

## Liz Lees

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**Liz developed a survey to assess retrospectively the level of satisfaction of carers of our palliative care cancer patients relating to the support and care provided across East & North Hertfordshire and West Hertfordshire.**

The aims of the survey were to:

- measure how well carers' needs are met
- ensure that the key elements of the National End of Life Strategy and related standards/frameworks are

being addressed.

- identify any aspects of the carer's experience where services and support can be improved
- share key information with all care providers so that the whole experience for carers is reviewed and the appropriate teams address any areas for improvement
- assess compliance against national end of life (EOL) initiatives.

The survey was initiated by our service user group CANE (Cancer Action East and North Hertfordshire) in 2007. A working party was convened incorporating all providers across Hertfordshire to produce a fifteen page questionnaire. R and D approval was also obtained at this stage.

The survey was personalised with the carers' name, an acknowledgement of the sensitive nature of the questionnaire and a contact number offering further support and discussion. A number of patients did contact the trust on receipt of the questionnaire, many wanted to tell their story, and some wanted additional support.

Despite the difficult nature of the survey the response rate was 31% for the Queen Elizabeth II Hospital in East Hertfordshire and 39% for the Lister Hospital in North Hertfordshire.

All organisations were sent their individual reports in January 2012. All providers were given a copy of the full anonymised report.

A task and finish group was convened to identify and address the higher level issues that affected pathways across Hertfordshire and produce an action plan. The key themes are currently being shared with all providers, GPs, district nurses, Mount Vernon Cancer Network, the end Of life strategy group and commissioners.

**Key themes from pan-Hertfordshire result requiring action:**

- communication, including lack of information, plans of care, discussion between health care professionals
- gaps in service i.e. out of hours
- coordination of care i.e. who to contact, delays in care and lack of continuity.

**Key themes from East and North Hertfordshire NHS Trust:**

- communication to families/carers, both written and verbal
- lack of time by nurses and doctors
- lack of understanding of staff of symptom management
- not achieving preferred place of care
- poor quality of care
- lack of support after death.

**Additional actions in progress:**

- East and North Hertfordshire action plan incorporating updated trust end of life strategy May 2012
- development of a Trust end of life group to address issues and other end of life initiatives
- dissemination across the organisation
- implement AMBER care bundle (for patients in acute hospitals who are at risk of dying in the next one to two months who may still be receiving treatment)
- workforce B education.

If you have any questions about Liz's case study please email Macmillan development manager Sheila Murphy [SMurphy@macmillan.org.uk](mailto:SMurphy@macmillan.org.uk)