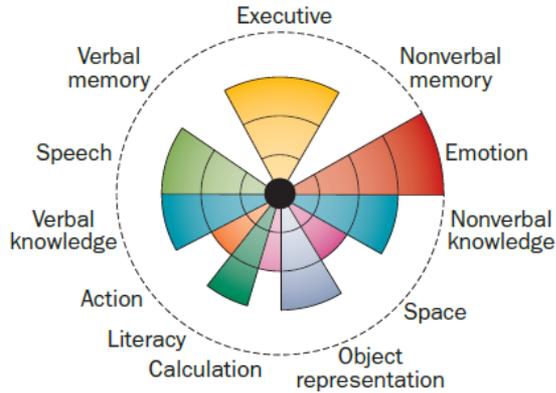


Implications for social prescribing of the lived experiences of people with rarer dementias

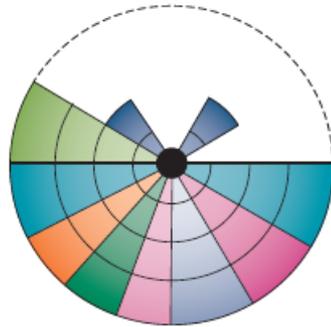
Sebastian Crutch

Dementia Research Centre, UCL Institute of Neurology

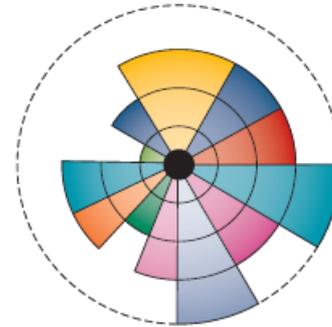
Memory
(e.g. typical AD)



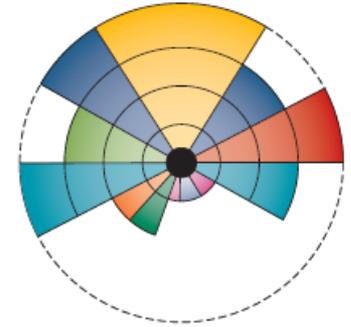
Personality, reasoning
(e.g. FTD)



Language
(e.g. PPA)



Vision
(e.g. PCA)



The person, the condition and so much more



PCA Support Group Meeting, The Hub, Wellcome Collection, November 2017

“Am I the only one with this?”

The impact of multicomponent support groups for those living with rare dementias

Funders: Economic and Social Research Council (ESRC) & National Institute for Health Research (NIHR)

Timeframe: 5 years (January 2019 – December 2023)

Summary: First major study of the value of support groups for people living with or caring for someone with a rare form of dementia. We will be looking at the benefits of meeting other people living with a similar condition, and sharing practical and emotional support.

Workstreams:

- **WS1: Retrospective cohort study (>1000 RDS members)**
- **WS2: Theoretical development (Theories of change)**
- **WS3: Measures development (e.g. resilience)**
- **WS4: Prospective longitudinal study (N=720; 24-48 months)**
- **WS5: Novel interventions (e.g. online support for FTD carers)**
- **WS6: Economic analysis of cost effectiveness**



Short Communication

Pronounced Impairment of Everyday Skills and Self-Care in Posterior Cortical Atrophy

Timothy J. Shakespeare^{a,*}, Keir X.X. Yong^a, David Foxe^{b,c}, John Hodges^{b,c} and Sebastian J. Crutch^a

^a*Dementia Research Centre, Department of Neurodegenerative Disease, UCL Institute of Neurology, London, UK*

^b*Neuroscience Research Australia, Randwick, Sydney, Australia*

^c*ARC Centre of Excellence in Cognition and its Disorders, Australia*

Handling Associate Editor: Carlo Abbate

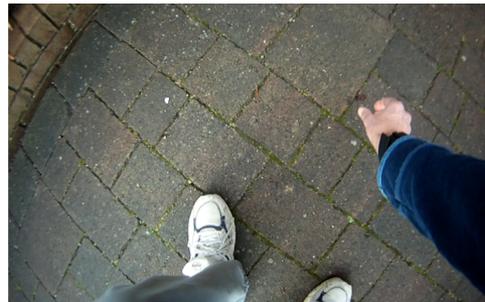


Psychosocial consequences of changes in practical activities:
dependence, independence, interdependence

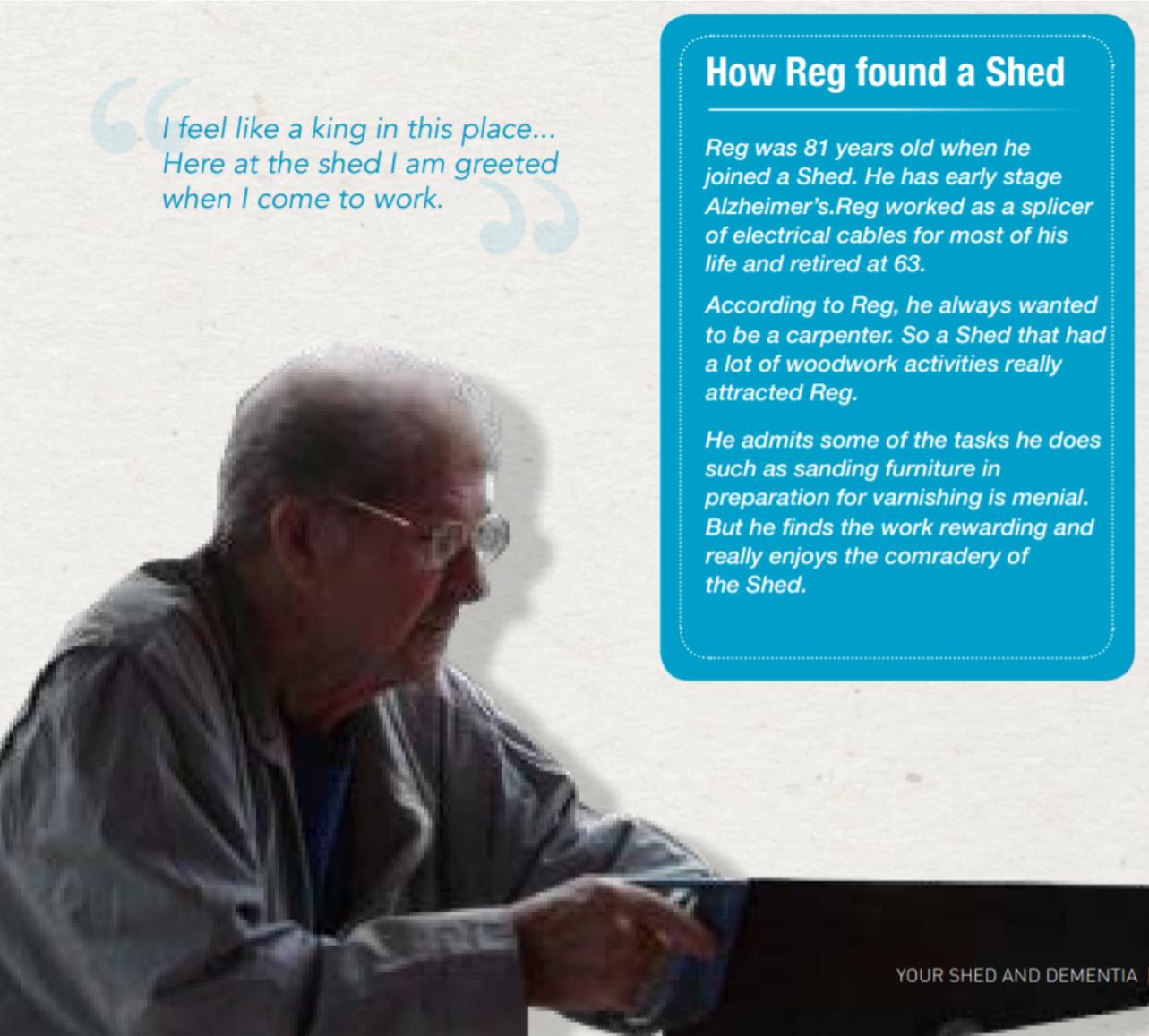
“Somebody who was perhaps a hundred percent academic - and good luck to them doing things that I couldn't do - but who wouldn't know which end of a screwdriver to hold wouldn't miss not being able to do those things, whereas everything you see in this house I built and now I'm just totally useless at all these things, it's so frustrating to me”



Psychosocial consequences of changes in practical activities:
identity



Psychosocial consequences of changes in practical activities:
identity



*I feel like a king in this place...
Here at the shed I am greeted
when I come to work.*

How Reg found a Shed

Reg was 81 years old when he joined a Shed. He has early stage Alzheimer's. Reg worked as a splicer of electrical cables for most of his life and retired at 63.

According to Reg, he always wanted to be a carpenter. So a Shed that had a lot of woodwork activities really attracted Reg.

He admits some of the tasks he does such as sanding furniture in preparation for varnishing is menial. But he finds the work rewarding and really enjoys the comradery of the Shed.

YOUR SHED AND DEMENTIA

Meaningful and social



Adapting not necessarily avoiding

Social prescribing case study (thanks to Nikki Zimmermann)

Gentleman 71, diagnosed with LPA 3 years ago

Speech problems limited engagement in amateur dramatics & associated with low mood

Tried an art class to find a new hobby and reduce anxiety/depression

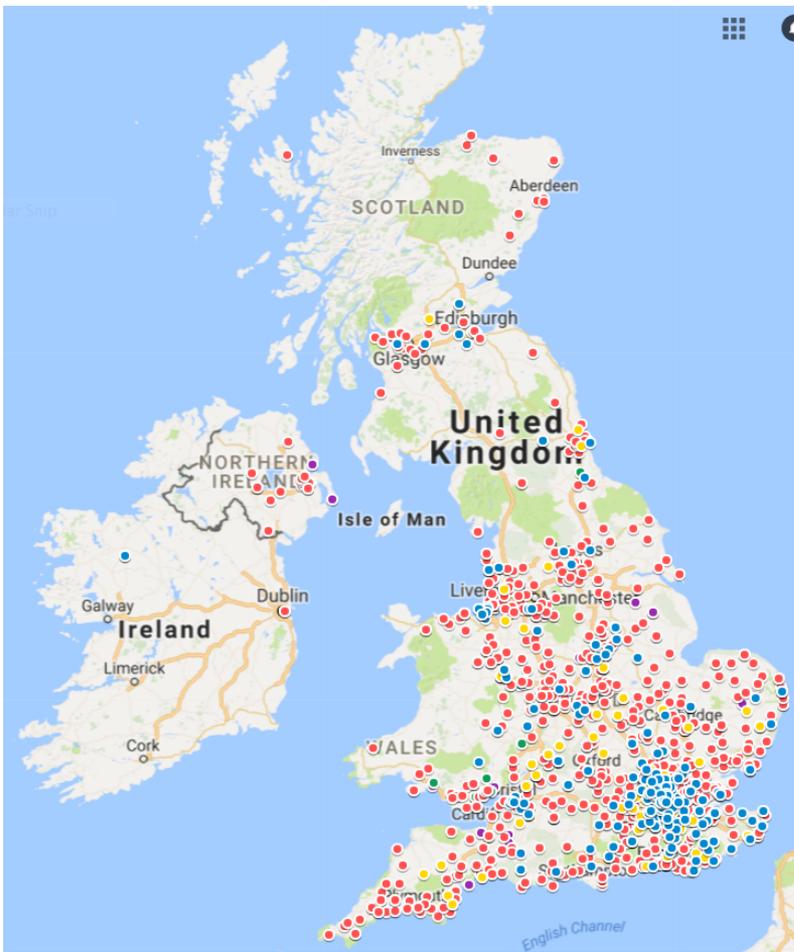
Found sense of achievement, enjoyed non verbal expression, looked forward to classes, and started drawing at home, in parks etc.

Received Student of the Year Award from the College

...and discovering something old, e.g. communication partner training with



Discovering something new



Shift.ms is more than just an MS forum, it's a community of thousands.

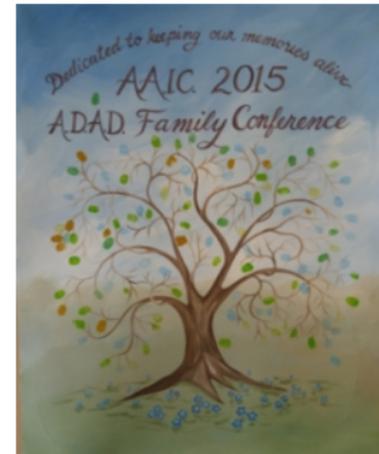
Whether you're looking for advice about living with multiple sclerosis, information about symptoms or just someone to talk to who gets it, you've come to the right place.



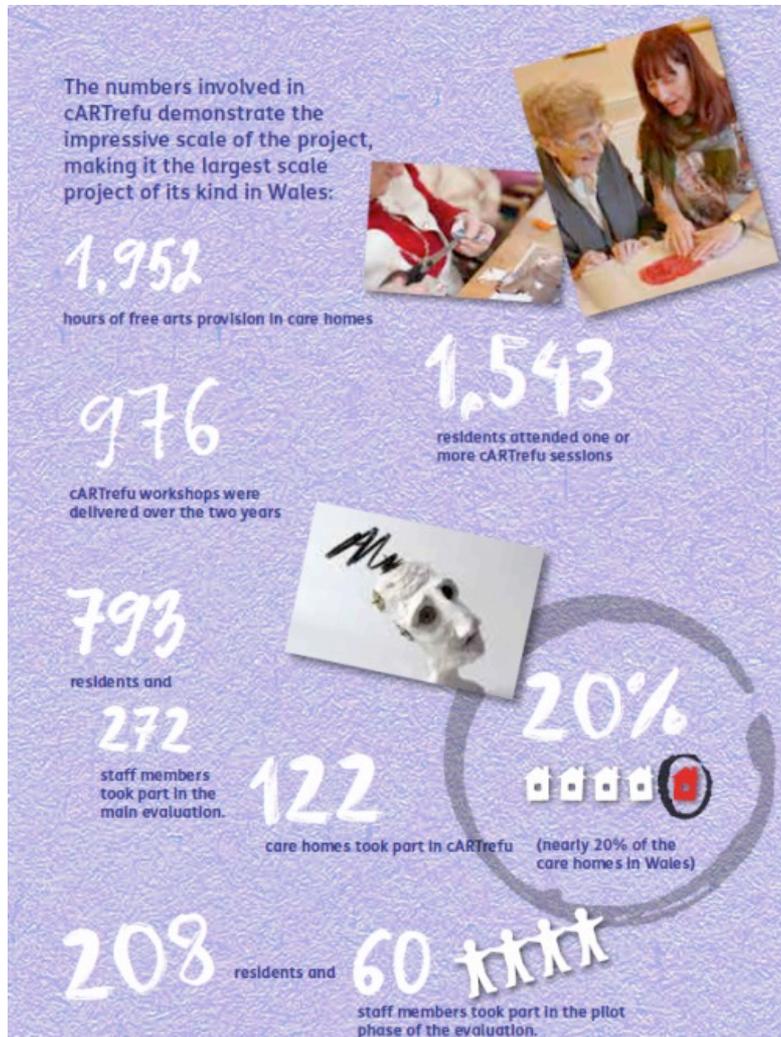
facebook

Posterior Cortical Atrophy awareness

Closed group



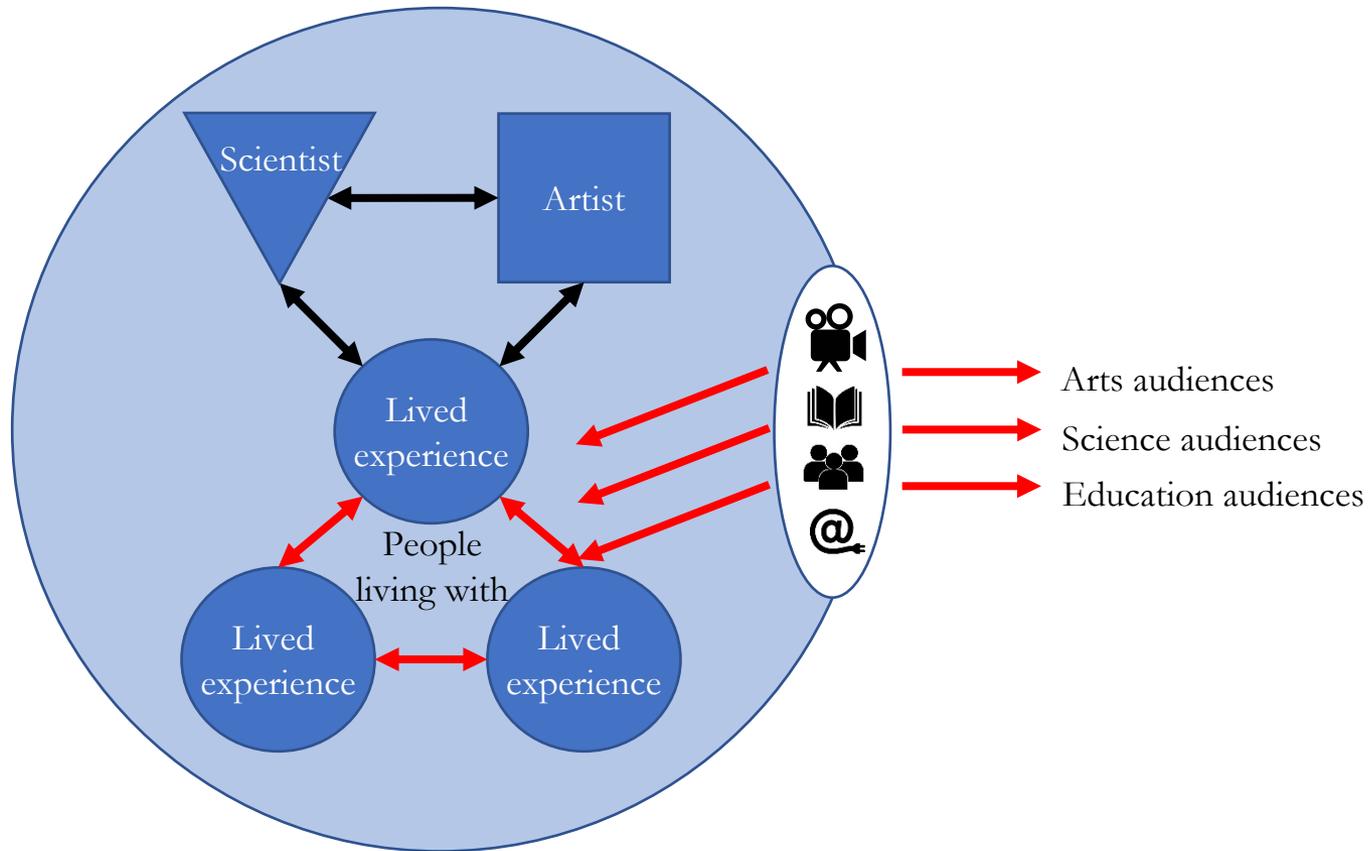
Nothing local is not the same as nothing available



<https://www.ageuk.org.uk/cymru/our-work/arts-and-creativity/cartrefu/>

cARTrefu carer:
 “It made me realise residents are more capable than one might give them credit for.”

Social prescribing FOR not just BY healthcare professionals



Social prescribing FOR professionals BY those with a lived experience



Simon
Ball



Jon Williamson
& Lori Hayden



Valerie
Blumenthal



Trina
Armstrong



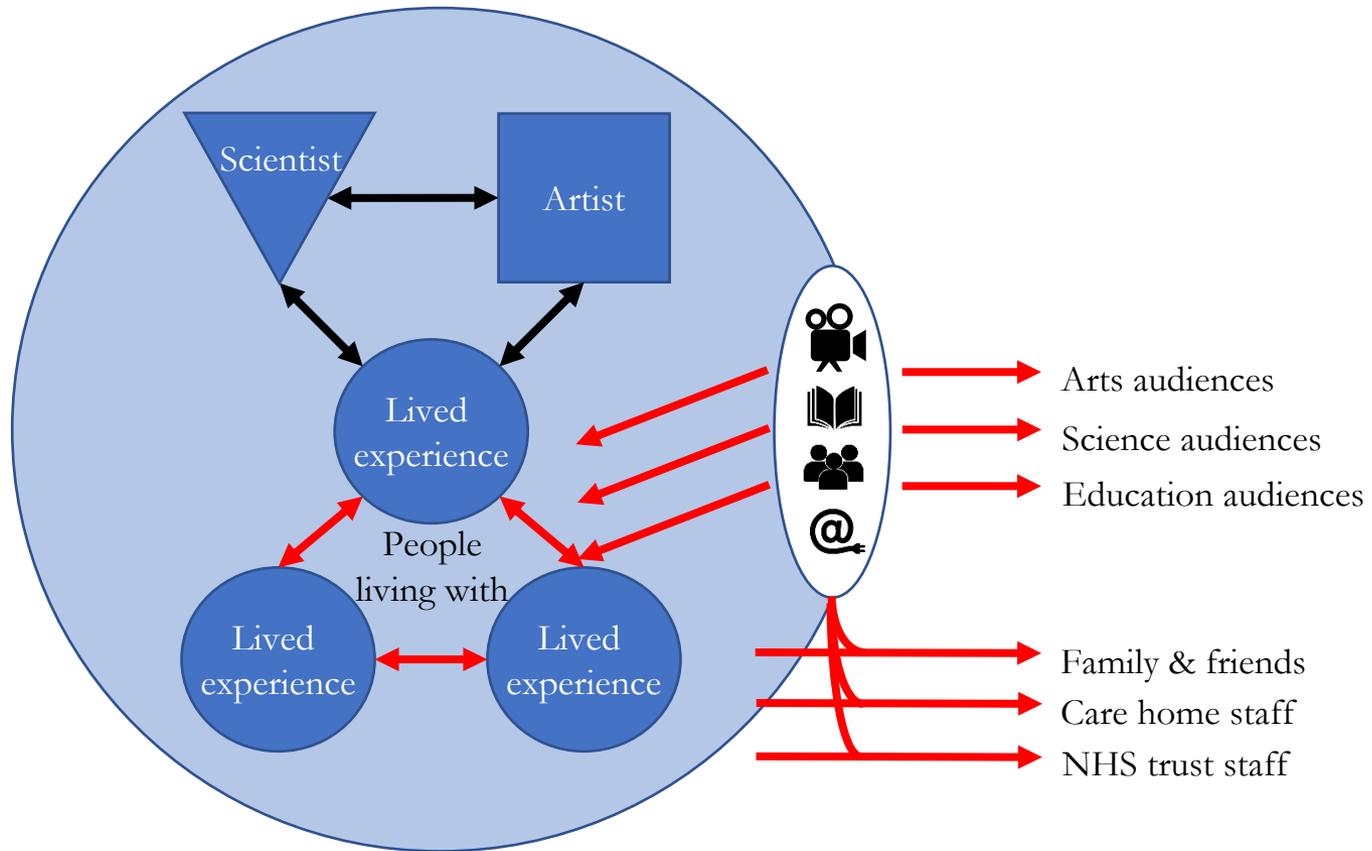
Graeme
Armstrong



Kailey
Nolan

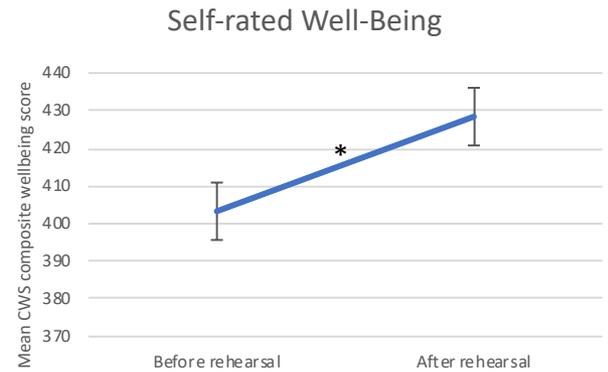
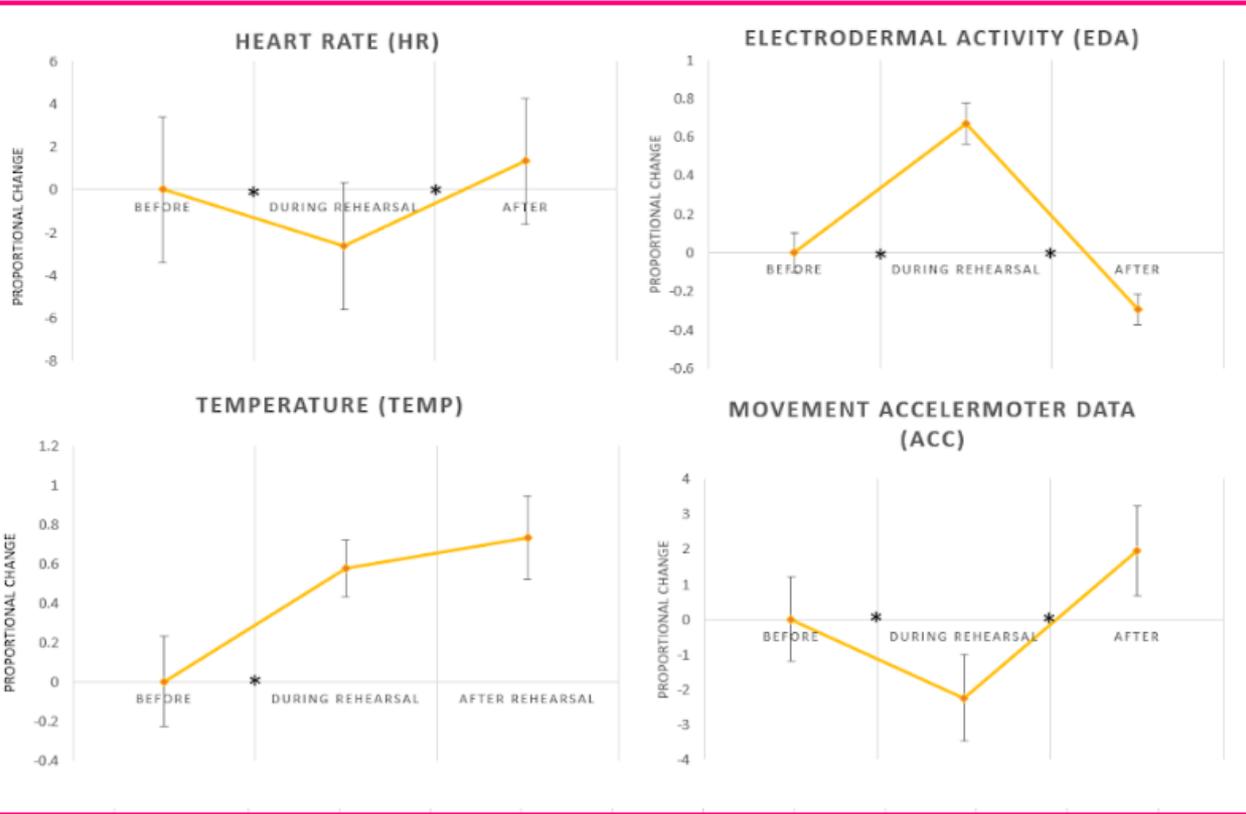
Do I See What You See?
Simon Ball, 2018

<http://www.createdoutofmind.org/stories-and-reflections/do-i-see-what-you-see>



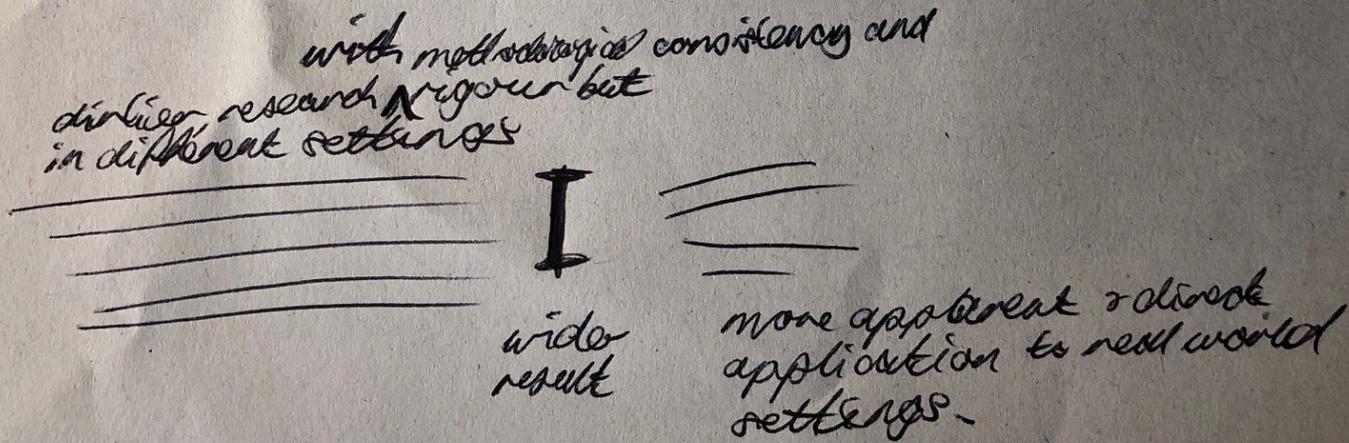
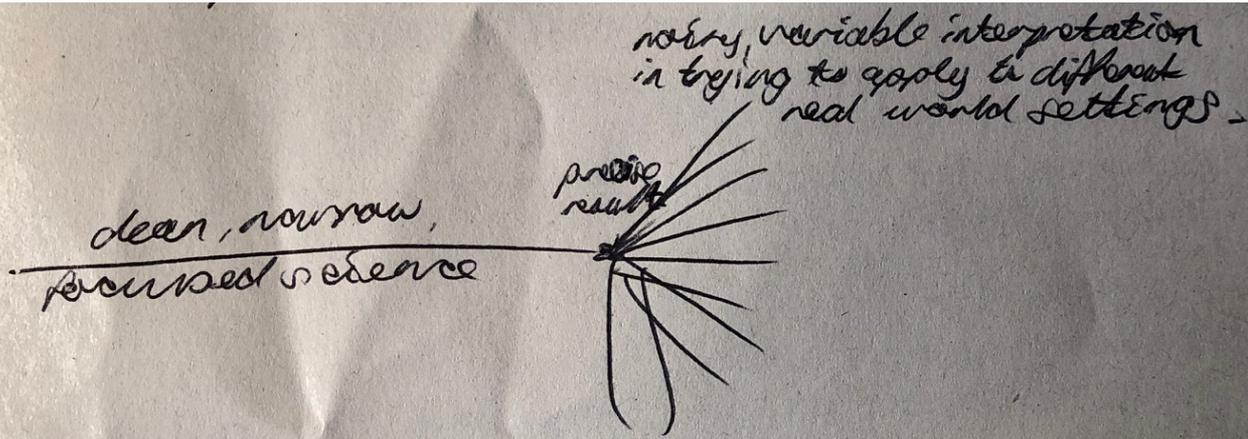
Social prescribing FOR professionals BY those with a lived experience

What should we expect from evidence?



Our Dementia Choir with Vicky McClure
BBC 1, 2019

What should we expect from evidence?



Clean and dirty science

“It’s made a real difference to me being involved in the trial. For many years, I felt useless and unable to have any effect on a disease that has been rife in my family. ... Being part of DIAN-TU and having such wonderful support has helped me grow stronger. It has enabled me to deal with many skeletons [in] my closet and leave them behind. The work that you do goes much further and deeper than a cure”.

Familial Alzheimer’s Disease clinical trial participant

...but also remembering the value of
science/research in and of itself



‘What is this new genre of science-weepy documentary, though?!’

William Utermohlen (1933-2007)



Crutch, Isaacs & Rossor, *Lancet*, 2001

A picture is worth a thousand
factsheets/policy statements/...



*For further insights into rarer dementias, and dementia and the arts,
take part in our free online video-based training courses:*

The Many Faces of Dementia

<https://www.futurelearn.com/courses/faces-of-dementia>

Dementia and the Arts: Sharing Practice, Developing Understanding and Enhancing Lives

<https://www.futurelearn.com/courses/dementia-arts>



**RARE DEMENTIA
SUPPORT**

Our vision is for all individuals in England and Wales with or at risk of one of these rarer forms of dementia to have access to specialist information and support, and contact with other individuals affected by similar conditions.

www.raredementiasupport.org



Leading the fight
against dementia
**Alzheimer's
Society**



Created Out of Mind aims to explore, challenge and shape perceptions and understanding of dementias through science and the creative arts.

createdoutofmind.org  [@createdhub](https://twitter.com/createdhub)  [@createdoutofmind](https://facebook.com/createdoutofmind)  [@createdhub](https://instagram.com/createdhub)