



**The UK Network of
Dementia Voices**

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

September 2017

Hello

Welcome back – we hope you’ve had a lovely Summer break and that some of you even managed to find some sun!

Since our last Update, so many new and exciting projects have begun under the new DEEP Involvement and Working Together Grants. Welcome to you all, and we look forward to working with you. A full list of grants and projects will be published on the website.

If you would like to put something about your group or project in the next newsletter please contact Paul Thomas, Rachel Niblock or Kate Berry.

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DEEP Vibes – access and inclusion

Together with the Dementia Action Alliance and Alzheimer's Society, DEEP Vibes (Scarborough) have been working with South Cliff Gardens to see how accessible they are for people living well with dementia.

Initial ideas have included dementia friendly events, memory walks (linking heritage and reminiscing), audio stories for the historic shelters and a sensory garden. We are looking forward to hearing more and seeing photos!

Memory Jar - update

Members of new DEEP group, The Memory Jar, have been enjoying reminiscing at their meetings – we enjoyed being reminded about mini skirts, and mini cars!



To see what they get up to at their meetings, click here:

<http://dementivoices.org.uk/wp-content/uploads/2017/09/Memory-Jar-GEM-10-08-17.pdf>.

The Memory Jar meets twice monthly on the first and third Tuesday of each month.

Creative Health: the Arts for Health and Wellbeing

We mentioned the publication of the Inquiry Report in our July Update. Keith Oliver (The Forget Me Nots, Kent) was part of the group. His role was to be the representative of people with dementia.

You can see an interview between Keith and Lord Howarth, the co-chair of the inquiry, by clicking here: <http://www.artshealthandwellbeing.org.uk/appg-inquiry/>.

New role for DEEP Buddy

Hazel Ratcliffe (Buddy Group, Leamington Spa) has a new role as strategic Project Touring Manager for Vamos Theatre's Dementia and the Arts Project. You can find details of their Autumn Tour here: <https://www.vamostheatre.co.uk/shows/show/finding-joy>.

network support

Post diagnostic course – local opportunities

York Minds and Voices members have this year produced a post diagnostic course for people newly diagnosed. It is very much based upon their own experiences and the messages they wish to pass on to others going through diagnosis.

We are hoping to secure funding for further courses so if you or your fellow DEEP group members would be interested in creating a course locally - that's designing the content, developing the course and delivering the course as tutors - then please do not hesitate to contact Damian for more information and to express your interest (damian@myid.org.uk).

Getting Along survey

Damian from Innovations in Dementia has produced a very short survey on relationships.

We recognize that families, where one person is living with a diagnosis of dementia, spend most of their time NOT in services but at home together. We are seeking to find out the extent to which people feel supported within their closest relationships.

Click the following link to complete the 3 short questions:

<https://www.surveymonkey.co.uk/r/3WH2LPT>.

have your say

Save the Date - CDAN Expert Seminar: Music and Dementia

This free event is due to take place on Monday 20 November 2017 in London.

Speakers and workshops feature some of the UK's leading musicians and professionals. The event also includes John Killick, Dementia Positive, who will be reading from and signing copies of his new book, Poetry and Dementia.

Booking is essential.

Contact admin@creativementia.org for more information.

Research request – book design

Marie Leahy from the University of Reading is looking at ways of improving the layout of texts for people with early stage dementia. If you are interested, click here for more information



<http://dementivoices.org.uk/wp-content/uploads/2017/09/reading-research.pdf>.

The Lancet – dementia friendly toilets

An interesting article spotted in The Lancet online recently:

[http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)31813-5/fulltext?elsca1=etoc](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)31813-5/fulltext?elsca1=etoc).

Service Use Survey - The Angela Project

The University College London and the Universities of Bradford, Northampton and Surrey are working together on a research study called the Angela Project. They want to understand how to improve support for younger people with dementia, families and supporters.

If you live with a diagnosis of dementia, which was received before you reached the age of 65; or if you are related to, or supporting someone with a diagnosis of young onset dementia; you can find out more and complete the survey online by visiting:

<http://dementivoices.org.uk/2017/09/service-use-survey-the-angela-project/>.

Feedback request – Sporting Memories

Comic Relief would like to hear your favourite sporting memories!

We are making a fundraising film about living with dementia and the positive impact of sport. Whether it's England's triumph at the 1981 Ashes or Usain Bolt securing the 100m world record, or maybe even your own personal moment of victory, we need your help.

If you have a favourite memory and would be happy to share it with us on camera we would love to hear from you.

Please email film@comicrelief.com or write to Broadcast Team, Comic Relief, 89 Albert Embankment, Lambeth, London, SE1 7TP. Tell us a bit about yourself, your contact details and what your moment is.

Dementia Action Alliance – from Seldom Heard to Seen and Heard

Dementia Action Alliance members and leaders launched the Seldom Heard Groups Campaign earlier this month.

Members come together to campaign for improved outcomes for people living with dementia and their carers and pledge to take action on seldom heard groups who need care and support including:

- BAME
- Travellers and Gypsies
- Irish
- Learning Disabilities
- LGBT+
- Prisons
- Social Deprivation
- Young Onset Dementia

You can read more and sign the pledge here: http://www.dementiaaction.org.uk/joint_work/dementia_and_seldom_heard_groups.

Rica research update

According to a new report by research charity Rica, taxi and minicab firms would deliver a better service if they showed more sensitivity to the needs of passengers who live with dementia.



The research participants, four members of DEEP group Camden Minds, all have Alzheimer's disease or another type of mild to moderate dementia. All of them travel by taxi or minicab at least once a month.

The DEEP group teamed up with Innovations in Dementia (iD) and Rica to investigate the experience of people with dementia when using taxis and minicabs, as well as how taxi services (both booking a cab and the journey itself) could be improved.

You can read a full copy of the report and find information on other Rica projects here: <http://www.rica.org.uk/content/dementia-research>.

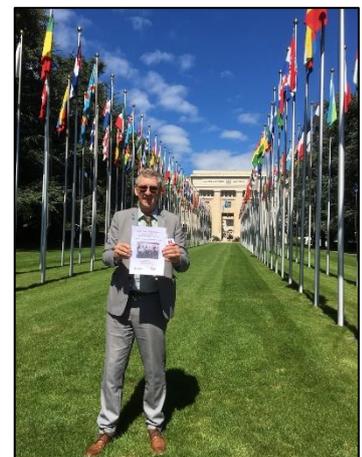
Save the Date - UK Dementia Congress: 7-9 November 2017

We are sure it is in your diaries but don't forget to keep an eye out for DEEP at UK Dementia Congress this November. Check out some of our members speaking at the opening plenary session Wednesday 8 November 2017. Click for more info: <http://dementivoices.org.uk/wp-content/uploads/2017/09/UKDC-Programme.pdf>.

spotted...

A little look at some of the things that have caught our eye this month and the places DEEP groups and people have been spotted recently (for further information, please contact the relevant group/person directly):

- “I realise change takes time, but time is one thing not on our side.” (@WendyPMitchell)
- Our Philly being totally awesome and running an Ultra Marathon for WaterAid (we are rather proud).
- Bradford FIT, Scarborough Deep Vibes and York Mind & Voices meeting and discussing “Our Right to Get Out and About” in Yorkshire.
- Debbie from Fuse and Muse and Teresa Davies (aka Dory) from The Old Brewery in newspaper articles.
- Keith Oliver presenting to the UN Committee in Geneva.
- ‘I Owe Everything to You’ released – a song written by Norms McNamara (Purple Angels, Torquay).
- Rachel N with Peter Berry and George Rook (and a wonderful roomful of nurses) at the Admiral Nurse Forum.
- Our DEEP friend and ally Tommy Dunne being interviewed for Elder – you can see the full article here: <https://www.elder.org/feature/an-interview-with-tommy-dunne-living-with-dementia-not-suffering-from-it/>.
- Great response to Bradford FIT’s film on making buses more accessible: <https://vimeo.com/232792316>.
- Radio 3 scheduling a 6-hour broadcast – living with dementia <http://www.bbc.co.uk/news/entertainment-arts-41095392>.



An open letter written to reach out to others living with dementia

In her message Anne Scott highlights the importance of receiving an early diagnosis and the benefits of becoming involved in Empowerment groups for those recently diagnosed.



To whom it may concern

"People often say there is no point in finding out that you have dementia, there is currently no cure so why bother upsetting yourself or family members by receiving the diagnosis? I think when people make these decisions on other peoples' behalf they forget there is a person like me behind that diagnosis. Yes, it is a terminal illness however there are benefits to knowing. People need to realise that there are medications to slow down the process and to ease the symptoms.

Is it fair to be left to wonder what is wrong with us? I don't believe so. We (the individual's living with the symptoms) need to be given the opportunity to understand what is happening to OUR bodies, to plan for OUR futures, and to also get the most relevant help and support that WE would like, being signposted to the relevant organisations to help us live happy lives.

When I was first diagnosed with Dementia and MS, I researched a lot. Unfortunately, I kept coming up against brick walls, everything seemed to be geared towards people over the age of 65, and nothing seemed to be suitable for my interests or age group. My circumstances were so different to someone of the 'stereotypical' retirement age that you would presume only get dementia. People who develop dementia at my age (49), may like myself have young children, a mortgage, hold down a full-time job and have a whole range of different circumstances. After a while searching I resolved myself to the fact that there was no help or support out there for anyone like me. It was a very depressing time, I felt ostracised from society and lost as to what would happen to me."

Then when two years later my daughter won the MS Young Carer of the Year award, I was put in contact with Dementia NI who offered me help and support. The relief that there were people willing to help and understand me was so overwhelming that

I broke down to tears. They were sad and happy tears; my emotions were all over the place. I just couldn't believe after two years trying to cope on my own that someone did want to help. I wasn't alone anymore and that was such a fantastic feeling.

Dementia NI is an organisation that was set up by people who are living with dementia. People who knew EXACTLY what I was going through and knew what it felt like to have dementia - because they have it too. We regularly hold group meetings which enables us to meet and share our stories with others in a similar situation and support each other. This understanding is why Dementia NI is so important to me. Being around other people who also believe that life doesn't end after a diagnosis of dementia is very uplifting. Dementia NI have members of all ages but with one thing in common, we all live with a type of dementia.”

Anne Scott is a member of the Dementia NI group. You can read the full article and letter here: <http://www.dementiani.org/woman-with-dementia-pens-open-letter-to-reach-out-to-others-living-with-condition>.

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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