

Dimbleby Marie Curie Cancer Care Research Fund - Project Grant

Project details

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Cascading knowledge about end of life care at home: the development and piloting of a training programme for those who help carers and a carer resource pack

Duration of project: 24 months
Start date: December 2012 (TBC)
Budget: £99,000 (TBC)

Abstract

Caregivers of patients approaching the end of life assume a great responsibility in ensuring that their relative or friend has appropriate care, often carrying out many aspects of care themselves. They often experience substantial difficulties; not least because the experience is likely to be unknown territory. This study seeks to provide an innovative means of addressing these issues by the development and piloting of a training programme for volunteers (who may include experienced or bereaved carers) as well as carer support workers, to enable them to cascade their learning to unpaid carers providing end of life care at home and to whom they provide mentorship and support. An associated resource pack will be developed for carers to enable reflection on their needs and access to relevant information judged as helpful by experienced carers (research partners: see below).

The aims of the project are thus:

- To develop and pilot a training programme for volunteers and support workers who help carers providing home based end of life care. The programme will use the domains of an evidence based carer support need assessment tool (CSNAT) as a framework.
- To develop a resource pack for carers, (including the CSNAT tool) to enable them to identify and prioritise areas of need and facilitate discussion in each individual case of what support is most appropriate.

We will draw on lessons learnt from development of a 'peer' education training programme in advance care planning for volunteers, published in 2011 by the National End of Life Care Programme and the National Council for Palliative Care. In addition, we will draw on our previous research relating to the Carer Support Need Assessment Tool for end of life practice at home (CSNAT), using the 14 items or 'domains' in the tool to structure the training programme. In addition, we will make the CSNAT available as a carer held tool in the associated carer resource pack. We will conduct the study in the Carers Federation Ltd, in East Midlands. We will work with bereaved carer 'research partners' in the project.

The project will last for two years and include four phases of work:

1. Development of core resource pack for carers; training needs analysis among volunteers and support workers;
2. Development of the training programme for volunteers and support workers
3. Piloting of the training programme
4. Revision of the training programme; publishing training programme and resource pack; dissemination