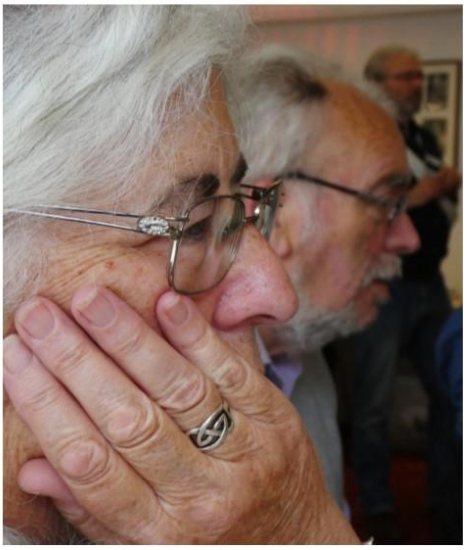
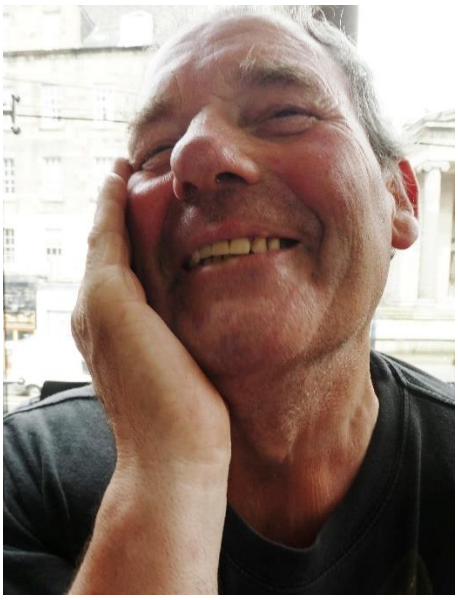
DEEP GATHERING EDINBURGH JUNE 2017 REPORT



Introduction and Thanks

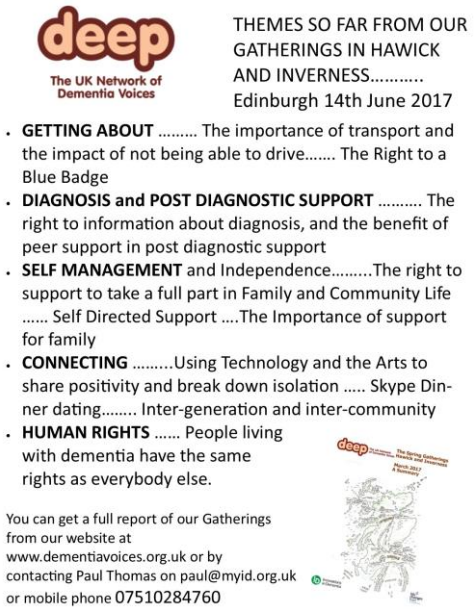
Thanks to the generous funding of the Life Changes Trust and the ongoing support of the DEEP network across the UK and the Directors of Innovations in Dementia, we were able to hold the third Scottish Gathering of 2017. This would not have been possible without the staff and management of the Edinburgh Festival Theatre providing their generous support and facilities.

On behalf of all who attended, our unqualified thanks to all, and on my behalf equal thanks to all the facilitators, managers and especially people living with dementia and their loved ones who contributed yet again to an inspiring and creative event. The narrative of experience has a great deal to contribute to changing the course and context of dementia.



Building on the open and intimate spirit of the previous two Gatherings, in Hawick and Inverness, our day in Edinburgh followed the same open and inclusive agenda, with a broad framework creating the time and space to enable positivity, laughter and the pooling of resources. We informed delegates of the progress made since our first two Gatherings, particularly

the projects which had begun to grow out of those discussions, and the themes of those March Gatherings.



deep
The UK Network of Dementia Voices

THEMES SO FAR FROM OUR GATHERINGS IN HAWICK AND INVERNESS.....
Edinburgh 14th June 2017

- **GETTING ABOUT** ..... The importance of transport and the impact of not being able to drive..... The Right to a Blue Badge
- **DIAGNOSIS and POST DIAGNOSTIC SUPPORT** ..... The right to information about diagnosis, and the benefit of peer support in post diagnostic support
- **SELF MANAGEMENT** and Independence.....The right to support to take a full part in Family and Community Life ..... Self Directed Support ....The Importance of support for family
- **CONNECTING** .....Using Technology and the Arts to share positivity and break down isolation ..... Skype Dinner dating..... Inter-generation and inter-community
- **HUMAN RIGHTS** ..... People living with dementia have the same rights as everybody else.

You can get a full report of our Gatherings from our website at www.dementiavoices.org.uk or by contacting Paul Thomas on paul@myid.org.uk or mobile phone 07510284760

These included the Scottish Dementia ALUMNI's "Self-Management" project and the "Digital Dining" Initiative begun between East Lothian and Arora.

This Gathering also provided an opportunity for many groups and individuals who had not previously been involved in the network to get a taste of its vibrancy and hopefulness, and also to consider applications to the upcoming DEEP influencing and networking grants. Many successful applications followed, and as a result the network in Scotland has grown from eight groups in June 2017 to 18 in October 2017.

62 people attended the Gathering, and unlike our previous get-togethers, we only worked on the one day. This meant that it was a different process (for example the noise level rose drastically as everyone talked at the same time around 8 tables), and while there was probably less intimacy, and no opportunity for an overnight stay, swim or sing song, everyone provided a rich source of ideas and developmental priorities.

32 people living with dementia attended, supported by carers and loved ones, and some facilitators provided wonderful support. To ensure that the voice of experience led our discussions, we made full use of our “I want to speak please” cards, although everybody spoke well regardless! People came to the gathering from as far afield as the Western Isles and Derby!

“There is so much Love and Enlightenment in the DEEP network”

DEEP दीप

Presentations

In addition to our general discussions, which followed on from open introductions and declarations of what people felt were important matters for discussion, we were privileged to have brief presentations from:

- Arora in the Western Isles, Paula showed us the Vinyl wall art they had so marvelously produced for a Care Home in Stornoway. This process had been fully informed by discussion at the Inverness Gathering in March and was led by a person living in the Care Home.

- Getting Along – Damian presented his inspiring programme which focuses on relationships and living with dementia.

- Julie from Making Space displayed the remarkable crochet work she had begun to develop since dementia had changed her life. Still young, she had embraced the new challenges positively, and she inspired us all.

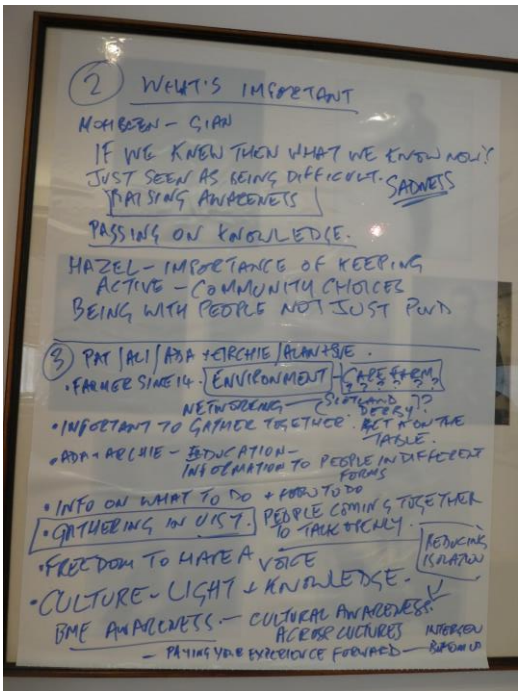
- SEWA from Derby gave an equally inspiring demonstration of the Sanskrit meaning of DEEP ("the illumination of the lamp of enlightenment") and before leaving performed their beautiful song for us.

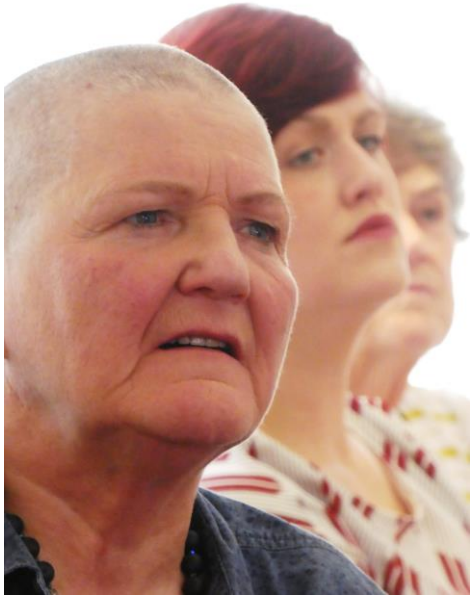
- It is fair to say that we were privileged to be in the company of a broad age range across a diverse range of interests and backgrounds. Smiles and grace illuminated our Gathering.

The Gathering.

The Gathering itself began with everybody being given the space and time get to know each other. It soon became apparent that over 60 people all talking in the same room was too complicated, so we re-arranged the tables to allow more space. It seemed to work!

Apart from the age range and diversity in the room, it was also clear from people's introductions of each other to the whole Gathering that it was not always easy to know who was living with dementia, and shows that assumptions can be dangerous. There was such a rich variety of backgrounds, professional and personal, present and such a broad range of supportive relationships that our conversations "segwayed" without difficulty into "What is important to us?".





The ideas poured out from table after table. It is interesting to observe that the emphasis was not so much on “services”. Priority was given to what we can do for ourselves and the importance of being regarded first and foremost as a person. Rights and the right to opportunities and information were high on people’s agenda.

What is important to me?

“Being with people, not just with people with dementia.”

“The importance of networking – Edinburgh meeting Derby.”

“The freedom to have a voice.”

“If we knew then what we know now. We can pass on our experience now, create awareness.”

“It is important to keep active, to have community based choices.”

“I worked as a farmer, being in the environment is very important to me”

“I worked in education. We need to get information to people in different forms, all languages, visual, video.”

“We have the right to do normal things together”

“We can use the arts, song, dance, and film to show what we think and feel.”

“Together we can find the magic of what can be produced.”

“We need to challenge the imagery of dementia, a wrinkled hand held in a young hand. Some of us are young too!”

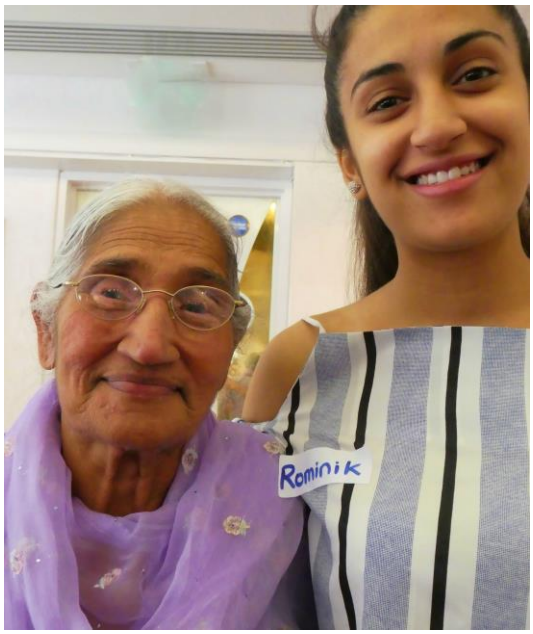
“We need to learn about the voluntary sector, social sector … what is out there, more useful than the usual health service type approach.”

“Together we can challenge the stigma. Dementia is not just about old age”

“Culture! Light and knowledge. Sharing cultural and BME awareness”

“Putting your experience forward.”

"Sharing across generations."



"Making local connections."

"Challenging inadequate assessment and diagnostic processes. There is too much emphasis on the physical and medical side."

"We just live in a different way. We are still the same people. There is a lady who lives in a care home, she doesn't speak any more but she still knits."

"Sometimes I get very frustrated because I want to do something and I just can't."

Our conversations moved on into more focused areas:

Connections:

"*Connections between us and those we love can be challenged and become difficult. We have a right to relationship help. You can end up hurting the ones you love. You still care, we are all carers."*

"We need to break taboos. Doing things in our communities, dance, art and drama all help build confidence. Doing things that aren't always about dementia is healthy."

"We have never all met before today but we are making connections and we will keep in touch. We want to jump into the DEEP end together"

"The bad side of dementia is mostly about loneliness, a lack of community spirit."

"I remember the sorrow of seeing my mother so lonely and sad. Relationships are so very important. Don't leave people alone!"

Personhood:

"I can retrain my brain. Living with dementia is a journey."

"You need to adapt, share your experience, accept a new journey, discover the DEEP end and swim in the ocean together."

"Gaining the confidence to use public transport, to learn how to use technology."

"Don't give me b…dy antipsychotics just because I throw my dummy out of my pram. I am just having a BAD DAY!"

"Keeping active, keeping friendship and community spirit in my life is really important."

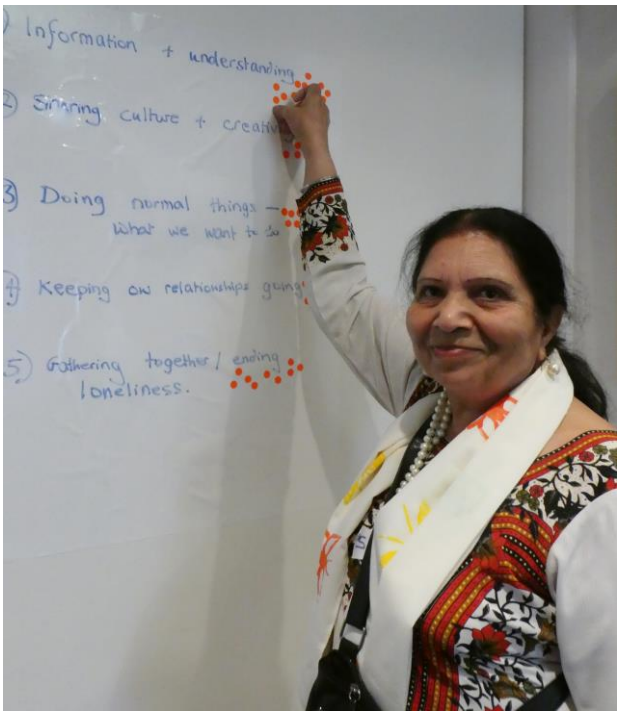
Religious and spiritual belief can become very important."

"Community can be found in unusual places, church halls, coffee shops, on our Island the post office is a great place, like a Ceilidh sometimes!!"

"Lots of these things can help to bring you peace of mind."

Prioritising

After a really good lunch and social time we voted on the themes that had developed in our earlier workshops. Each person had two dots to place on the options boards.



We all agreed that the options we had developed were:

- Information and understanding
- Sharing Culture and Creativity
- Doing normal things – doing what we want to do
- Keeping our relationships going
- Gathering together – ending loneliness

When we reconvened, the themes that had gained the most votes were:

- Gathering Together
- Keeping our Relationships Going and
- Information and Understanding

It was a fine line which put these options first, everything received plenty of votes, but we spent the rest of the day discussing what we could do to build on these two priorities.

Gathering Together

"Use the arts to bring people together."

"I enjoyed our local festival and accordion night. I could relax with people and just do what I wanted."

"Getting together like this is very important, we have different backgrounds but a common bond."

"Sharing eating together, through Skype, sharing recipes, sharing and teaching skills."

"Through Skype you can involve all your family together."

"United we stand, together we are stronger."

"Right now, I feel full of hope."

The group were very much in favour of more DEEP Gatherings.

"Could we meet on Uist, an island Gathering?"

"Why don't we think of approaching a school, or gathering in an Arts centre, invite young people too?"

"We could meet across different centres, using Skype ort Zoom."

Relationships

"Services should work together, not in silos."

"All should be based on respect and dignity. Never underestimate a person."

"Show the Getting Along video and programme to professionals, NHS and Local Authorities. Make the economic case. Relationships are vital."

"Getting Along is a working model, use it."

"Gatherings can help us to share with others how we got through it."

"Be humble and polite."

"Involve everyone in decision making."

"Be willing to normalise your situation, always acknowledge the 'elephant in the room'."

"Like today, we can help professionals to meet people living with dementia as people."

"Don't mix with moaners and groaners – stay positive."

"Getting Along is the key. I wish it was around when J….. was diagnosed. We were about to get divorced."

Five Thousand Pounds (sterling)

We finished the discussions with a decision on how we would spend £5,000. There were lots of great ideas, including:

- A Gathering in Harris
- A Gathering in Stornoway (or North Uist)
- A TV or radio advert – video telling people what we think
- More work for young carers and young families
- More work on relationships and counselling
- Make a video for GP's.
- Better images of people with dementia, across all ages, diagnoses and cultures
- More cultural exchanges
- This is what I have learned about dementia since my diagnosis video for professionals
- A guide about dementia reviews and how to communicate with people of you are a professional.

Some people had had to leave by this point (trains etc) but the final vote on how to spend the £5,000 was cast solely by people living with dementia

A further Gathering won the vote.

A guide for GP's came second.

We considered what kind of Gathering we could hold. The priority was that it should be based on "people meeting people" as a starting value.

Our consensus was that we should hold an event for professionals, perhaps at the Cross Parliamentary Group at Holyrood, or failing that at an independent venue, where our work could be presented and that this event could be followed by a social gathering, so that all bases were covered.

We would aim for September / October 2017.

Andy and Paul said they would contact MSP's and most people agreed that they would want to attend.

SEWA

During our afternoon tea break, we had all been treated to a beautiful performance of SEWA group's song "Memories" in Urdu. The video of this performance can be found on YouTube.

We also had a final mini Ceilidh at the end of the day, with coffee and cake to help it all along. We bid farewell with lots of love, warmth and hope in our hearts, feeling positive about our journey with dementia. Coming next – “People Meeting People” Gathering.

This Gathering shows the strength of people getting together and sharing their experience of dementia, an experience often described so negatively. We hope that this brief report shows how that expertise can inform and improve attitudes, services and strategies, and therefore quality of life for us all.

Our thanks are also due to Christeen and Jenny from Cormorant Films for their videos and fotos, and to James, Philly and Ali for their fotos and videos.

Especial thanks to the professionals and facilitators who so "humbly and politely" gave of their time, and provided a perfect example of how to be with people who live with dementia.

Paul Thomas

Oct 2017.