Research study: Changing practice for people with memory problems in care homes; developing and testing evidence-based interventions towards the end-of-life: PHASE TWO

SPRING NEWSLETTER 2011

Introduction
This is the first newsletter for Phase 2 of the Evidem End of Life research project. The research team consists of Prof. Claire Goodman, Dr. Elspeth Mathie, Ina Machen, Dr. Sarah Amador (University of Hertfordshire), Dr. Caroline Nicholson (Kings College London), Marion Cowe and Margot Smith-Holmes (Public Involvement in Research group members).

Natasha Baron has now left to work at Cambridge University. The study is due to finish in September 2011.

Study progress
Phase 1: Is complete; the research team collected information from 133 residents’ care notes and medication records held in six care homes, for 12 months. The team also interviewed care home staff, GPs, district nurses and a sample of residents. These interviews discussed how end of life care is provided, residents’ wishes for the future, and where appropriate, their hopes regarding their end of life care. Findings demonstrated that there were opportunities for care home and NHS staff (GPs and District nurses) to work together to improve end of life care for older people. That decision making about what was best for the older person was often not straightforward for people with dementia.

Phase 2: Three care homes and the NHS staff who visit them have agreed to take part in phase two. With the help of care home staff and where appropriate relatives, we have recruited 74 residents. Many thanks to everyone for your help; it has it been invaluable.

Phase two is testing a particular approach to introducing change and building relationships in organisations called Appreciative inquiry. Care home staff and their associated NHS practitioners (i.e. district nurses and GPs) are being asked to identify an area of end of life care that they would like to work on that draws on the findings from phase one. Everyone has committed to
meet regularly to discuss and plan together over the six months and in between the meetings to work together to implement the agreed changes.

**Appreciative Inquiry**

So far we have had two one hour meetings and care home and NHS staff have contributed fully. The meetings included ‘good gossip’ – that is, retelling positive stories about what works well. For example, we have heard stories of joint decision-making, between GPs, care home staff and relatives that enabled a resident to remain in the care home to die in familiar surroundings.

Hearing about examples of good care provided in the care home, what works and what staff can do has proved to be a useful way of using current achievements to inform learning about how to introduce change in the future:

- **Talking about dying with residents and families** (how and when do you bring up this difficult subject?)
- **Out of hours GP checklist** (how to provide sufficient information to Out of Hours GPs so that calls are appropriate and the resident receives the best care possible)
- **Do not attempt resuscitation policy/documentation** (by looking at some recent events surrounding the deaths of residents we have found that wishes of residents have not always been known or if known may not be easy to act on in a moment of acute crisis; for example when paramedics are called).

This study fits with other educational and practice developments that are happening in Hertfordshire and we are hopeful it offers a way of strengthening collaboration between care homes and primary health care services for the long term benefit of residents.

We hope that all staff members have heard about what is happening in your home. If you haven’t ask your manager! It would be great if you could all be involved in improving End of Life care which is often a difficult and really important part of your job.

If you would like more information or would like to talk to us about the study please contact Claire, Elspeth or Sarah (emails below):

- c.goodman@herts.ac.uk
- e.j.mathie@herts.ac.uk
- s.amador@herts.ac.uk

If you would like to know more about the study visit the web site for the EVIDEM research programme: [www.evidem.org.uk](http://www.evidem.org.uk)

Finally, the researchers would like to say a big thank you to all of those that took part in phase one of the study and those who are continuing to take part in Phase 2.