



The UK Network
of Dementia Voices

‘The Zoomettes’

The story of a virtual peer support group



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Innovations
in Dementia



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zoomettes

We are a
group
in the **deep** Network

deep

The UK Network
of Dementia Voices

10

Anniversary
2012 - 2022



To begin at the beginning...

I met a lady living in Hampshire who had no support and wanted to connect with other women who had dementia. I also knew another woman, Dreane, who had been part of a group, which had closed, and she too felt bereft. I realised that there were many other women who felt exactly the same. I thought 'how can we connect these women who are alone'?

Looking back through my archives, I found an email from March 18th 2019 to Dreane. I wrote that I'd thought about 'trying out a virtual DEEP meeting and christened it as a working title 'Ladies Live'. We will connect over a programme called Zoom (a bit like Skype or Facetime, if you have used anything like that before).

Dreane responded saying:

“ I've used Skype, so I am prepared to give Zoom a go. Nothing ventured, nothing gained. ”

And so, the Zoomettes were born.

Three years later Dreane says:

“ Little did I know when I switched on my iPad to enter the then-experimental Zoom just what exactly was before me. A group of women all with dementia, and just how much it would change my world. Knowing you are in a safe place where everything and anything is talked about and confidentially shared just with each other. In sad and bad times, I would long to give a hug to my then Zoom buddies, wipe away their tears or share our laughter. ”

After a few weeks of giving it a go and calling in favours from mates, the green light was given, with a go-ahead on Monday 24th June. Anna Harrison and Aimee Day began kindly and ably to facilitate the group. A small DEEP grant was initially awarded to capture some of the learning and guidance for other virtual groups in the future. **In handing over the group to Anna and Aimee I said to the Zoomettes:**

“ I hope that you continue with the fun, generosity, honesty, love and warmth I experienced with you. ”

You can read the **Zoomettes evaluation** below.



Or scan the QR code below with your phone or tablet to go to the pdf.



Click here to download a pdf of the 'Evaluation report for ZOOMettes'

On completion of the grant Anna and Aimee generously continued to volunteer to facilitate the Zoomettes until the summer of 2021.



The Zoomettes take part in a 'Women and Dementia' gathering in London (July 2019)



Some of the original Zoomettes joined other women in London for a 'Women and Dementia' event in July 2019. Jane Garvey (from Radio 4's Woman's Hour) facilitated the gathering. She wrote about her experience afterwards.

I was afraid of spending a day with women living with dementia- but it was life-enhancing

I realised to my shame that I had been frightened – what of, I'm still not entirely sure



Socialising at The Alzheimer's Society (Photo: Alzheimer's Society)



By Jane Garvey

August 14, 2019 2:47 pm (Updated October 8, 2020 10:38 am)



Do I "do a lot for charity"?

No. But I will do a bit, if I can. Earlier this year on Woman's Hour I interviewed [Wendy Mitchell](#), author of a book about dementia called *Somebody I Used To Know*. Actually, it's a memoir – her own account of her early-onset dementia.

Or scan the QR code below with your phone or tablet to go to the web page.



Click here to read the online news article by Jane Garvey



I was afraid of spending a day with women living with dementia.- but it was life-enhancing. I realised to my shame that I had been frightened - what of, I'm still not entirely sure. I spent a day facilitating a conversation in a London basement. I hadn't been sure what sort of "conversation" would it, could it, be? I hadn't got my hopes up. But my mood altered almost as soon as I arrived – all I could hear was the sound of laughter and cup-clanking. The unmistakable clamour of an all- female gathering in its early stages. And could these women talk? Yes. I was surprised that not all were based in the south of England: there were contributors from Wales, Northern Ireland and Scotland. Women in their eighties; women younger than me. Most on their own, some with female partners, relatives, or friends. A last-minute addition to my glittering show-business diary meant that I had to make a quick exit to record a podcast, but I'd already been reassured. Incredibly, this was fun- I couldn't wait to get back and get talking , and listening, again. My disappearance did cause a flurry of speculation (a mystery assignation? a sudden need for alcohol after exposure to the group?) and so I was firmly established as the butt of the joke by the time of the afternoon session. This was a chance for an open conversation about the topics closest to their hearts. We'd established the idea of a safe space, where no one would be judged whatever, they said, however they expressed it. And there were cards to hold up -" I want to speak please " – so that thoughts weren't lost. A simple and obvious idea, perhaps, but I'd never have dreamt of it. It was my job to make sure I got to people quickly enough. I didn't always get it right. This "facilitating " lark turned out to be harder than I thought. And of course, not everyone wanted to speak at all. I suppose I'd been prepared for family issues of one sort or another - but not for the subtleties. The fact that doting grandmothers felt they were no longer trusted to care, and how much they missed doing it; the competent, organised heads-of-households who weren't consulted or involved much anymore. The way some friends and relatives pitch in and help, exceeding expectations - and the fact that some people - once "close friends", sometimes your own children - just don't want to know . Or simply "can't cope". (And I'm not judging - I haven't been tested myself). There's also the sometimes-devastating loss of confidence. Insomnia. And, of course, the subjects that are really hard to talk about – the loss of intimacy. Continence. If I learnt anything that day, it's that accessible, free, public toilets are an absolute necessity. It may well be one of the least glamorous but most important issues of our time. And I'm not joking. There was more laughter, and some tears, inevitably, but most prevalent was a sense of shared understanding. There is no sugar-coating this: Dementia is vicious. It's cruel. To get through it on your own must be impossible. You deserve the support and the company of your peers, and the understanding of the rest of us. That day in the London basement turned out to be educational and life-enhancing in equal measure.



There is a film capturing this day called **‘Is dementia a women’s issue – Speaking from the heart’**.



[Click here to view the film](#)

Or scan the QR code below
with your phone or tablet
to go to the film.



It was a rare (and, honestly, very expensive) opportunity to bring women from all corners of the UK together in person. But how can that ‘shared understanding’, ‘tears and laughter’ continue? The next best thing, we decided, was to continue to connect on a weekly basis through Zoom – the Zoomettes was firmly forged.

Little did we know the benefit that the Zoomettes model would bring to the world less than a year later. From April 2020 we were faced with two years where the only contact we could have with others was through Zoom.

The Zoomettes report Autumn 2019 said that:



It was felt that meeting face to face and online both had their value, although not being able to give each other a hug was felt to be a downside of meeting virtually. Positive feedback for using Zoom was that it would be very difficult for them to meet as often using any other means. Another major benefit was not having the stress of having to travel to see each other.



Zoom groups don't work for everybody

There's no doubt that sometimes it is a difficult to get a word in edge ways in a group of people, all hungry and eager to connect (not just women). Hence the yellow '**I want to speak cards**' have worked really well for us and many virtual meetings. But no matter how skilled a facilitator – it is sometimes really tough trying to interpret body language and mood on a computer screen.

“**I want to speak please**”

“**I want to speak please**”

Or scan the QR code below with your phone or tablet to go to the web page with download option on it.



[Click here to download a pdf of the 'I want to speak cards' in English](#)

Some of the difficult issues people have talked about are:

“

I felt so alone when the screen suddenly goes blank after an hour or so of company. It felt harder and harder to balance the time of joy with the loss after the call had ended. In a way I felt more alone.

”

“

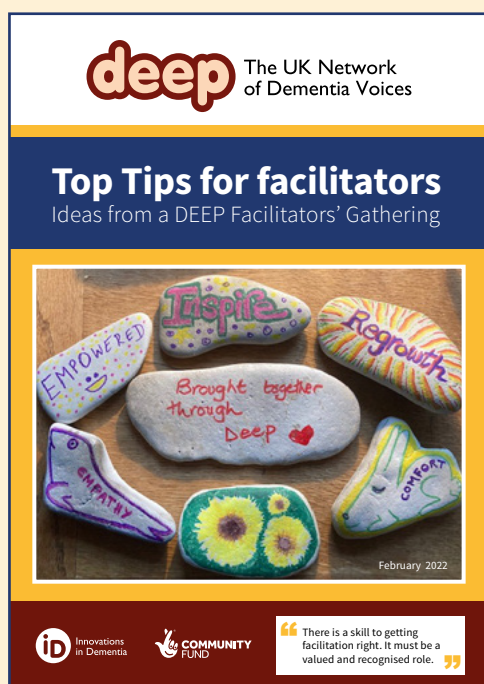
Sometimes I didn't feel able to talk about what I had planned to talk about because I didn't have the confidence to speak up. Then I felt short changed afterwards.

”

As with any group of people, there may be different personalities and opinions which might get in the way of enjoying the experience, and in a tight knit group it can be difficult if you don't see eye to eye.

It is quite tough as a facilitator to help a group find a balance if somebody is talking about an emotional issue which they really need to get off their chest – how do you stop them from talking?

You might find it useful to look at the **DEEP facilitator's resource**.



Or scan the QR code below with your phone or tablet to go to the pdf.



Click here to download a pdf of the 'Top Tips for facilitators'

The group have recognised that it works better with a facilitator. They had a period of trying to facilitate the meetings themselves, but as Chris says:



This is the only meeting I go to which is for me. All the other things I do are about helping other people. This is my time.



In the early days too Aimee and Anna noted that:



All the women agreed that having a facilitator on the call was vital, in order to direct, focus and initiate conversation. It was felt that it helped mitigate the worry of someone having a bad day and either dominating the conversation or saying something hurtful.



Agnes agreed that they need to trust a facilitator:



I trust you to stop me from going on – because I know I will!



Ground rules and terms of reference

Being clear about why you are meeting and what you need to get the most from your experience are essential. You can call them ground rules and terms of reference, guidance or just the nuts and bolts of how and why. They can help everybody to re-focus and to remember your agreed etiquette. The Zoomettes reviewed theirs in April and were very clear about not wanting too many rules and regulations.

The Zoomettes

We are a UK wide group for women living with dementia meeting on the virtual platform, Zoom, for friendship and support.

- We meet every Monday 5pm and 6pm through Zoom.
- Members can drop in as and when they wish.
- There will be no more than 8 group members (living with dementia).
- There are currently six members.
- There will be a professional facilitator. Currently this is Fran Hamilton.
- It will be a closed group – this means that only people who are invited will be able to join in.
- This is a group where we have a chat with each other as friends, and share what we have been doing.
- Review in September 2022. Zoomettes to review if they wish Fran to continue as facilitator. Is Fran able to and does she wish to continue to facilitate?

Consent and details of nominated contact

- We agreed that everybody should provide consent and the details of a nominated contact agreeing to the following:
- If the facilitator of the group, or anybody else, has any concerns about my well-being during or after the virtual meeting I agree that:
 - the facilitator may contact a nominated person on my behalf to check that I am safe and supported.
 - the facilitator may contact other group members to let them know that I am okay. If I am not okay that they can share the basic information with the group to ensure nobody worries that I am alone.
 - this information will be kept securely by the facilitator and DEEP Network admin.

Guidance

- Please use the yellow 'I want to speak please' cards.
- Please mute your microphone when not speaking.
- Please be respectful of each other's opinions.
- Be and feel safe – respect confidentiality.
- What we say in the group stays in the group, unless there is a concern about someone's safety.
- We will not post photos, information, or quotes from the meeting on social media unless expressly agreed by all participants at the time.
- We will make sure we are dressed (at least from the waist up).

Practicalities

- DEEP Network admin will send out an email reminder to all group members on the day of the call.
- It is hoped that if there are any issues arising within the group that these will be addressed and sorted out within and by the group.

This information has been agreed by the group April 2022

Safe guarding in a virtual space



Setting a space and a place for safe honesty.



One of the concerns raised by colleagues when we first had the idea of a virtual group was where the responsibility lay for the safe guarding of the members of the group.

In their report Aimee and Anna wrote:



We also noted that when members of the group had had a particularly difficult day, they still felt able to come onto the call and just listen rather than participate in the conversation themselves, such was the value of belonging to the group. Often, the group used humour to distract when a difficult subject was discussed, which could quickly lift the mood. This was particularly important if the meeting was coming to a close, as no-one wanted anyone to leave the meeting feeling down.



However, we have had a few situations where we have been really worried about somebody. This may have been because they have been quiet or that they had talked about something distressing. We were left wondering afterwards – who was going to check they were okay and safe? By sharing DEEPer stuff was there a danger of adding a ‘burden’ to others?

Would everybody take it on their shoulders to check someone was okay who had been upset. Sometimes when you are upset you just want to be left alone!

Everybody knew what would happen in a concerning situation. We hoped this would alleviate some of the after-the-Zoom worries. So we established an agreement which is completed by everybody in the group.



Consent to contact next point of contact (and who)

I am a member of the Zoomettes group.

If the facilitator of the group, or anybody else, has any concerns about my well-being during or after the virtual meeting I agree:

- the facilitator may contact a nominated person on my behalf to check that I am safe and supported.
- the facilitator may contact other group members to let them know that I am okay. If I am not okay that they can share the basic information with the group to ensure nobody worries that I am alone.
- This information will be kept securely (password protected document) by the facilitator and the DEEP Network admin.

Name	Landline	Mobile	Contact	Landline	Mobile
Group member	000112233	445566	Nominated person	778888	99990000

It is also important to note that the facilitator also has somebody they can discuss/offload to so they can get a good night's sleep too. Especially important with an out of office hours call.

The impact of Zoomettes on lockdown

Little did we know that, only a year after the seed of an idea had sprouted, the world would be heading into a physical world lockdown as a result of the COVID-19 pandemic.

Wendy says that:

“Especially during COVID, Zoomettes became a lifeline. I could rely on cheery faces to be there, and I relied on Anna and Aimee as our able facilitators to be the constant I so desperately needed. A screen full of smiley faces. Everyone could do with a Zoomettes in their life at a certain point and time.”

The Zoomettes weren't the first group to meet online, but they were the first group to help others with their resources to help people connect.

The film **‘How to use Zoom’**, created by Madeleine Cary, Aimee Day and Frances Isaacs has been watched 4,466 times since it was posted.

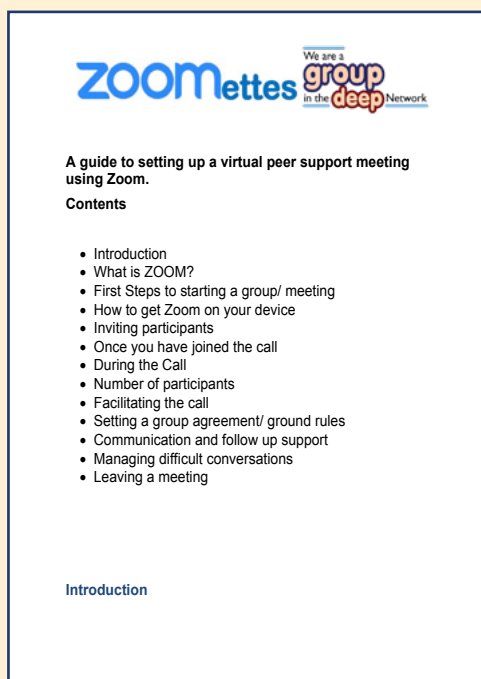


[Click here to view the film](#)

Or scan the QR code below
with your phone or tablet
to go to the film.



A written guide also accompanies the film, which has also been translated into Welsh by Dr Catrin Hedd Jones.



[Click here to download the written
‘How to use Zoom’ guide](#)

Or scan the QR code below
with your phone or tablet
to go to the guide.



A new facilitator

After two years of unwavering commitment to the Zoomettes (only a small part of their time was paid time) Anna and Aimee had to say farewell to the group. Their departure was tough for them and the group. For a time, they felt they could continue to meet as they were, but soon found they missed the person or people who facilitated. Perhaps this is the right time to recognise the importance and skillset required of a facilitator. The group were supported through the transition and came up with a suggestion to approach Fran, who was known to many of the Zoomettes through her involvement with Dementia Diaries and formerly a facilitator for D-Mob in Brighton. The skillset of an Occupational Therapist felt like such a good fit for the Zoomettes. **Fran writes:**

“

I'm an Occupational Therapist, and I was delighted to be asked to facilitate the Zoomettes. I've been following the progress of this amazing group since they started, before the rest of us started using Zoom regularly, and they've been trailblazers. My role is to spend an hour with these amazing women once a week and just enjoy their company, but also to make sure that everybody gets some space to use the time as they want to. It's always a delight, lots of laughter, some tears sometimes – but then it's an opportunity for everybody to relish the friendships they've made and really have that lovely time together with a group of people that absolutely understand the activism that everybody is doing. Everybody within the Zoomettes is doing amazing stuff, on a day to day, month by month basis, really making a difference to how people across the UK and beyond are viewing and supporting people with dementia. But really, more than anything, showing that a life can be lived well with a diagnosis of dementia.

”



How does the group continue? – plans for the future

As well as a change of facilitator, the group has got smaller too. The loss of friends from the group however does not mean the loss of the friendship outside of the group.

As Agnes said:

“ There is a natural growth, people move on and you move on and that is life. ”

Gail talked about the process of joining the Zoomettes and how much it helped her for a time. It also helped her to see her life and prioritise the skills and confidence she had been inspired and acquired as a result of the connections she had made. Frannie taught her to paint.

As a group gets smaller we feel the need to ‘recruit’ more people. Frannie talks about the privilege and the benefit to her life by being a part of it.

“ I feel we shouldn’t keep this as a mutually exclusive club for us. Many of us have moved on in life and do other things, all thanks to this start we have had. ”

Yes, it would be wonderful to come along to Zoomettes when we feel like it and have that closeness and friendship that has led us to how we are. I think of you as friends. But, she talked about how she felt that opportunity should be made available to more people.

So, the dilemma – new members.

Nobody felt comfortable with the idea of people being vetted by the group as ‘suitable’ or not. **“We wouldn’t like it if we were being spoken of in that way”**. So, it was agreed that, as in physical groups, people can come along and, if it is the right place for them, they will continue to come.

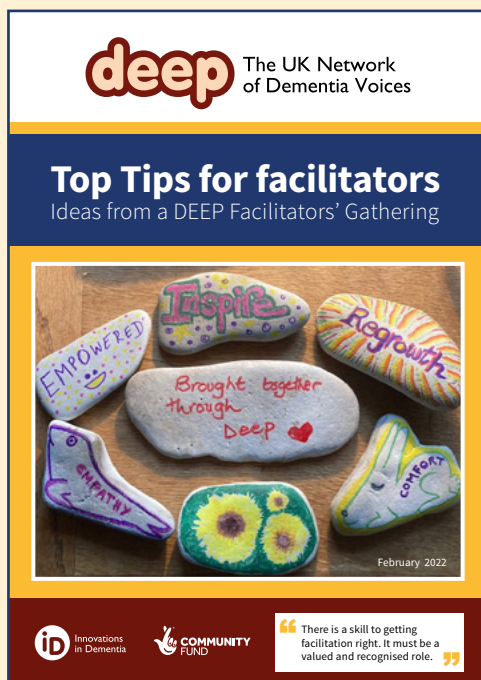
We did feel that, by sharing our resources and our learning, it may inspire other people to form their own version of Zoomettes. For a while there was a Menettes group. There are groups who still regularly meet through Zoom. Before lockdown, many groups would meet on a monthly basis and talked about wishing they could meet more frequently. For some Zoom is enabling that to happen. Most important of all is that somebody in Scotland can talk to somebody on the South Coast of England or Northern Ireland with the ease and safety that has evolved over this time.

Funding

Dory shaved her hair off and raised £1,000 (live on Zoom whilst the Zoomettes watched with baited breath to see if any blood was shed). Julie's group closed and she passed over the group funds towards a get together. This money was used to partly fund the Woodbrooke event. Dreane made a valuable contribution too and said she was so grateful to the rest of the group.

But the reality is that it is difficult to get funding for this type of group. What do you need the funding for, you may ask? I previously referred to Anna and Aimee giving freely of their time. Apart from a small grant from DEEP and a small COVID grant from the National Lottery Community Fund, that was all they took as a financial payment for their time. In the early days they both said it would feel wrong to be paid to do it.

As groups and as facilitators it is important to recognise the need for that support and the skills that a facilitator brings to your group. You can read more about this in the previously mentioned facilitators' resource **link below**.



Or scan the QR code below with your phone or tablet to go to the pdf.



Click here to download a pdf of the 'Top Tips for facilitators'

When Fran and I were discussing her time, it felt comfortable to suggest that for an hour Zoom meeting you need to add at least half an hour either side to be realistic about the time you will spend in that role.

You can find out more about funding ideas in **‘Top tips for writing successful applications to grant-giving trusts.’**



Or scan the QR code below with your phone or tablet to go to the pdf.



Click here to download a pdf of the 'Top tips' guide



Where we are now

I hope that you will read this alongside watching the film of the **Zoomettes at Woodbrooke**. I hope you feel the mood of the group through their film.



Film coming soon

**Or scan the QR code below
with your phone or tablet
to go to the film.**



Frannie taught us all how to paint flowers which she has used to bring together to create a Zoomettes version of the Tom Kitwood flower from 'Dementia Reconsidered'.

In 'Dementia Reconsidered' Kitwood's flower focuses on love at the heart with attachment, comfort, identity, occupation, and inclusion in the petals surrounding the heart.

The Zoomettes flower focuses on love at the heart with attachment, comfort, identity, occupation, and inclusion in the petals surrounding the heart.





deep

ZOOMettes

deep

deep

Julie's Poem

Never ending undulation
Up and down like hill and vale
Ever needing expression
Showing a smile and having a wail
All necessary stress relief for coping
But a store of resilience is required to keep on coping

Leaning on the bottle becomes not healthy
A diet of chocolate is not good, and I'm not wealthy
My walking days are much restricted
And romantic occurrence cannot be predicted
Where to look, what to do?

I think I know
My Zoomettes will help me
That's where I'll go!
Womanpower and girly glee
The very best medicine
An hour spent with my friends
Will make my worries jettison

deep 10

“ 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! ”



**DEEP thanks to all Zoomettes past,
present and future.**

Rachel Niblock May2022



 www.dementiavoices.org.uk

 @Innov_Dementia

 UK DEEP Network

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