



The Dementia Engagement  
and Empowerment Project

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

**September 2014**

Dear All

I'm pleased to update you on some of news from across the DEEP network in the last month.

### **Getting your story into the media**



Comic Relief are a joint funder of the DEEP network (with the Joseph Rowntree Foundation).

You have probably heard of **Red Nose Day**: an evening of TV that is about raising money for the good causes that Comic Relief supports. As one of the funded projects, Comic Relief are keen to share stories with the media about DEEP groups. This might be print media, radio or TV. They want to show how people can live well with dementia with the right support.

Would your group be interested in this opportunity to publicise its work? Or maybe you would be happy to share your individual story? A journalist working in the media team at Comic Relief would work with you or your group to write your story in the first instance. We are working with Comic Relief to create guidelines for other journalists about the best ways of engaging with people with dementia.

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**Get in touch if you would like to tell your story to a wider audience**

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## Up to £500 for good ideas!

Does your group have a good idea that would benefit the rest of the DEEP network? Perhaps you have some resources you could share; maybe you have some great learning from a project...



If there is something you think would benefit the rest of the network, but you need a bit of money to produce it, write it up, take photos, record it....then get in touch.

**Remember** - this is about getting your ideas out to the rest of the network. For projects that benefit your own group, read on....

## DEEP involvement grants -round 2

We are pleased to announce the second round of DEEP involvement grants. Last year we were able to support 15 involvement projects with £30,000 worth of funding from Comic Relief and Joseph Rowntree Foundation.

Projects included:

- Buying i-pads so that people with dementia can communicate at a distance
- Making an awareness raising film
- Set up costs for new groups
- Funding travel for psychology students to continue to support a group

We have a further £30,000 to distribute for projects that will run until September 2015. The deadline for applications is **5th December 2014**. The average grant awarded last year was for £2500, but you are able to apply for up to £5000. Information about the involvement grants will be sent in a separate mailing.

## Dementia words matter

The Service User Reference (SURF) Group from Liverpool helped to organise a DEEP day to discuss the words used in the media to talk about dementia.

20 people with dementia identified the words they believe should **never** be used to describe dementia or people with dementia. These are words that have been used in print media over the last couple of years.

These were considered to be '**curl up and die**' words:

- words that make people physically flinch when they hear or read them
- words that send out the message that a life with dementia is not worth living, that people are helpless and have nothing to contribute
- words that are negatively attached to the person rather than the condition of dementia
- words that create stereotypes

### Words to avoid

Dementia sufferer

Demented

Senile or senile dementia

Burden e.g. people are a burden or cause burden

Victim

Plague

Epidemic

Enemy of humanity

Living death e.g. dementia is a living death

People recognised that particular words are used to create a good story and catch the reader's attention. Words can raise awareness about the existence of dementia, create a sense of urgency about the need for research and treatment developments, and increase funding for dementia.

However, people with dementia make a distinction between a) extreme and ‘sensationalist’ language choices and b) language which is accurate in the information it seeks to share.

People with dementia strongly recommend to journalists that they thoughtful about their choice of words rather than lazy! Any evocative words should be chosen with intent and careful consideration of the message that will actually be received – and the impact it may have on people with dementia themselves.

**DEEP guidelines are being produced and will be sent to all regional offices of the BBC.**

## **Dementia Voices website**

Don't forget you can add your own news items and stories to the Dementia Voices website: [www.dementiavoices.org.uk](http://www.dementiavoices.org.uk)

**If your group would like to learn how to add your own content to the website do let us know!**

## **Dementia friendly communities**

The Mental Health Foundation is currently undertaking a project to identify processes and practices in dementia friendly communities, and similar initiatives, across Europe. If you have views and experiences about dementia-friendly communities please complete their online survey by following the link below:  
<https://www.surveymonkey.com/s/JFPJ2DK>

The survey will be available online until the **14<sup>th</sup> November 2014**.

# Your news

## Young Dementia UK (YDUK)

Part of the YDUK aim is to raise awareness of younger people with dementia. The team has recently helped to organise the first conference on this issue for 8 years. The conference was called “A life worth living” and focused on dementia services and support for younger people with dementia. At least 20 people with dementia took part in the conference, as speakers and audience members.

YDUK has also made great progress in creating a specifically planned supported living facility designed for people who are living with young onset dementia..



Some of the groups supported by YDUK are called **Like Minds**

The group, based in Oxfordshire, was started by Jill who said she didn't want a support worker but did want to meet other people. The first group started in Oxford, 18 months ago. Now, there is also a group in Abingdon and Banbury.

The groups meet in cafés or pubs, once a month; partners, supporters or support workers are also welcome to join group members. Guest speakers are sometimes invited and others have visited to consult the group about services or developments that they are proposing.

## **The Cornwall and Isles of Scilly Leadership Group**

The group recently took part in the ‘Decision Making in Dementia’ Survey, a collaborative piece of work between the Department of Health and the Alzheimer’s Society regarding the Mental Capacity Act. Members of the are also working with the Alzheimer’s Society to develop current evaluation processes and also with the Creative Spaces Project. This project aims to reduce isolation for people with dementia who live in rural communities.

## **‘The Cameos’ renamed—Camden Minds**

The Cameos have recently changed their name to Camden Minds, which they felt suited the group much better.

Camden Minds have been working with Age UK Camden to make sure their pamphlets about dementia services are dementia friendly. Camden Minds have also taken part in research with PhD student, Nicole Batsch, from King’s College London. They participated in a focus group to discuss *“living and coping socially in everyday life”*.

The group plan to work with school children to develop a Camden Minds logo and pamphlet. They are also planning to work with a comedian to develop a short stand-up comedy show about living with dementia. Camden Minds feel that comedy is great way to break barriers!

A member of Camden Minds, David, has been collecting weekly news articles about dementia. David has been working with Nada to get an overview of how dementia is described in the national media.

## Making changes to Virgin Atlantic

Virgin Atlantic are working with the Purple Angel Association to give their employees a greater understanding about dementia and how to best support any passengers with the condition. Specially made videos and factsheets are being designed and will soon be available to Virgin Atlantic staff members, through training sessions and via the internet. The Purple Angel was established in 2013 by Norman McNamarra, who is living with early onset dementia. The Purple Angel has quickly become a globally recognised logo. Displaying a Purple Angel sign indicates to customers that staff have an understanding of dementia, which helps to reduce stigma and isolation.



## A new film

The Peer Support Workers in Kensington and Chelsea have been working with the Media team at the Mental Health Foundation to develop a film. In the film, group members talked about their experience of receiving a diagnosis of dementia, as well as how they live well with dementia in their community. They offered tips for how to look after yourself and how being a member of the Peer Support Workers has helped them.

You can watch the film on the Mental Health Foundation website by following the link below:



<http://www.mentalhealth.org.uk/get-involved/your-stories/patricia-story-dementia/>

## **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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