

SEED Newsletter

April 2016

Seeking Excellence in End of life care in Dementia (SEED programme)

The SEED programme aims to support professionals to deliver better quality, community-based end of life care to people with dementia and their families. Our ultimate goal is to look for examples of good practice and see how we can translate these on a wider scale into the real world. We hope to influence both professionals who provide hands on care and also those who commission care.

The programme began in October 2013 and is made up of 6 related streams of work which have separate aims;

1. Mapping current guidance and identifying how good quality care is measured.
2. Exploring how care is currently provided to people with dementia at the end of life.
3. Development of a new intervention to support good quality care.
4. Trial of the new intervention.
5. Evaluation of the intervention.
6. Understanding of how services are commissioned and development of new guidance.

Each workstream has a different start date and duration, with workstream 1 coming to an end, 2 also nearing completion, 3 in its early stages and workstream 6 ongoing. We have made a lot of progress over the past year and would like to share with you the achievements we have made since the March 2015 newsletter.

Workstream 1

This workstream is almost complete and looked at existing guidance for good practice in end of life care in dementia, alongside specific examples of services delivering good end of life care. We also looked at how to measure 'good' quality care, and used a novel Q-sort method to find out what people with dementia and their families think are priorities for end of life care.

What we have achieved:

- Review of guidance and end of life care is complete
- Survey working with National Council for Palliative Care (NCPC) is complete. 15 services responded to the survey
- Q-sort and analysis has been completed with 58 participants including people with dementia, bereaved carers and current carers
- Publication submitted to International Psychogeriatrics

Workstream 2

The focus of this workstream is how care towards and at the end of life for people with dementia is provided; specifically looking at examples of good practice. At the beginning of this workstream we spoke with national experts, service managers and some frontline staff who care for people to seek their views on good practice. We have since spent time observing care work in several services, and talked to family carers, staff and other health professionals to find out more about the care provided at end of life.

What we have achieved:

- We have interviewed 27 family carers of people with dementia, both current and bereaved
- We have carried out 241 hours of observations in 3 care home sites to further explore end of life care
- We have conducted interviews/focus groups with 82 frontline staff and healthcare professionals

Workstream 3

Workstream 3 will use the information gathered in earlier workstreams to develop an intervention to support the provision of good quality end of life care for people with dementia.

What we have achieved:

- 6 workshops with the SEED project team to focus on potential nature and content of the intervention
- 1 workshop with the Patient and Public Involvement (PPI) group to draw on their experience and knowledge with the development of the intervention

Workstream 6

Building on workstream 2, this aspect of the programme is concerned with how end of life care services for people with dementia are commissioned.

What we have achieved

- 20 of interviews with commissioners, CCGs and local authorities
- Narrative review of existing national guidance is ongoing
- Publication in preparation to BMJ Open

Presentations & Publications

Conference presentations:

- MedSoc conference, Newcastle University, November 2014.

- International Psychogeriatric Association (IPA) conference, Brussels, December 2014.
- Seminar Series, Medical Humanities Sheffield, University of Sheffield conference, December 2014
- European Association for Palliative Care (EAPC) conference, Copenhagen, May 2015.
- British Society of Gerontology conference, Newcastle University, July 2015.
- Q-methodology conference, Ancona, September 2015.

Book chapter:

Macdonald, A.S., & Robinson, L. (2015). Care at the end of life: design priorities for people with dementia, In (eds) Y-W. Chen, C. Torro, S. Tanaka, R.J. Howlett & L.C. Jain, InMed 2015: Innovation in Medicine and Healthcare 2015, 45(47), 519-526. Switzerland: Springer International Publishing. ISBN 978-3-319-23023-8

Journal paper:

Lee, R. P., Bamford, C., Exley, C. and Robinson, L. (2015). Expert views on the factors enabling good end of life care for people with dementia: a qualitative study. *BMC Palliative Care*, 14, 32.

Project Team



Sarah Amador



Claire Bamford



Anne Corbett



Cath Exley



Claire Goodman



Zoe Gotts



Karen Harrison-Dening



Sarah Hill



Julian Hughes



Emma McLellan



Richard Lee



Alastair Macdonald



Helen Mason



Angela Mattison



Sandra Neves



Marie Poole



Louise Robinson



Liz Sampson



Sue Tucker



Luke Vale

Further Information

For further information please contact:

PI: Professor Louise Robinson a.l.robinson@ncl.ac.uk

Programme Manager: Mrs Angela Mattison angela.mattison@ncl.ac.uk

Website: <http://research.ncl.ac.uk/seed/>

Funding Provider:



SEED Partner Organisations:

