



**The UK Network of
Dementia Voices**

**DEEP engages and empowers
people living with dementia to
influence services and policies
that affect their lives**

November 2017

Hello

It was great to see so many of you at Congress earlier this month – see page 2 for a lowdown on DEEP’s involvement.



York Minds and Voices were pleased to see their poster displayed there. They said “We were pleased with how clear and simple our poster looked, which reflects the simple thing we are doing - a course for people with dementia delivered by people with dementia as tutors”.

If your group has something they would like to see in the next Update, please contact Paul Thomas, Rachel Niblock or Kate Berry.



In this month’s Update:

network news:

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- Happy 1st Birthday Buddies
- Northern Update from Paul Thomas

have your say:

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Dementia Congress in Doncaster

DEEP groups and people with dementia were very busy at the UK Dementia Congress.

- A film about End of Life discussions opened the whole Congress. This was made with Fabulous Forgetful Friends and EDUCATE members, as well as carers from the TIDE network.
- Wendy from Minds and Voices talked about 'Why being involved is my Sudoku'.
- Elaine from Minds and Voices described the group's involvement in the 'Right to get out and about project'.
- Steve from EDUCATE talked about his role as a Dementia Diarist (see also page 5).
- Nigel, Chris and Jayne from Wales discussed their influence as people with dementia and carers in the development of the first Wales dementia strategy.
- Chris and Chris from east Kent Forget Me Nots had a (very funny!) conversation about the symptoms and impact of Frontotemporal Dementia.

And finally, Wendy, George and Dory were asked to choose a word or a phrase to describe what it means to be involved as part of the DEEP network.

This is what they said:

"...a firework, a disruptor, a headlight, I can, its the future, togetherness"

What word would you use to describe being part of DEEP? Do let us know - email rachael@myid.org.uk or telephone 01392 420076.

Happy 1st Anniversary Buddies!

As The Buddies near their first anniversary, they share this update with us:

We have had a slow but steady build in membership. The Group really values the time spent out with each other. The members are keen to be asked to and involved in events. Ken and Hazel will be checking out how dementia friendly The Belgrade Theatre in Coventry is – we will let you know how they get on. The Fat Pug Pub where we meet each week gets a gold star for being very inclusive. They have been quick to respond to the needs and expectations of the members. Some of the group members hope to support the development of a new group in Southam – watch this space.

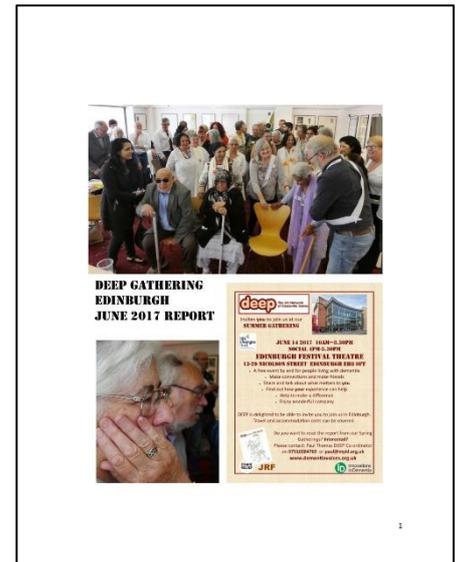


Northern update from Paul Thomas

Scotland

A very big thank you to everybody who helped at the Edinburgh Gathering in June. We had so many positive outcomes as a result of this fantastic event.

There are now 17 active groups in Scotland, and several new projects as a result of grant applications. A big welcome to the Eric Liddell Centre, Impact Arts, Lingo Flamingo, The Portobello Group, Grampian Arts Trust, Evanton Community Woodlands and Life Care Edinburgh. With thanks as well to the Glasgow Film Theatre for their wonderful engagement with DEEP.



The full Scottish Gatherings report is available here: <http://dementiavoices.org.uk/wp-content/uploads/2017/11/DEEP-report-Edinburgh.pdf>, or you can contact me directly for a copy (paul@myid.org.uk).

A couple of other current opportunities you may be interested in:

- **Short notice opportunity #1 - Scotland's 3rd Dementia Strategy**

An important conference is taking place in Edinburgh on 13 December 2017 discussing the implementation of Scotland's 3rd Dementia Strategy.

Attendance fees and expenses can be paid by Life Changes Trust and DEEP if you are interested, though places are running out quickly.

<http://www.holyrood.com/event/implementing-dementia-strategy-2017-2020>. Please contact me if you are interested.

- **Short notice opportunity #2 - Rail Accessibility Competition**

Although the deadline is just days away (30 November 2017) we have been invited in joining with UPSTREAM in submitting a bid to the above fund. You can find out more about this project, which is about improving transport access. If your Scottish Group is interested, please contact me directly.

<https://www.rssb.co.uk/innovation-programme/funding-opportunities/rail-accessibility-competition>.

- **The Scottish Dementia Alumni** are doing fantastic work with their Self-Management Project. They have interview forms available which I can help you access if you are interested.

- **Scottish Universities Insight Institute**

DEEP in Scotland is working with SUII on an interesting gathering on 31 January 2018 in Haddington. If you would like to join us for an active and productive workshop, please contact me for more details.

- **Paths for All**

DEEP has been approached to take part in an exciting day early next year shaping access to open spaces in Scotland. If any group or individual in the DEEP network would like to help me shape and present our contribution, please contact me directly. The date and venue are yet to be confirmed.

<https://www.pathsforall.org.uk/>.

Time to think about next year's gatherings.....

England

- **Care Quality Commission**

DEEP has been approached by the Care Quality Commission to present input into their North East Regional Conference in York on 12 December 2017. They have a budget to cover costs and accommodation. If you would like to work with me to put a presentation to this conference, please contact me directly.

- **Guidelines for Meaningful Participation**

DEEP in Liverpool have been working with the Faculty of Art and Creative Technology to write Guidelines for Meaningful Participation in Co-Production of Creative Opportunities. If your group would like updates and involvement in this project, please let me know. We are also hoping to run a project enabling diversity and cultural inclusion. We would welcome further interest from anywhere in the UK with an interest in Creative and Cultural opportunities.

Northern Ireland

We are hoping to organise a small Gathering in Northern Ireland in early February 2018. There will be a few places available for Scotland and the North of England. If you are interested in joining us please contact me and I will co-ordinate!

Warm regards,

Paul

Dementia Diaries

Dementia Diaries is a UK project funded by Comic Relief and The Big Lottery Fund. It is co-ordinated by Innovations in Dementia and closely aligned with DEEP. By enabling people to talk about their lives to the public, they hope to improve understanding of the diverse experiences of living with dementia.



They are particularly interested in finding individual diarists from BAME, LGBT, Traveller and rural communities. They would also like to encourage DEEP groups to become diarists recording as a group or an individual representing a group. You could even take it in turns to report the activities you are doing.

For further information or to become involved speak to Rachel Niblock (niblock@myid.org.uk) or visit: <http://dementiavoices.org.uk/wp-content/uploads/2017/11/Dementia-Diaries-info.pdf>.

First 2020 Dementia Challenge Citizen's Engagement research survey now live!

Please visit www.opinionresearch.co.uk/dementia2020panel. This survey is for people to complete who have had a diagnosis of dementia and for their carers. They must also be living in England. So please do circulate throughout your networks and encourage as many as possible to take part. This first survey gives people affected directly by dementia the opportunity to share their experiences of diagnosis, care and support and the results will inform the Department of Health in England during the implementation stages of the 2020 Challenge Plan. Four further surveys will be available over the next 18 months.

ALSO ... Is anyone interested in being part of the Dementia 2020 Citizens' Engagement Panel? New members are still being recruited.

If you have any questions about the research or need email or hard copies of questionnaires please contact:

- Claire Thomas at ORS on 01792 535 337 / claire.thomas@ors.org.uk, or
- Daniel Morris at ORS on 01792 535 324 / daniel.morris@ors.org.uk.

Rica

We have been working with Rica (The Research Institute for Consumer Affairs) for several years. Projects involve consumer testing of products and services by people with dementia. This might mean getting people together to discuss a particular service or asking people to test a new piece of equipment. Details of current Rica/DEEP projects (including Bingo to Shakespeare!) can be found here:

<http://www.rica.org.uk/content/dementia-research>.

If you have something of interest to your group that you wish to explore or report on, Rica would like to hear from you. Please contact Gareth Edwards (garethedwards@rica.org.uk).

Rica would like to do this work in January or February 2018 and would ideally visit your group before the end of this year to discuss and begin setting up the work. Rica has money to pay for expenses and costs and a further £500 as a thank you for any DEEP group involved, to help support it's activities.

Research request: early onset dementia and the internet

Alexandra Young from the University of Nottingham is researching how people with early onset dementias, and their families, are using the internet to find and access support and useful information after a diagnosis. For more information visit:

<http://dementivoices.org.uk/wp-content/uploads/2017/11/AY-research-overview.pdf>.

Diary Date: Managing Demand, Improving Care – 5 December 2017, Birmingham

This conference from Open Forum Events will seek to share a greater understanding of the impacts of Dementia and how these affect individuals and their families. The agenda has been designed to explore the Five Year Forward View from NHS on tackling and improving care for those living with Dementia.

For further information visit: <http://www.openforumevents.co.uk/events/2017/dementia-2017-managing-demand-improving-care/>.

How it feels to complete DWP benefit form

I received this letter the other day
I recognised who from straight away.
That thick brown envelope with the form inside
I wanted to run far away and hide.

So many pages, with questions galore
Starting here turning forward to there
At the back of the form and then to the front
This form was designed by one total "PERSON".

So, I started this form on a Monday morning,
After two hours I found myself yawning.
Time for a coffee and a piece of cake
Just enough to keep me awake.

Reaching page six, I became so frustrated
I thru my pen down and felt so deflated.
I put it away for another day, once refreshed
After a sleep and when I'm not so stressed.

Now on day two and with very little sleep
I must carry on and try not to weep.
I know this form must be done quite soon
Oh how I wish I could fly to the moon.

I have several ailments to write in detail,
and at this point I was feeling frail.
I shouted at hubby and then I cried.
Then I slept for a while in my little Hyde.

I wish those people could see us deplete
as we with Dementia try to complete
Those dreadful forms, and how difficult it is
when you're exhausted and your head's in a tizz.

Three emotional moments, some shouting out loud
Many brain in a spin my head in the clouds
Lost sleep, tears, screaming and not fun
Four days later and I'm finally done.

Stress, stress, and more stress. Just what a person with Dementia needs!!

Carol Fordyce is a member of Forget me Nots in Kent and a Dementia Diarist. You can hear her reading this poem on the Dementia Diaries website:

<https://dementiadiaries.org/entry/5805/carol-stress-stress-stress-dwp-stress>.

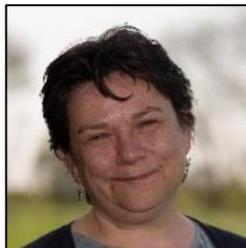
w e l c o m e

Please extend a DEEP welcome to:

- Up and Go (Leeds) <http://dementivoices.org.uk/group/up-and-go-leeds/>

keep in touch

Let us know about your work – it is great to share it through the DEEP Update. Here are the contact details for Rachel, Paul and Kate:



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