



The Dementia Engagement  
and Empowerment Project

**DEEP (dementia engagement and empowerment project)** – helping to connect involvement groups of people with dementia

**August 2014**

Dear All,

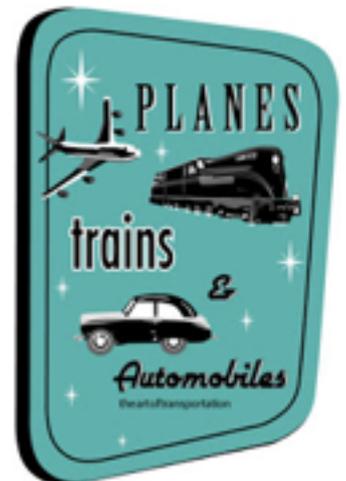
It has been another busy month. It is great that more groups are now sharing their work with the rest of the network. Keep your stories coming in!.

## **Fancy a trip?**

Would your group like to visit another DEEP group - to see how they work and the kind of things they are involved in?

Perhaps you would be interested in sharing with other groups some of your own approaches and successes?

DEEP can cover expenses for group members who wish to make a connection with another group.



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**Think about the kinds of things you would hope to find out from another group. We can then work out which group might be a good match for you.**

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## DEEP networking event in Liverpool

There will be an event for DEEP groups in Liverpool on 24th September. The focus of the event will be around:

- the words used to describe dementia, especially in the media
- a chance to meet the evaluation team who are capturing the work of DEEP

We will be looking at the way dementia is discussed in newspapers and on television, and by other people. Many people say that they don't like words like sufferer, burden, victim - and that dementia is often talked about in negative terms.

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**Date:** Wednesday 24th September 2014

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**Time:** 10.30am for an 11.00am start until 3.15pm

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**Where?** The meeting will be held in Liverpool - venue to be confirmed

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Please let Katrina from the Mental Health Foundation know if members of your group would like to attend the meeting. Email: [KJenkins@mentalhealth.org.uk](mailto:KJenkins@mentalhealth.org.uk)  
**Your expenses will be covered.**

## Meeting on inequalities and dementia

Members of the Peer Support Project in Kensington, Chelsea and Westminster went to a meeting with Public Health England. The meeting discussed how some groups of people with dementia may have more difficulties getting care and support compared to other groups. These are called health inequalities. For example, people with learning disabilities who also have dementia, or people from some Black, Asian or minority ethnic groups often face health inequalities.

Members of the Peer Support Project talked about their experiences of getting care and support. The meeting also discussed how dementia could be legally defined as a disability. This would mean that people with dementia have the right to not be treated differently because they have dementia.

## Dementia Alliance International - a global involvement network



Dementia Alliance International (DAI) is a not for profit group of people with dementia, from the USA, Canada, Australia and other countries. It aims to represent, support and connect people with dementia across the world. Membership of Dementia Action Alliance is open to anyone with dementia.

You can read more about the organisation, and become a member here: <http://www.dementiaallianceinternational.org> or email [info@dementiaallianceinternational.org](mailto:info@dementiaallianceinternational.org)

DAI runs weekly 'Master Classes' by people with dementia. These take place through a computer. You can read more about this process on the DAI website

Date	Time	Class	Teachers
<b>3rd September</b>	6pm UK time	I've just been diagnosed: What's next?	Sue Stephen, Canada Sid Yodowitch, USA
<b>10th September</b>	6pm UK time	My conversation with my doctor	Dave Kramer, USA John Sandblom, USA
<b>17th September</b>	9.30pm UK time	Advocacy and speaking out	Kate Swaffer, Australia Janet Pitts, USA Richard Taylor, USA
<b>24th September</b>	9.30pm UK time	My conversation with my family	Dena Dotson, USA Chris Roberts, UK



- **Forget Me Nots on the radio**

Some members of the Forget Me Nots in Canterbury have been part of a life story writing group. In August the group were featured on the Radio4 programme, 'You and Yours'. You can listen to a segment from this programme by clicking [here](#).

(When OneDrive opens, double-click the 'R4 Forget\_Me\_Nots' file to play.)

- **West Berkshire Empowerment Group**

The West Berkshire Empowerment Group was recently visited by the Information Officer (Legal and Welfare Rights), from the Alzheimer's Society. Sam talked about the Mental Capacity Act and Lasting Powers of Attorney. Members of the West Berkshire Empowerment Group found the session very informative.

**"We all agreed that it is very important to raise these issues—prior to today's discussions I wasn't aware of their significance." (John, a member of the group).**

The Empowerment Group has also been asked by the Alzheimer's Society to comment on aspects of services provided to people living with dementia. Individual group members offered comments about the usefulness and importance of advice and information services following a diagnosis. The group discussed with the Alzheimer's Society the role of a befriender and whether telephone support might also be useful.

- **Scottish Dementia Working Group at Dementia Awareness Conference**

The Scottish Dementia Working group played a large role at this event in June. Their booklet “Core principles for involving people with dementia in research” was launched.



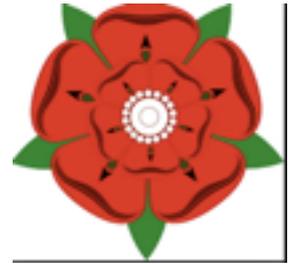
You can read the booklet here: <http://coreprinciplesdementia.wordpress.com>

The IT group also ran a session - members Archie, Brian and Peter shared their experiences of using iPads to stay connected with each other.



After a few technical difficulties and a big cheer from the audience, the session was joined by Nancy McAdam, from Inverness, on the large screen via FaceTime. Nancy told how using the iPad for Face Time to attend meetings has kept her more involved in the group and reduced the need to travel frequently to Glasgow.

- **Lancashire Dementia Voices**



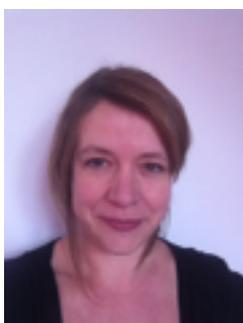
Lancashire Dementia Voices, a new group, has been slowly expanding. They are still waiting for news about funding. This would provide core costs for the group over the next 2 years. Lancashire Dementia Voices have continued to focus their efforts on trying to get directly involved with dementia services in Lancashire and two recent events have help this task become a reality.

- Firstly, a master class of 150 GPs and the Clinical Commissioner from East Lancashire. Alex, a member of the Lancashire Dementia Voices, gave a presentation regarding himself and the new emerging group. A carer also gave a presentation about his own journey. A great deal of interest was raised around the Lancashire Dementia Voices. The group was snowed under with requests to work with clinicians.
- A member of Lancashire Dementia Voices, Pam, took part in the National Institute for Care Excellence Annual Conference. As she could not be there in person, a video was made about her journey with dementia.
- Alex has also been accepted to join the Strategic Clinical Network for Lancashire and Manchester, and South Cumbria Dementia Steering Group. This marked an important partnership involving people with dementia at a senior level in dementia services.

## **Keep in touch**

It is always good to hear from you. And I like to get 'out and about' so feel free to invite me to your group.

Here are my contact details:



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