



**The UK Network of
Dementia Voices**

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

January 2017

Happy New Year and welcome to the first DEEP Update of 2017.

From Countryfile to Emmerdale with radio, TV and broadsheets in between, we have seen dementia talked about and portrayed more than ever in mainstream media.

What are your views on how this is done – do you generally see this as a positive step? How do you feel about the language used? Share your thoughts in next month's Update.

You might like to read more about the Dementia Words Matter call to action - led jointly by DEEP and the DAA (#dementiawords). We included this in last month's Update <http://dementiaaction.org.uk/dementiawords>.

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The Buddy Group - we did it!

The Buddy Group in Leamington Spa proudly had their first meeting this month at The Fat Pug Pub on Rugby Road.

Initial comments were: terrifying, nice, good company, interesting, diverse, comfortable, interesting and hilarious!

Photo shows Ken, Sue, Charles, John, Jill and Hazel.



Lifting the Cloud – thumbs up to Derby Royal Hospital

Following a problematic admission, stay and discharge, members of Lifting the Cloud DEEP group attended the Derby Royal Hospital Dementia Support Workers Induction Training.

Dai (a patient with dementia) and Glenda (his carer) intended sharing the problems and obstacles they had faced hoping to help improve the overall patient experience.

The Support Worker group were receptive, interested to listen to Glenda and Dai's experience, asked pertinent questions, listened to suggestions and pledged to use good practice in their own practice.



A subsequent hospital admission was a very different experience for Dai (and Glenda). Well done and thank you DRH.

Laverstock Memory Support Group

The Laverstock Support Group is an experiential memory support group for people living with dementia. The group is funded by Wiltshire Council and meets in Laverstock, Salisbury. A separate carer's group runs parallel to the main group.

Find out more about them and see their latest newsletter here:

<http://dementivoices.org.uk/group/the-laverstock-support-group/>

Changes at Innovations in Dementia CIC



After 10 years, Nada has decided that it is time to leave Innovations in Dementia and move onto new things.

Nada set up Innovations with Rachael in 2007. She has been the life and soul of the organisation ever since. You will probably know her for her huge smile and warm heart. We can't imagine what it is going to be like without her.

Nada has contributed so much to Innovations in Dementia. These are just a few of her highlights:

- her early work was focused on making computers and technologies accessible to people with dementia. She involved people with dementia in some really interesting projects including helping developing the AT website <https://www.atdementia.org.uk>.
- Nada and Steve worked on our ideas to make the world more accessible for people with dementia. They called this 'Start Making Sense'. This turned into guidance for the Local Government Organisation on building "dementia friendly communities", which we have seen grow in leaps and bounds ever since.
- Nada's enthusiasm and commitment to involving people with dementia helped us to set up the DEEP programme. She is a well known face at DEEP groups, and has involved people with dementia in a range of interesting projects www.dementiavoices.org.uk.
- The Women and Dementia project was initiated by Nada. This project has considered the experiences of women affected by dementia <http://www.dementiawomen.org.uk>.
- Nada has also strengthened our links with universities and research. She has worked with York University looking at Life Stories with people with dementia, and at women and dementia, and with Exeter University on the IDEAL project.

We are hopeful that there will be pieces of work that Nada will come back and work with us on. So I'm sure many of you will still see her around.

Welsh Dementia Strategy collaboration between AS Cymru and DEEP

As well as all the work highlighted in the [‘Wales Dementia Strategy: a starter for ten’](#) blog, Alzheimer’s Society in Wales have been working in collaboration with DEEP to ensure people affected by dementia have a voice in the development of the Wales Dementia Strategy.

To read more about the collaboration, click: [Welsh Dementia Strategy collaboration with DEEP.](#)

If you have any feedback or questions contact Rachel Niblock (niblock@myid.org.uk).

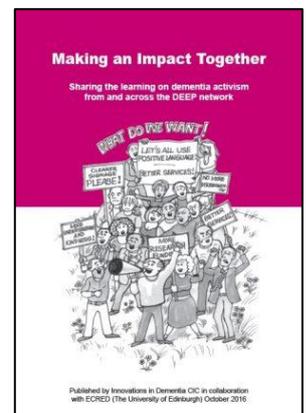
Making an Impact Together

Most of you will have received five hard copies of our new publication 'Making an Impact Together' by post.

This guide has been produced by several of the DEEP groups working together over a period of time.

We hope you find it interesting and useful - do give us feedback if you can. You can also download the pdf for free at:

<http://dementiawithoutwalls.org.uk/thinking-differently-about-dementia/engagement/>



have your say...

Museums for people with dementia

Museums in Ripon and Harrogate are hosting a series of free activities for people with dementia, their families and carers. They are open to anyone living with dementia, whether they have a particular interest in art and history, want to have a go at something new such as rag-rugging, print making or pottery.

For more information about dates and venues, contact Wendy Hunwick-Brown on 01765-690799 or email wendy.hunwick-brown@riponmuseums.co.uk.

Do let us know how you get on if you visit one of these museums or any other dementia friendly venue/event (see also DF Picturehouse Screenings on page 5).

Dementia Friendly Picturehouse screenings



Picturehouse have introduced Dementia Friendly screenings to 20 of their cinemas across the country, with the aim of making cinema more accessible to local dementia communities.

Dementia Friendly screenings seek to provide a fun and inclusive experience to enable people living with dementia, their families and carers to attend the cinema in a safe and welcoming environment.

You can read their full press release here: <http://dementiavoices.org.uk/wp-content/uploads/2017/01/DF-Picturehouse-PR-Dec-16.pdf>.

New DRI Director announced

Bart De Strooper, from the University of Leuven in Belgium, has been appointed as the director of the new Dementia Research Institute (DRI). The Institute's 'Hub' will be based at University College London (UCL) which will link closely to a number of yet to be announced centres across the UK.

You can read a blog here: '[Creating a culture of involvement for the UK Dementia Research Institute](#)' to hear from those who took part in the panel.

Emmerdale Farm

Did you see the special Emmerdale episode in December offering a unique insight into how Ashley – a person with dementia – now sees and experiences the world?

What did you think of it?



Alzheimers Research UK Christmas advert

Did you see the Christmas advert from Alzheimers Research UK where Father Christmas has stopped visiting youngsters on Christmas Eve because he has dementia? What are your thoughts?

<http://www.telegraph.co.uk/science/2016/11/16/father-christmas-gets-dementia-in-alzheimers-research-uk-advert/>.

Please Hear What I'm Not Saying – a poem

Paul Wiggins' recital of a poem evoking emotions displayed by the carer and the cared for has been used in a Derbyshire NHS Trust resource video.



You can find out more at:

<https://www.youtube.com/watch?v=XYLV7Tgbv8w&feature=youtu.be>.

Norrms – a short film

Norman McNamara would like to share a short film with you – telling his story and his vision for a dementia friendly world.

http://livingwithalz.org/user_submitted_film/norrms/

Unlocking Dementia - a play

Commissioned by Doncaster Council and Doncaster Clinical Commissioning Group, Unlocking Dementia is an interactive show based on real experiences of people in Doncaster living with dementia.

The play has been performed all over Doncaster in workplaces, doctors surgeries, residential care homes, libraries and other community spaces and aims to show some of the small things we can all do to help people with dementia.

A copy of the film, full report and findings from the 2016 tour can be downloaded from <http://www.thepoint.org.uk/article/unlocking-dementia>.

Young Dementia UK's new film

Eight people living with young onset dementia discuss support and the impact it has on their lives in Young Dementia UK's new film.

Click the link below to see the film and what types of support the people interviewed benefit from, what it enables them to do and why it is #simplylifegiving.



<https://www.youtube.com/watch?v=KXSrfKe-c1s>

Feedback request – independence enabling equipment

Diana is setting up a new DEEP group in Wrexham and has asked for ideas for independence enabling equipment:

In 2003 I was able to buy simple items like day date clocks, dry wipe boards, memo minders, automatic lights, Buddies and more which all remain staples of our equipment for people living with dementia and other conditions. We now use MemRabel 2, talking myhomehelper and more. I have found some really simple Dictaphones, a voice activated telephone dialler, a simple music player, near field communication badges .

Does anyone have any ideas for items that would make life better? I'd like to find a good easy to use walking Sat Nav (one or two step use only).

Please contact Rachel Niblock in the first instance (niblock@myid.org.uk) who will forward your replies.

Games for Dementia

Do you play any games that help with symptoms of dementia? Or do you do any activities that help you socialise, communicate or learn new things?

Ben Hicks is a researcher at the University of Bournemouth. He is developing some technology around games for people with dementia.

You can email Ben on bhicks@bournemouth.ac.uk.

First Taste Charity – Resources for those with Dementia

First Taste have asked that we share their website with you where you can purchase resources for people with dementia. These resources include:

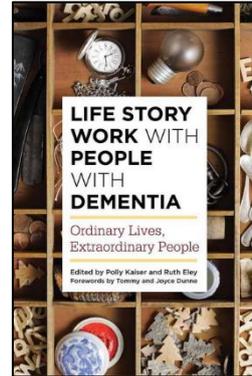
- DVDS (Where'er you walk and Food for Thought) to help with reminiscence work.
- CDs (Even More Music to Move and Yet More Music to Move) specifically produced to support chair based exercise.

Visit www.firsttastecharity.co.uk for more information or to order.

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):

- Daffodils in January
- A Recipe for Reciprocity
- Emmerdale Farm
- Countryfile
- Dementia and it's impact on farming families
- A poem and a play (see page 6)
- Hashtags #simplylifegiving #dementiawords
- Dementia Pooh-isms #winniethepoohday
- Dementia on the ITV This Morning sofa (again)
- A new book – Life Story Work for People with Dementia, Ordinary Lives, Ordinary People
- Random Acts of Kindness and a Princess (Dementia Diaries)



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 and Paul:

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