



Hand out – The Power of Partnership

Summary

Project Aims:

- To scope current patient and public engagement activities (PPE) in Haringey PCT
- To explore ways of engaging with people with dementia and their carers to improve end of life care

Activities:

- Scoping patient and public engagement at Haringey PCT
- Exploration of:
 - o Current local and national practice in PPI with people with dementia and their carers
 - o Models of engagement to empower people with dementia and their carers, provide opportunities to consider their end of life wishes and preferences and inform service planning and delivery.
 - o The use of art as a means of enhancing communication and encouraging reflection on end of life needs and wishes, including a practical artistic session with carers

Key learning points

- This project was pioneering in that it brought together three developing and discrete specialisms:
 - o Patient and Public Engagement
 - o End of life care for people with dementia
 - o The use of art as a means to improve communication
- Artistic methods proved to be successful in enhancing communication and building rapport
- There is scope for the use of artistic activities as part a series of sessions, along the lines of the 'expert patients program' in order to:
 - o Empower patients and carers
 - o Provide a forum for planning care as the condition deteriorates and at end of life
 - o Inform commissioning and development of responsive services for people with dementia at the end of life.

Next steps

- Share the learning from this project
- Carry out a follow on project to develop a structured program for engaging with and empowering people with dementia and their carers to improve end of life care.

More detail

What did we do?

We wanted to explore models of engagement for both people with dementia and their carers. There were two main options within the 3 month time frame:

- a) Review models of patient and public engagement through further research and stakeholder workshops and to recommend next steps for Haringey and
- b) Pilot practical methods for people with dementia. We chose this option.

Process

1. Semi structured interviews with key people e.g. commissioners, dementia care professionals, art therapist, hospice staff, PPI staff, expert patient program organizer exploring their perspectives on the use of art in engaging with people with dementia and their carers.
2. Research into other examples of using art to improve communication with people who have dementia. Meeting with John Killick. References included below.
3. Approached The Grange to gain feedback about potential for “have a go” session. Participants were interested in having a go but a bit nervous about art.
4. Amazing offer from Nigel Hartley to provide services of Marion Tasker to carry out session.
5. Session making silk scarves. Great fun, therapeutic for those involved and a great “leveler” in the conversation.
6. Review of process, planning next steps.

What did we learn?

Art can work – real potential benefits to carers and people with dementia.

If communication is improved, this will have an indirect benefit in empowering them to verbalise preferences.

Knock on effect of being able to inform commissioners and providers about what is needed in dementia care.

What is needed next?

- More research and pilots of artistic methods. What works best?
- How to introduce conversations about end of life care into these environments
- Planning and piloting how the model of engagement would run i.e. how many weeks, who would run it, what else would it incorporate

Ultimate aim

A model of engagement which incorporates:

- Time out for carers
- Empowerment for carers and people with dementia
- Artistic activities to provide an enjoyable activity and aid communication
- Opportunities for carers and people with dementia to explore their wishes and preferences around end of life care
- Structured ways of feeding the learning back to commissioners/people who deliver services

Further reading

Full reports available on www.ncpc.org.uk/users/resources.html and www.ncpc.org.uk/freedownloads.html

McAndrew F (2006) “How all Voices are heard for strategic planning” in Journal of Dementia Care Volume 14 no 3 P22-24

Benson S (2002) *Dementia: Topics for the millennium and beyond* Second edition. Hawker publishers. (Chapter 27 “Hearing the voice of people with dementia” Kate Allan)

Gilfoy K, Knocker S (2009) “Magic across the generations” in Journal of Dementia Care Vol 17 no 3 p22-25

Benson S (2009) “Ladder to the Moon: Interactive theatre in care settings” in Journal of Dementia Care Vol 17 no 4 p20-23

Ashley P (2009) “Valuing the contribution of people with dementia” in Journal of Dementia Care volume 17 no 3 p16-18

Allan K, Killick J (2000) “Undiminished possibility: the arts in dementia care” Journal of Dementia Care volume 8 no 3 p16-18