy, namely:

- Compassion
- Bereavement
- Humanity
- Kindness
- Spirituality

The strategy would be revisited to reflect this.

Further focus groups have been arranged for later in the year with students from Dudley College.

A Dying Matters work stream is being developed to look at planning for the next year.

Vamos masked theatre have shown an interest in the work and will be attending a focus group as they are interested in researching death and dying for a future performance.