



**The UK Network of
Dementia Voices**

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

October 2017

Hello

This month we say hello and welcome to new DEEP group Going Forward from Cwmbran – we hope to hear more from them in the coming months. We also say hello and welcome back to Lancashire Dementia Community (previously Lancashire Dementia Voices). You can read more about their new name and mission on page 3.

Keep an eye out for DEEP friends and allies at Congress next month and send us your feedback and photos. We spotted Wendy Mitchell (York Minds and Voices) and Philly Hare auditing Doncaster Race Course specifically for the event.

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.



In this month's Update:

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UN/Think Tank Update

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Think Tank – United Nations Update

On behalf of Dementia Policy Think Tank, Keith Oliver presented to the United Nations Committee on the Rights of People with Disabilities.

Keith is the first person with dementia ever to do this.

Keith presented a report co-written by him and seven others living with dementia, which can be found at

http://dementivoices.org.uk/wp-content/uploads/2017/07/Our-Lived-Experience-270717_1.pdf.

He also had a private interview with the Rapporteur, who conveyed to us his view that, although the UK has the legislation to address the rights and needs of people living with dementia, the government is not doing enough to ensure it is correctly implemented.

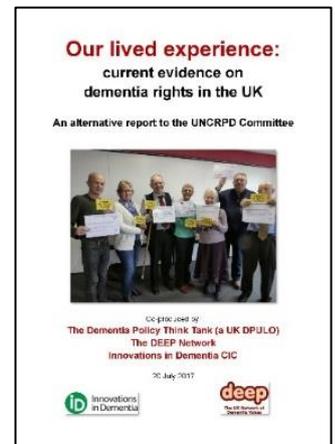
Keith and Philly Hare (who supported Keith with his wife Rosemary) have written an article about their experiences. This will be published in the next edition of the Journal of Dementia Care.

You can download a copy of the report here:

<http://dementivoices.org.uk/2017/07/taking-our-views-to-the-united-nations/>.

Keith talks about the impact and success of the mission (as he calls it) in this Dementia Diaries article:

<https://dementiadiaries.org/entry/5087/reporting-back-after-the-un-committee-on-rights-of-persons-with-disabilities>.



Dementia Travel Insurance

Keith and Rosemary researched travel insurance for their recent trip to Geneva.

They highly recommend All Clear – insurance specialists for people with pre-existing medical conditions. You can find out more here: <https://www.allcleartravel.co.uk/travel-insurance/dementia/>.

Lancashire Dementia Community

Lancashire Dementia Voices has a new name and a new mission building on its strong local and national links.

The group sadly lost some of its members in 2016 resulting in the closure of the group. During its previous operations however, it became self-evident that although Lancashire is a large county, it is mainly rural. Unfortunately this results in many dementia services and support not reaching these communities.

As it has no offices or paid staff, the groups' volunteers will be moving around the county with various roadshows. They aim to bring friendly support to those who sadly do not have a voice but from people who know what it's like to live with the condition first hand. Built on solid foundations and understanding from its previous work, the group hopes to provide this rural service in the coming months.

You can find out more at www.lancshiredementiacommunity.org.

If you have positive or negative experiences of engagement with and supporting rural communities please do let us know (steve@myid.org.uk).

'New Dementia': Widening choices for our future support

Members of Dementia Alumni and The Scottish Dementia Working Group have taken part in co-producing a briefing paper called The 'New Dementia': Widening Choices for our Future Support. The paper was presented to a mixed audience of influencers in September at the Festival Theatre, Edinburgh.



The paper aims to start a new conversation about the choices open to people with dementia who may no longer be able to live in their own homes. Discussion was stimulated by presentations on small group models in Canada, Japan and Australia.

The hopes, fears and reflections of the group focused on:

- Making decisions – and needing support to do so
- Choice
- Informality
- Freedom and risk
- Physical space and opportunities for quiet
- Who schemes are for
- End-of-life care

This project raises questions and challenges that we would like those in a position of influence to consider. These include:

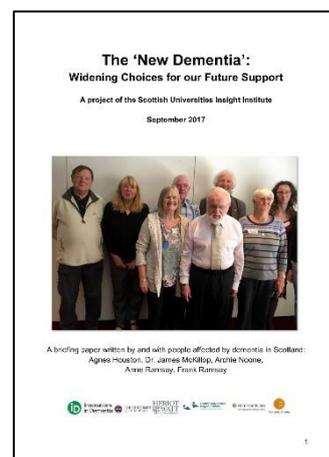
- How can choice and decision-making be supported?
- How can we understand better the priorities and aspirations of people living with dementia, and also of their families?
- How can planning for the future help us to meet these aspirations?

Feedback included:

- "These examples from overseas help to show what we could aspire to in this country. But would we accept the cost?"
- "But can we afford not to change things? The cost to the 'human element' could be more in the long run if we don't. If it's not working, let's look through a different prism. We need choice."

Click here for a copy of the paper:

https://www.ed.ac.uk/files/atoms/files/widening_choices_suii_report_final.compressed.pdf.



have your say

Keeping the Action Going

Damian Murphy wrote about asset based working in this month's York DAA newsletter – you can read the full newsletter here: <http://mailchi.mp/yorkcvs/york-dementia-action-alliance-october-newsletter>.

Diary Date: National Disabled People's Summit - 4 November 2017, London

The summit will bring together Deaf and Disabled people from the trade union movement, Deaf and Disabled People's Organisations and grassroots campaigns. It will explore how to effectively co-ordinate campaigning in identified areas. The event will largely be workshop based. The idea of the Summit is to inspire concrete activity that will lead to real change. Click here for further information:

<http://dementiavoices.org.uk/wp-content/uploads/2017/10/National-Disabled-Peoples-Summit-4th-November-1.pdf>.

Please book via: <https://www.eventbrite.co.uk/e/national-disabled-peoples-summit-tickets-38706991654>.

DEEP Grants update: Congratulations to the groups that got a DEEP grant.

We have been delighted to give out £73,158 in DEEP grants to 26 groups.

The decisions were made (over a very long day!) by two people with dementia, a DEEP group facilitator and Rachael Litherland from Innovations in Dementia.



Influencing grants - up to £2000 to help with local influencing work.

Scotland	
Life Care Edinburgh	Creating memory books so that people with dementia can say how they want to spend their time now and in the future
Lingo Flamingo	Befriending to help people with dementia who have reverted to their native language, communicate in care settings
Grampian Hospitals Art Trust	Costs for Art Room - a patient led arts project
Arora An Lanntair	Making a short film about expressive dance as a method of engagement
Evanton Community Wood	To run woodland sessions with people with dementia as a means of engagement
Beth Johnson Foundation	Supporting the costs of the group
Eric Lidell Centre	Increase the involvement of people with dementia in a craft cafe
Wales	
Dementia Matter in Powys	Setting up three new groups
Memory Jar Cafe	Costs for a new group
Kymin Group	Creating a leaflet for clinicians to improve how they give a diagnosis

England	
Buddies (Leamington Spa)	Making the group more solid and supporting a new group
Young Dementia UK	Creating film clips for training and a post diagnostic support programme
Laverstock Memory Support Group	Conducting dementia friendly audits of buildings and venues
Craven Dementia Friendly Communities	Setting up a new group to influence dementia friendly Craven
Dementia Voice Worcestershire	Transport and venue costs for the group
Chinese Wellbeing (Liverpool)	Running costs for the dementia network and Chinese teahouse
Lancashire Dementia Voices	Revitalising the group and linking to rural communities via roadshows
Wigan Dementia Action Alliance	Setting up a group to influence dementia friendly Wigan
Together Dementia Support	Transport and support costs for the group

Working Together grant - up to £7500 to help two or more DEEP groups to work together, on something useful to the rest of the DEEP network.

Scotland	
Dementia Friendly East Lothian and An Lanntair	Testing out digital connections (Zoom technology) to share food and make connections
Scottish Alumni	To gather examples of self management approaches across the DEEP network
Wales	
Me, Myself and I	Creating a South West Wales DEEP hub
North Wales Dementia Network	Creating a North Wales DEEP hub
England	
Cheshire and Wirral Partnership Foundation	Setting up three new groups, including on an inpatient ward
Making Space	Setting up three new groups

the last word

The Hills of Home

The hills of home, that's what I want to see on the wall.
The view from my window, across the hills,
With a light mist over them.
I miss that view.

The view across outside, far distant views
Of the village and the loch.
The way the hills ripple on the skyline.

What about this caravan?
It looks like the bones of it, and the house!
And this shielding? There's not much left of it...

This machair might be Bragar, plenty of machair in Bragar.
That's a rainbow, all right!
He is a lovely dog.
He looks like he is enjoying his walk.
Oh the dog, the dog, ...he is lovely.

If you cut the peats in autumn, you can still get away with it,
If you cut them thinner. You just need to cut them so they dry quickly.
Oh, that smell of peat smoke, nothing like it.

This one, this is my favourite.
Who built this house?
Who lived in it?
Maybe that is a tunnel underground?
Or for the sheep...that's it.
That view from the windows...
What a lovely place to have a home. Someone built this and loved it.
I wonder who they were?
My father would know.

The evening light is more golden, don't you think?
And the morning more hopeful. Brighter.
Will the dark make me feel dark?

Oh that's a beaut! Berautiful! Notrth Uist, Aye!
That's a beaut as well!
Is this the Clisham? I climbed the Clisham, oh aye, many years ago.
No, it's not changed.

He's not bad with the camera is he, Alex Boyd?

National Poetry Day collage poem by Paula Brown (<http://dementivoices.org.uk/group/arora-dementia-friendly-community-project-an-lanntair/>). Taken from the words of people in Western Isles Hospital & Care Centres participating in the Life Changes Trust/DEEP Hills of Home Project with Alex Boyd.

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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