

# RESEARCH DIRECTIONS

## Creating community at end of life

**Dr. Debbie Horsfall and Associate Professor Rosemary Leonard from the Social Justice Social Change Research Centre, together with Kerrie Noonan from HOME Hospice and Cancer Council NSW have been awarded a UWS Research Partnership Program grant to explore if, and how, providing care for the dying at home contributes to the development of social capital.**

'The proposed study will focus on core networks and relationships which potentially undergo transformation as a person is supported to die at home. This transformation can occur as social relations and networks are mobilised to support and help with care-giving. There has been a significant change in the way society cares for its dying since the middle of last century. Today, despite most dying people preferring to remain at home the majority die in institutions and while most of the final year of life is often spent at home most people are admitted to hospital to die', says Dr. Horsfall. 'The most common reasons people are admitted to hospital are `carer breakdown' and `symptom control'. The present research shifts the attention from the needs of the terminally ill person and carer to the affects of caring for a dying person at home on the wider community. In doing so it asks if there are potential benefits for a community in caring for their dying people in their homes.'

Cameras will be given to participants, which include carers and their support networks, to take photos of their lives. This will enable them to express themselves in their own images and tell visual stories. Focus Groups will also be held to discuss the photos and effects on social networks and community building and participants attitudes towards end of life care and dying at home.



The project results will provide new knowledge contributing to a community development, social capital approach to end of life care. This pilot study will lead to the development of a larger national study, in collaboration with Home Hospice and the Cancer Council NSW.

**Project Title:** Bringing our dying home: Creating community at end of life.

**Funding has been set at:** \$10,000

**Contact Details:** [d.horsfall@uws.edu.au](mailto:d.horsfall@uws.edu.au)  
<http://www.uws.edu.au/sjsc>

**March 2009**

**For more information on UWS Research Partnership Program, check:**

[http://www.uws.edu.au/research/ors/funding\\_opportunities/internal\\_research\\_grants](http://www.uws.edu.au/research/ors/funding_opportunities/internal_research_grants)