



Good Endings Event Summary

October 2017

The End.

About Us

Healthwatch Leeds is here to help local people get the best out of their local health and care services by bringing their voice to those who plan and deliver services in Leeds.

Introduction:

Nationally and locally we know that people do not always die at a place of their choice. People may also be sent for urgent care when it is not their informed choice. Locally people providing and commissioning end of life care know that uptake is different between different communities and cultures.

Aim of the event:

We worked to bring together and share as many different viewpoints and experiences of what would a good death look like combined with information about what is available in Leeds and an effort to consider how that offer could improve.

Outcomes:

- Local people with an interest, providers and commissioners increase their understanding of what local people want and need.
- Local people and Healthwatch Leeds learn about the options available and share knowledge with their communities and networks.
- Summary of the event is shared widely and influences future planning and provision of end of life services and support.

The Event



About 50 people, a mixture of volunteers and people who provide end of life services and support attended the event. Xina Gooding Broderick, Owner & Funeral Director at Gooding Funeral Services shared her experience of supporting individuals and families from a range of cultural

backgrounds. Xina emphasised the importance of engaging with families and carers as well as patients to understand and deliver person centred care and shared her knowledge of cultural needs in different communities.

We then had a presentation about the range of services, support and choices available in Leeds from the hospital, hospices and community nursing team. The key points were about individuals and families

having options to access support in any setting including their own home.

Staff from Wheatfield's Hospice then delivered a role play about shared understanding and accessible language between relatives and professionals, followed by workshops on both good communication and



best provision of support, information and choice when people know that they are dying.

Key points from the workshops:

- People don't know that being "fast tracked" within 14 days may be

because of suspected cancer. It is important to think of both explanation to patient and think of support available to them.

- Shared summary care record in Leeds should provide a more complete picture of the individual and help professionals to communicate and plan in a more person centred way.
- Many people talk of experiencing "information overload", made more difficult if they are in receipt of bad news. There should be a clear summary document that identifies key links for support, additional information and contacts that patients and families can take away from early appointments.
- People may have other conditions or issues that make accessing print or receiving complex spoken information difficult including physical issues like hearing loss or conditions like dyslexia. Every discussion should begin with a check of information access needs.
- A booklet to be given to the patient with key facts and a telephone number to call back later if the patient has any questions was seen as a good development. The booklets would need to be available in accessible/alternative formats.
- If people fully understand their condition they can make informed choices about their care and next steps, especially if a family member is present to hear the diagnosis too. If a potential for bad news exists, an invitation to bring some one along should be automatic because a person receiving bad news may be in shock and not absorb crucial info.
- Increased awareness of older people's dementia assessment services and how to access them.

- Knowledge on future planning and legal issues e.g. advance decisions and lasting power of attorney.
- Better understanding of different healthcare professional roles.
- Realisation of progression of condition (dementia) and considering options for end of life care.



Afternoon Workshop

“Collecting people’s experiences of end of life care in a meaningful way”.

Background to project

All service providers value the feedback they receive about the care dying patients and their families receive whilst in their care. This helps service providers make improvements in areas where the care has not been at the standard they would like and also enables them to give staff positive feedback about excellent care. In Leeds the hospital has been collecting information through a bereavement survey since 2013 and in the last two years all care providers have undertaken joint work. The subject is difficult and at present the survey is offered to relatives with the death certificate, very soon after the actual bereavement. The afternoon’s workshop looked at the current themes and format of the survey, looking to make it more accessible and flexible in order to maximise feedback about care and services.

People in the groups participated actively and made good suggestions for the improvement of the survey.



5 questions were considered by the workshop groups

Q1: What is important about the care dying patients and their families receive?

Involving families. Compassion and dignity. Pain control. Making contact with families when patients become poorer. Named nurses identifying themselves

Q2: Are there any different issues to consider according to locations? (Hospice, Home/care home, Hospital)

Generally the issues are the same. Decision making. Knowing what's available to support patients and families. Communication with families prior to any transfers between care settings. Clinical knowledge of staff. Having the right information at the right time

Q3: How would you like to feedback areas for improvement and areas of good care?

Not a huge questionnaire. Use a variety of methods including social media. Ask families if they would like to take part and when? The information handed out with the death certificate should promote ability to feedback at a later time. Availability of an interpreter is crucial.

Q4: What are your thoughts about a short draft survey we have shown you asking you only 3 questions?

(From your experience what part of care were good in Hospital/home/care home and hospice. What could work better/be improved? If you could change one thing regarding the care your relative received, what would it be?)

Very good to be short and will improve completion by families. Easy to translate as short. Only focusses on the patients' needs and not the families. Can it be completed online? Good as a starting point and can ask families if they would like to tell us about other facts. To have a variety of contact details on the form.

Q5. What is the best way to share the results of our surveys and what we have done to alter care?

Combination of methods. Summarise the issues and say what we are

doing about them. Use Healthwatch and bereaved carers groups as conduits as well.

Service providers will use this feedback to help design their new survey, with the aim of hearing more from families and also reaching all of the population.

Summary of last years bereavement survey will be available early 2018 and on the Healthwatch Leeds website www.healthwatchleeds.co.uk

Next steps:

- The summary report will be shared and promoted with all health and care commissioners and providers as well as the palliative care network.
- Professionals will be provided with feedback which will be included in training and awareness raising across teams.
- Information provided at present will be reviewed to identify where it can be made more accessible.
- The palliative care teams in Leeds are very grateful for everyone's time at the event and will continue to work with Healthwatch as they make progress with their next survey.

