

Involving and supporting carers in end of life care in acute hospitals



NCPC is working with the National End of Life Care Programme on a new project to highlight the importance of involving carers in end of life care in acute hospitals.

Whilst many hospitals provide excellent end of life care, some carers describe feeling excluded from the process of care-giving when the person they care for is admitted to hospital. In this project, we hope to show that when carers are fully included and involved, the care provided by acute hospitals to people who are dying can be greatly enhanced, and the experiences of the person who is dying, their family and friends and the hospital staff can all be improved. We will be working with carers and former carers, carers' groups and acute hospital trusts, to produce resources which:

- Encourage and empower carers to stay involved in end of life care in hospitals
- Describe practical ways for professionals and carers to work in partnership to provide the best possible care
- Explore ways for people with personal experience (patients, carers and former carers) to be involved more broadly in evaluating and improving services.

If you are interested in getting involved in this project, please contact Lucy Whitman, Involvement Officer, NCPC L.whitman@ncpc.org.uk 020 7697 1520

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‘Carers are central to the team that cares for somebody at the end of life and they should be treated as “co-workers” with the health and social care team.’

(National End of Life Care Strategy 2008)

I was told I could telephone the ward at any time. My husband needed rest and the staff were very happy for me to sit in the waiting area at any time so he always knew how close I was when they didn’t want visitors in the ward, but most of the time I was by his bed, helping with the nursing and being allowed to continue to care and support him as I have done for many years.

We were in a busy hospital but the family were made to feel comfortable and involved and able to spend time with him as his energy allowed. I was supported by the medical and nursing staff through telephone and face to face contact for the few days we were there, and above all I was with my husband at the end of his life. There is nothing I would wish to have been done differently.

As I grow used to life on my own the incomparable gift I received from the hospital of their unfailing compassion and professionalism is sustaining me tremendously. I am so grateful to them all. I would like to celebrate the service that enabled us to end our time together so gently and well.

Kate Cotton, carer for her husband who had emphysema and fibrosis of the lungs

‘Carers’ needs and ability to cope, including their own health and emotional wellbeing, should be reviewed and discussed at significant stages of the pathway, such as at the point of diagnosis, during treatment, when the illness is advanced and when the likely outcome is death.’

(National End of Life Care Strategy 2008)

NB. We use the term **carers** to describe those providing unpaid/informal support or care for someone who is nearing the end of life. This can include, but is not restricted to, friends, family and partners.