

The Power of Peer Support

Finding your voice after a diagnosis of dementia

Fran Hamilton

Occupational Therapist, Consultant and Trainer

Deputy Dementia Lead at Sussex Community NHS Foundation Trust



@FranHamilton_OT

Research opportunity



University of Brighton

NIHR | National Institute
for Health Research

2017 Health Education England Integrated Clinical Academic Programme Internship (ICAP)

2017 – 2019 National Institute for Health Research (NIHR) funded Clinical Research Masters at University of Brighton

Dissertation: “Nothing About Us Without Us” Narratives of living with dementia

THEMES



Diagnosis and dementia



Loss



Having a voice



Memories



Health and Social Care



Public Perceptions

Impact

Internalising negative assumptions leading to:

Anxiety and low mood (Ashworth 2017)

Diagnosis avoidance (Bunn 2012)

Social isolation (Keady 1995)

Giving up activities pre-emptively (Low et al 2018)



But....

Involvement in everyday activities:
sense of belonging, retention of
identity and autonomy (Phinney
2007)

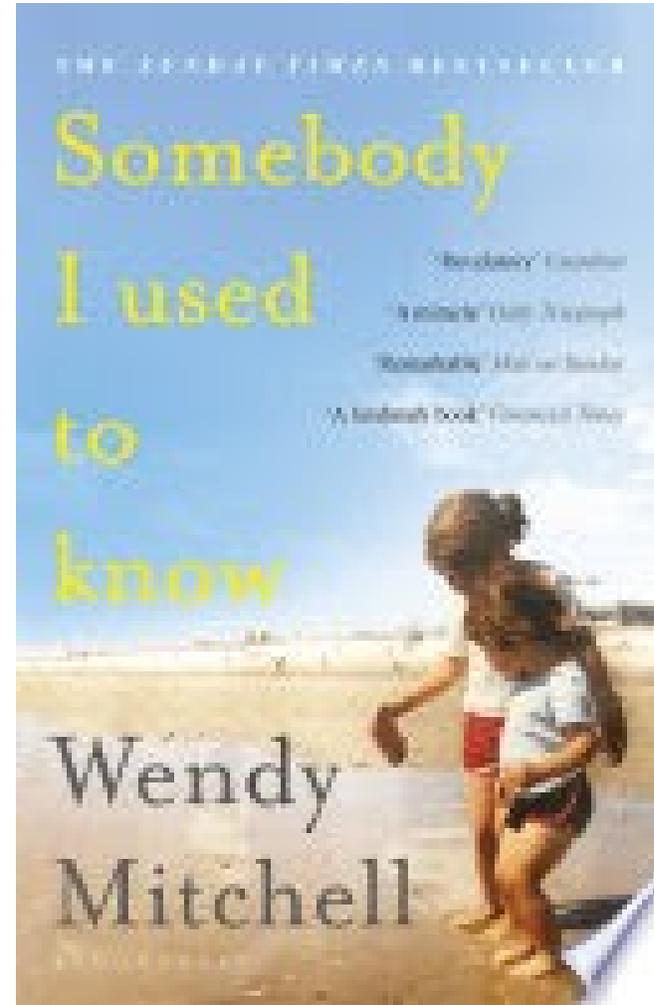
Thriving when focusing on abilities
and coping strategies (Cotter 2009)

Hope: central to the adjustment
process in early stage dementia
(Wolverson et al 2016)



Wendy Mitchell bestselling author of Somebody I used to know

*“When people think of dementia,
they think of the late stages. They
forget that there is a beginning
and a middle”*



Epistemic and Testimonial Injustice

Epistemic injustice results from partial or full exclusion of selected persons from the construction of knowledge (Fricker 2007)

Testimonial injustice occurs when the hearer undervalues the speaker's credibility due to their own prejudice (Young et al 2019)



Peer Support

“Dementia is a lonely existence but hearing others, in the same boat, talk about their challenges and successes makes you feel part of one large extended family”



RCOT Conference with Dory



- Presented my research at the RCOT Conference with Theresa Davies “Dory” who is living with dementia

Our unity



Respect



Love



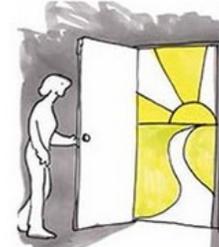
Our rights



Our voices



Opportunity



About DEEP

DEEP stands for the Dementia Engagement and Empowerment Project – it is the UK network of dementia voices. DEEP consists of around 80 groups of people with dementia – groups that want to change things.

Type search term here...

Click here for results

Twitter feed

Innovations in Dementia

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Innovations in Dementia

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RT @AboutDementiaSc: We were fortunate to be joined by



d-mob

Don't get left-behind folks









***** STEVE MICHAELS IS
HONORED TO ANNOUNCE AS THE NEW HOST OF
THIS IS ELVIS
A NEW MUSICAL

Disney's
HIGH SCHOOL MUSICAL
ON STAGE
15 - 29 July

LOVES FESTIVAL
MILE & CHIC
JESS GYNNIE
RAYE GABRIELLE
ARAHNA AND THE BOSS. SOHRETT
KORINNE COOPER. KELLY PLAMBECK
CHRIS DANIELA. THE SONGS PROJECT
MONDAY NIGHT BOOGALOO. BINKY LIVE STAGE

THE KING
IS BACK
PORTSMOUTH IS ELVIS - 2018

THE HUMAN LEAGUE
LIVE 2018

D
National Youth Dance Company
Used To Be Blue

NYDC

Sharon Eyal



D-Mob comments

“The group allows me to meet a wide variety of people, I often have fixed ideas, but I like to hear other people’s ideas and experiences.”

“The biggest thing for me is regularly meeting each other and remembering we are mates and that we can talk about our experiences of dementia in the town.”

“It’s when I get with nice people, that I feel so comfortable.”

“In the D-Mob group I feel safe around people with the same diagnosis as me, thank you for setting it up!”



d-mob
Don't get left behind folks

we are a
group deep Network

www.dementivoices.org.uk

[p/d-mob/](http://www.dementivoices.org.uk/p/d-mob/)

www.dementivoices.org.uk



D-Mob involvement Dementia Congress

October/November 2018

Special Brighton Edition

deep Voices
News and updates from the UK Network of DEEP Groups

UK Dementia Congress November 2018



D-Mob is part of the DEEP network. We formed in early 2018 with the partnership of Brighton and Hove DAA's Matthew Moors and the support of local OTs Fran Hamilton and Louisa Marchant. We are a young group (in how long we have been together, but very young in our spirit too!) finding our feet together in the Dementia World.

We come from all walks of life, some of us have lived in Brighton or Hove (actually) all our lives and some of us have moved here. Some of us are living with dementia and some of us are supporting people living with dementia. We meet in central Brighton each month.

We've been quite busy so far. We're supporting each other with laughter, friendship and advice. We've created this local information guide for people living with dementia attending Congress and we've offered advice to make the Dementia Congress venue more dementia inclusive. We're pleased to have been asked to help local museums and amenities to get things right for people living with dementia.

In our workshop we will share with you the adventures of our first year as a group and what dreams and challenges lie ahead for us.

We want to make sure that nothing in Brighton and Hove happens about dementia without us having our say. By sharing our thoughts and experiences about what it is like to live with dementia here we hope to make the town and local services work for everyone living with the condition.

We welcome you to our home town! Watch out for the seagulls, the bikes and too many chips!

D-Mob November 2018

For your diary:
Meet and talk with D-Mob at Congress on Thursday 8th November at our workshop between 2.10 and 3.00pm

A special edition of DEEP Voices created by D-Mob

Created for people living with dementia attending the Dementia Congress

where to get the best fish and chips, or a pint or a quiet cup of tea, where to stay and how to get from A to B.

Memories of Brighton

A copy in every delegates welcome pack

D-Mob Workshop at Dementia Congress



Talking to Sussex Community NHS Trust



Brighton Library Audit



AMEX Brighton Albion Football Stadium

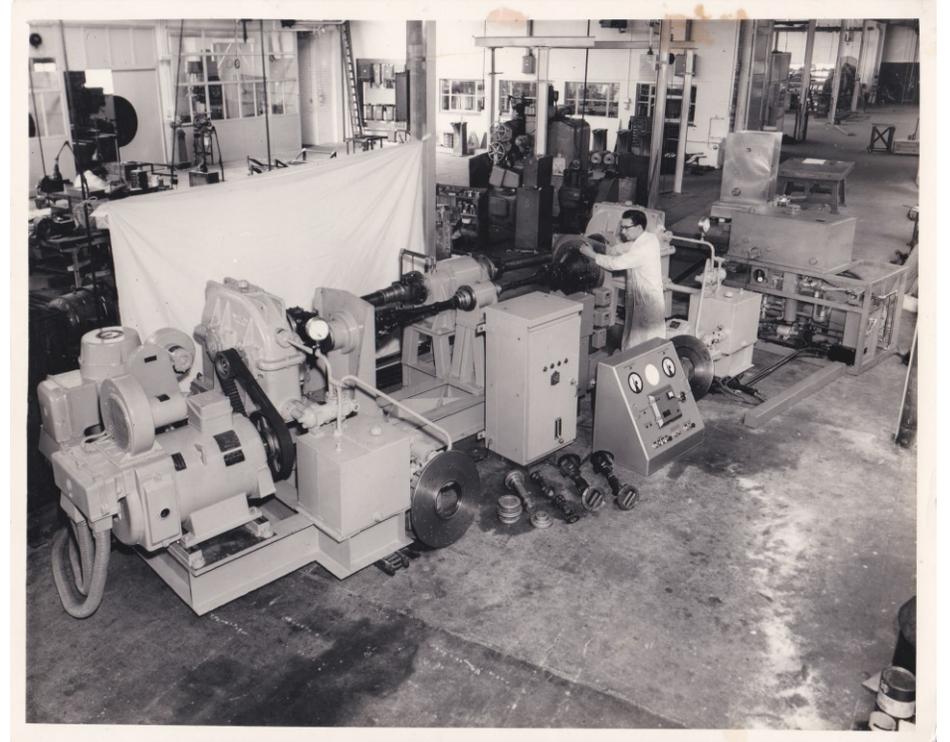


Lock down Zoom calls

- Weekly phone calls to individual households
- Some reticence about the technology
..... so we had individual practice calls
.....step by step instructions
- Two of our households did not use tech, so linked in with Digital Brighton and Hove and Citizens Online loaned us two tablets
- Then fortnightly Zoom calls



Life Story Snippets



Life Story Snippets



Women with Dementia: Speaking from the heart

14 women living with dementia (and some supporters) spoke openly about:



- Retaining femininity
- Respect in the workplace
- Making adjustments and compromises within the family
- Incontinence
- Sex
- Role as a mother
- Living alone and worries about safety
- Growing older without children

National Dementia Action Alliance

Chaired a panel discussion:

Learning from people living with dementia and carers: what they want you to know about the care home to hospital experience

“The ladies living with dementia sharing their stories, inspirational, heart-breaking and warming, simply powerful”.



connecting people, connecting support
occupation matters



An online resource where you will find 28 topics full of information and resources to explore living well with dementia. *“Having all this in one place is great... People feel like they’ve won the lottery when they see the website!”*



Each topic has things to chat about, try, play and more!
The resources and activities have been tried, tested and recommended by people living with dementia and those who support them.

Involvement

Sensory Changes and Dementia Webinar with 3 Nations Dementia Working Group



England • Wales
Northern Ireland

Heckle and Jeckle Podcast Australia (via Zoom!)



Shared my research findings and the stage with Chris Maddocks who is living with dementia as guest speakers on University of Brighton Masters Module



University of Brighton

Chris sharing her experiences and wishes to aid staff training at Sussex Partnership NHS Foundation Trust



Now.....

New role as Deputy Dementia Lead at Sussex Community NHS Foundation Trust – 3 days a week

Providing ad-hoc Training and Consulting around dementia to Care Homes, Community Organisations and NHS Trusts

Get in Touch

Fran Hamilton

Occupational Therapist, Consultant and Trainer

www.franhamilton.co.uk



Twitter @franHamilton_OT

Email: franhamilton_ot@yahoo.co.uk

Enabling wellbeing at all stages of dementia and later life