October/November 2019

Our deep News

The Newsletter from the UK Network of Dementia Voices

Together we are strong...

Together

It's a tough life out there and we need to pull our allies around us

I came to the group crying and I left laughing



Take the time to watch the sunset
you don't know what tomorrow holds
don't give up, keep on smiling
and your dreams could turn to gold
when you're feeling kind of low
and you want to moan and groan
look for what we have in common
before too low.

Clear Voices, Bedford



Real Lives event Dementia NI



York Minds & Voices Shrewsbury Riversiders

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Group facilitators – peer support

Group facilitators in the DEEP network

Facilitators of groups may be a professional or a volunteer. Many groups are also facilitated by people living with dementia.



Sometimes groups face joyous moments to be shared as well as some difficult challenges. We have talked about a few DEEP dilemmas in the past and the network came up with some solutions.

We wanted to find out more about how facilitators could have the opportunity to work together to find solutions.

So, a virtual peer support pilot project was led by Dr Jane Rowley from Trent Dementia to discuss the support needs of DEEP facilitators. They also tested the virtual meeting space of ZOOM.

The zoom facilitators meetings were used to discuss ways of supporting, sharing and learning from each other.



The groups (or host organisations of groups) who took part in the pilot were: DEEP in Deeside, Nottingham's 'Friends for Life – Ey Up Me Duck'. Beth Johnson Foundation, Kindred Spirits – Alzheimer's Support. YODA, Kent and Medway NHS and Social Care Partnership Trust, Together Dementia Support, York Minds & Voices, For Brian CiC and Dandelion CiC.

To find out more please go to the reports section on the DEEP Website where you will find the complete summary and a supporting film.

DEEP Facilitators virtual peer support will begin on Wednesday 20th November with a lunchtime and an evening session.

We will run the meetings on the 3rd Wednesday of every month.

There will be:

- one session at 12.30pm for one hour

or

- second session will be at 7.00pm for one hour

The Zoom link to the meetings will be emailed to you, once you register interest by emailing **Niblock@myid.org.uk**

Meet a group in the DEEP network

The Zoomettes



The Zoomettes is a virtual group in the DEEP Network for women with dementia. It uses ZOOM to connect women from across the UK. The group offers a safe space for ten women with dementia to meet up for friendship and support.

The pilot project ran for 12 weeks with a working together grant between York Minds and Voices and DEEP in East Sussex.

The group is facilitated by Anna Harrison and Aimee Day.

The aim of the group has been to connect women who had little, or no, access to support in their area.

We have coproduced a guide for using ZOOM.

The zoom guide and film will be available on the DEEP website's resources page.



We plan to:

- raise funds and to continue with Zoomettes.
- explore extending and developing the reach of The Zoomettes type of group.

> Technology working at its best to bring people closer and **no longer alone**.

> Zoomettes offers me the **ONLY lifeline** of speaking with other women with the same condition.

> Thank you for being my lifeline and **lifesaver**.

> For me the most important part of Zoomettes is the feeling of being in a **'family'** of friends who understand each other.

> **I love the group** because I don't feel like I'm on my own with some of the things I have trouble with. There is always someone who has the same problem.

> We identified a need and found our solution – we called the solution The Zoomettes. It's worked. I've found a **safe space** once a week to be amongst my tribe The Zoomettes. Long may we survive!

Regional Updates – What are we doing?
Share 'Our Voices' in 'Our Deep Newsletter'

Dementia Enquirers

> To be part of the driving seat/co-pilots in a time when, after many years, our voices are finally being heard.

Tommy Dunne from **DEEP THRED** writes:

"We are fast approaching the season of goodwill. We would like to appeal to all members of the DEEP network to come on a journey with us. We hope it will help prevent social isolation.



Paul Hitchmough, Pat Broster and I have set up a group called THRED. We would like to invite all of you to be part of this group. It doesn't matter where you live.

We are currently looking at transport and how it can affect you by not being able to get out and about.

Working together will allow us to gather and analyse information which has been gathered by the people affected and involved. We think this is a unique opportunity for all of us living with dementia to have control over things that affect us. It will give us the opportunity to come up with some solutions.

It's a well-known fact that freedom to get out and about can be beneficial to wellbeing. We can prevent people from being isolated by the provision of a transport system that meets the needs of us all. We need to put a stop to this epidemic of loneliness. This is not only to improve our quality of life. We also must save thousands from reaching crisis point where people are admitted to hospital unnecessarily or care homes early.

It would be great to gather some creative ideas about transport. For example: lift shares, volunteer driver schemes – what do you think?"

DEEP THRED will be:

- setting up a Zoom meeting to talk
- arranging to visit you and discuss exactly how we can work together

THRED
Transport
Health
Research
Economy
Dementia

If your group, or you are interested please contact:
Tommy Dunne **tommy.dunne2017@hotmail.com** or
Pat Broster **phbroster18@hotmail.co.uk**

Regional Updates – What are we doing?
Share 'Our Voices' in 'Our Deep Newsletter'

'Ferry cross the Mersey'

SURF Liverpool are working on a guide for people living with dementia who may visit Liverpool. They hope that this guide will provide practical tips to make a stay straight forward and enjoyable.

It covers areas:

- Arriving in Liverpool
- Getting help
- Food, drink and nightlife
- Top tips for visiting Liverpool

Each section provides practical hints and tips to support your visit.



The famous Liver Birds

Does your town or city need a guide like this? The members of SURF brought wonderful knowledge to this project.

It was wonderful to spend time exploring some of our city's finest places and a lot of fun!

When we were on the Mersey ferry one man looked very thoughtful – he said that he had done this as a child, and it brought back so many happy memories for him.

"If I lived in another part of the UK and was visiting Liverpool with friends/family to have a travel guide available which took into account that I had dementia covering the content (dementia friendly) of all major aspects of the city it would be a very useful tool in my pocket" Roy Foden



Ferry cross the Mersey

Date for the diary in Wales:

Sharing a diagnosis of dementia:

Guidance for clinicians

Tuesday 12th November 2019

12.30PM - 1.30PM

Committee Room 4, Ty Hywel, Cardiff Bay.

"**Trust has to be developed between us and the clinician**"

The Kymin Group

The official launch of the Kymin Service User Group's Guidance for clinicians.

The leaflet has been written by people living with dementia who are members of the Kymin Group and DEEP Network.

See the Kymin group page **https://bit.ly/31XvOtz** to see the leaflet.

Regional Updates – What are we doing?
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Official unfurling on banners! – A grand occasion

Date for the diary in Kirklees:

When: Friday 22nd November at 1.00 pm at the Brian Jackson Centre

How: Contact terryann.shaw@kirklees.gov.uk for further details

There will be tea and cake!

The Kirklees DEEP group have been working on creating two banners to explore the ways people have found of coping and living well with dementia.

The group decided to focus their banners and poetry around the difficulty of accessing services and knowing what is available at diagnosis.



Work in progress
Ian Beesley

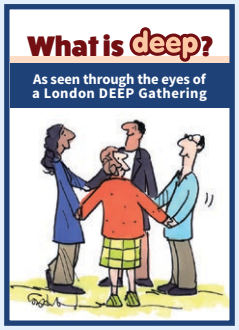
There is also a representation of a 'what good looks like' banner.

We have been really lucky to work with artist Ian Beesley, poet Ian McMillan and cartoonist Tony Husband.

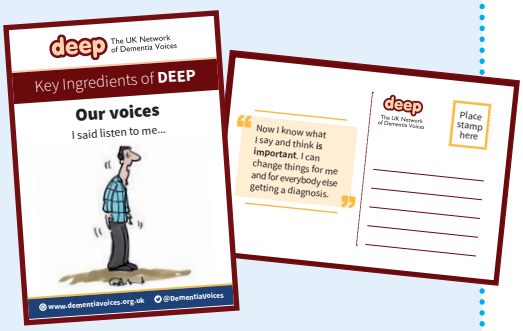
Banners and poems from the Kirklees and other groups will be displayed at the People's Museum of Manchester with a launch on **16th December 2019** – please contact **Niblock@myid.org.uk** if you are interested in going.

We've had a second print run of 'What is DEEP'

If you would like another copy (or more) please get in touch with us.



We have also a limited print run of six of the **Key Ingredients postcards** – first come first served!



Melvyn from East Kent Forget me Nots talks about his group and 'A Friendly Face' in Wales



Hello, it's Melvyn here. I would like to say we've got a project going at the Forget me Nots; there is five of us in our group that have formed a committee that is going to shape how dementia is in care homes and in hospitals. I will never see the end of it in my lifetime, but we've made a start and we will be asking for help. I don't really want to say a lot more, but it is definite that we will be asking for help through every group in DEEP for help with this project. We will be sending every MP, when we finally get an election, probably Christmas and hopefully not before. We will be writing to all MPs as the Lords because most MPs do not take any notice of us. We have a voice and one voice in DEEP hopefully will be the ginormous part of our project because it would be so many people involved that they won't know what hit them, so the project is going to be something fantastic.

I would like to say that Friendly Faces in Wales, it's fantastic, and I'm going to phone up to speak to someone tomorrow, fantastic and well wow-wee, I really love that, being able to phone up, just to talk to someone else with dementia from different parts of the country, well in Wales and I'm looking forward to it and that's where our strength will come when we join as one. So, I will be phoning these people up and having a good chat. It's a really good fantastic idea. Fantastic.

Date for the diary in Scotland:

Dementia Friendly East Lothian Gathering

When: Tuesday 26th November 10am – 3.00pm

Where: The Maitlandfield House Hotel, Haddington

Dementia friendly EAST LOTHIAN
Curious | Connected | Active

How register on **www.eventbrite.co.uk** and search dementia friendly East Lothian or call: **07727 883881**

Catch up with friends, share projects and passions and change the world.

Closing thoughts

A poem that came out of the launch event of a new group 'Like-Minded' in Brecon by Wendy Mitchell

Raucous laughter
Hugs galore
Greetings like old friends
Sad no more
Talking about anything
Personal, this and that
Sharing secrets
Amongst the chat
No need for Time
To kindle this friendship
An instant bond
Our very own kinship
Who are these people
These three dear friends
not long ago they were strangers
Now dementia has brought them
together like contented bookends



Next Month!

- More Working Together Grant feedback
- Capturing a 'Moment in Time'
- The future – funding for DEEP

Share our news...

...get in touch with your news, stories and images. You can:

- Post them to: **PO Box 616, Exeter EX1 9JB**
- Email them to **Niblock@myid.org.uk**
- Telephone them to **07720 538851** or if you are a **Dementia Diarist you can record your news item there.**



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www.dementiavoices.org.uk **@DementiaVoices**

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