



The Dementia Engagement
and Empowerment Project

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

March 2015

Dear All

I hope you are enjoying the arrival of Spring. Please continue to share your work with the rest of the DEEP network - it is very inspiring for new groups to hear about the range of work taking place.

“Dementia diaries”

In January 2015, On Our Radar launched the ‘Dementia Diaries’ project in partnership with DEEP and Comic Relief. The project is a series of audio diaries, which you can hear at www.dementiadiaries.org



25 people from 5 DEEP groups across the UK have been trained to share their experiences using a simple handset. **This is Gina from the SURF group in Liverpool, with her audio recorder.**

“I just push ‘report’ and everything you need to know comes out”

People can record short audio diary entries and capture their thoughts and experiences as they occur. Each diary entry is automatically sent via the internet to a dedicated team, who listen to it, transcribe it and add it to the Dementia Diaries website.

Ongoing training and support is provided for every participant via the telephone.

“Its a great project, helpful staff - especially when I go into a haze”.

So far, the Dementia Diaries participants have submitted over 450 diary entries. The project has been featured on BBC radio and television, and in national and local newspapers. More than 3.8 million people have seen it on Twitter as well.

Due to this success, we would like to extend the opportunity to take part to 3 or 4 more DEEP groups in the UK. If members of your group would be interested in taking part, please contact **Olivia**:

by telephone on **07814 273 789** or email olivia@onourradar.org

Twitter take over day

On 26th February, Comic Relief gave over their Twitter feed to people with dementia. Many people from the Dementia Diaries project got involved.

If you search Twitter using **.#dementiadiaries** you will see all the discussions that took place on that day.

We will be producing DEEP guidance notes about Twitter.

If your group is interested in beginning to use Twitter, get in touch.

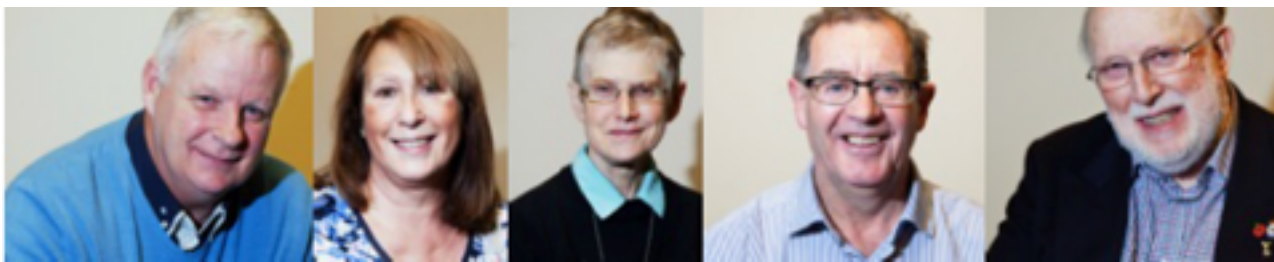
If you want to read Tweets from DEEP groups already using Twitter then you can follow:

@S_D_W_G (this is the Scottish Dementia Working Group)

@EKForgetMeNots (this is the Forget Me Nots from Canterbury)

@SURFLiverpool (this is the SURF group from Liverpool)

A 'Call to Action' about the use of language



“Join our ‘Call to Action’ about the language that is used to describe dementia, particularly in the media”.

This Call to Action is in partnership with the Dementia Action Alliance (DAA). The DAA is a membership organisation. It brings together organisations across England committed to transforming the lives of people with dementia and their carers.

People with dementia are asking the media and all organisations to think carefully about the words they use to talk about dementia. People ask that the words that make you want to ‘curl up and die’ are **never** used. These include

- demented
- sufferer
- senile
- living death

This Call to Action came from the work of DEEP groups, and the DEEP guidelines <http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>

Organisations are being asked to sign up to the 3C’s:

Check the words and descriptions used in your printed materials against the DEEP Guide “Dementia Words Matter”

Change any words and descriptions that people with dementia have identified as ones to avoid

Challenge words which you recognise as ‘*curl up and die*’ words - in newspapers, on TV, on websites and in conferences and meetings.

It would be great if you could promote this Call to Action in your own work. In the summer, we plan to hold an event with journalists and press officers, to start a conversation about language. If your group or organisation would like to 'sign up' to the call to action please visit:

<http://www.dementiaaction.org.uk/dementiawords/signatories>

Let us know of any successes (or issues) you have when challenging language

Join Dementia Research

People with dementia are invited to register for this new service. If you register your interest in taking part in dementia research, you will be matched to suitable research studies. The research might be about genetics, cognitive testing, nutrition, talking therapies, drug trials, life style or questionnaires. The participation of people with dementia, helps researchers to carry out better research.

There is a leaflet included with this update. Or you can visit:

<https://www.joindementiaresearch.nihr.ac.uk>

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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