Study on last years of care

A TEAM of researchers headed by Dr Debbie Horsfall from Western Sydney University will be holding focus groups on the Central Coast as part of a Caring At End Of Life study.

The researchers are encouraging healthcare workers and volunteers to attend the focus group, to be held on March 13.

For more information on the research contact Niki Read on 4736 0368.
ST MARYS

Death with dignity study continues

THE University of Western Sydney is continuing a study of the resources and support systems required to allow more people their wish to die at home, surrounded by friends and family. Dr Debbie Horsfall and her team will hold a series of focus groups in the St Marys and Mt Druitt area. She wants health care workers and volunteers to participate. For more details go to: http://caringatendoflife.wordpress.com/
Time to speak up

Caring for a loved one with a terminal illness at home is an immense task. The University of Western Sydney is continuing a study of the resources and support systems required to allow more people to die at home, surrounded by family.

Lead researcher and Associate Professor Debbie Horsfall, said the next phase of the study would start soon and researchers wanted to speak with people about the experience of providing care and support in a private residence for a terminally ill person.

"If you live in greater western Sydney and work in any field that relates to the support of terminally ill patients and their carers, please contact the UWS researchers and offer your assistance in this important study," she said. Details: 4736 0368 or visit caringatendoflife.wordpress.com.
News on the fly
End of life study
The University of Western Sydney is continuing a study of the resources and support systems that are required to allow more people at the end of their life to have their wish to die at home, surrounded by their friends and family. For more information or to take part call 4736 0368; caringatendoflife.wordpress.com.
End of life a community affair

Initial results from ongoing research show families and friends are adept at providing care, but that doesn’t mean they don’t need support. Darragh O Keeffe reports.

The majority of Australians may spend their final days in hospitals, hospices or residential facilities, but the bulk of end of life care is still delivered in the community.

While 70 per cent of people die in institutions, up to 90 per cent of people with a terminal illness spend most of their final year of life at home, and 80 per cent stating their wish is to die at home.

Further, the average length of community-based palliative care is 119 days – 117 days of which is provided by family and friends.

Despite this, the perception persists in the community that dying at home isn’t an option or that permission must be obtained, said Associate Professor Debbie Horsfall from the School of Social Sciences and Psychology at the University of Western Sydney.

Horsfall is leading a research project looking at the informal and formal supports for people caring for a loved one with a terminal illness at home.

The project’s pilot phase involved focus groups and interviews with 96 participants which focused on their informal supports. It was conducted in conjunction with Home Hospice and Cancer Council NSW.

Those results illustrated that the experience of caring was a transformative one for the individual and the community, Horsfall said.

“People learnt that you could die at home,” she told INSite. “It was very surprising to us that a lot of people thought that you weren’t allowed or someone had to give you permission to do that ... So the popular view is you have to die in a hospital, which is just mind blowing really.”

Horsfall speculated that this may be because dying had been institutionalised and to some extent power had been handed over to experts. “Clearly you need expert intervention and assistance, but anybody can care, anybody can cook, anybody can sit with someone; they’re not specialised tasks,” she said.

There were other key themes that emerged from the discussions with the carers, as set out in the resulting research paper, Bringing our dying home.

Participants articulated clearly that when it comes to caring for a loved one with a terminal illness at home, it takes a community. More specifically, they discussed the importance of having two networks of support – core and outer.

Horsfall admits the notion of two networks of informal support wasn’t one the researchers had anticipated, but it was a persistent one among the
The core network typically consisted of the primary carer, family members and close friends. They could be relied on to provide whatever was needed: emotional support, food. The outer network, made up of other friends and work colleagues, could be called on for other assistance, such as dropping children to school or doing shopping, she explained.

Another theme to emerge centred on the need to avoid social isolation. Participants talked about the importance of technology in facilitating this connectedness, as well as good communication and humour.

Horsfall said participants were very conscious that they risked becoming isolated as they cared for their loved one at home and they actively tried to counter it.

The diversity of caring tasks was another theme to emerge from the focus groups. They discussed the importance of people providing assistance that was needed, as opposed to that which was merely perceived as being helpful.

“Where it worked best was when the people in the core network were able to be quite assertive; to articulate what they did or didn’t need. The diversity of tasks was enormous. There were some pretty clear things that were essential; food was really important for everybody, transport, people to do the shopping, looking after the garden.”

Overall, Horsfall said one of the most pertinent findings was that people in the caring networks typically didn’t see the value of what they had done. She said that one driver behind the research was the need to document the amount of end of life care being provided in the community by informal caring networks.

“It can be a burden if people are left to do this on their own,” says Horsfall. “But if they’re supported to develop a network or use their network then it’s less of a burden. Nobody [in the study] mentioned the word burden. They talked about it being a privilege; there was a lot of joy involved; they talked about love. [That] isn’t spoken about much in the literature,” she said.

To this end, the research paper discussed the lack of current programs or schemes which provide for community development in terms of end of life care.

“Community development approach is about acknowledging there are people already doing this, and they know what they are doing. It’s about how can we support them to do more of it, rather than telling them what to do, which is more of an educational approach,” said Horsfall.

When examining the Home Hospice program, which was a key focus of the pilot phase research, the team found it was an effective model of community development in end of life care (EOL). The program provides a community mentoring program which pairs experienced individuals with people caring for relatives at home. The mentor supports the primary carer in mobilising and developing their networks of support.

For now, the study enters “phase one”, a series of focus groups with healthcare professionals and support organisations. The first focus group took place recently and more are planned in weeks ahead. Unlike the pilot, phase one will examine the relationship between formal and informal care networks in caring for someone dying at home.

“We want to understand the relationship and potential relationship between formal support networks and informal support networks. So when we talk about formal support, it’s not just service providers, it could be support groups, church groups,” explained Horsfall.

Following that, phase two will return to carers and their informal network for further input.

Healthcare professionals in the greater western Sydney, north coast NSW or central coast and south coast ACT regions interested in taking part in the focus groups should go to www.caringatendoflife.wordpress.com. InSite will report on further updates on this research in future issues.
Support for the dying

STUDY INTO
HOW TO DIE
AT HOME

Alexis Carey

A UNIVERSITY of Western Sydney research team is determined to help people achieve their dying wish.

The team is conducting an extensive study of the resources and support systems needed to allow more people to die at home surrounded by friends and family.

The three-year research program is funded by the federal government in partnership with Cancer Council NSW, and will involve focus groups across NSW and the ACT.

UWS associate professor and the project’s chief investigator Debbie Horsfall said the research would improve services and networks to assist the terminally ill and their carers.

“We are interested in looking at how people come together to support people to die at home,” she said.

“We want to hear what works and we are not coming from a negative perspective.

“We are coming from a positive perspective, because most people do want to die at home.”

Research assistant Niki Read said the aim of the project was to talk to people who have cared or are caring for someone who is dying at home, to find out what does and does not work.

“We want to capture what works and share it with others,” she said.

“When there are networks in place, one or two people don’t have to carry the whole thing themselves.”

She said people with experience in caring for the terminally ill were welcome to get in touch to share their experience.

Details: Email n.read@uws.edu.au or call 4736 0368.

Academics Niki Read and Debbie Horsfall are researching people’s final wishes.

Picture: MATT SULLIVAN
End of life a community affair

By Darragh O Keeffe

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Horsfall speculated this may be because dying had been institutionalised and to some extent power had been handed over to experts.

“Where it worked best was when the people in the core network were able to be quite assertive; to articulate what they did or didn’t need. The diversity of tasks was enormous. There were some pretty clear things that were essential; food was really important for everybody, transport, people to do the shopping, looking after the garden,” said Horsfall.

“People thought they weren’t doing anything special. We think that by documenting what people are doing we can encourage, strengthen and support that work,” said Horsfall.

“The danger is when it’s invisible, people do become isolated and it does become a burden. Whereas when we make it visible and we talk about how important it is, it’s less likely to be a burden because people are going to be supported.”

One of the more pertinent findings was people in the caring networks typically did not the value of what they had done, she said.

“People thought they weren’t doing anything special. We think that by documenting what people are doing we can encourage, strengthen and support that work,” said Horsfall.

“The danger is when it’s invisible, people do become isolated and it does become a burden. Whereas when we make it visible and we talk about how important it is, it’s less likely to be a burden because people are going to be supported.”

The paper points out previous research had mainly focused on the burden experienced by people as they care for terminally ill relatives at home.

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this on their own,” said Horsfall. “But if they’re supported to develop a network or use their network then it’s less of a burden. Nobody [in the study] mentioned the word burden. They talked about it being a privilege; there was a lot of joy involved; they talked about love. [That] isn’t spoken about much in the literature,” she said.