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# Supporting wellbeing through PEeR Befriending Outcomes of the SUPERB trial for people with aphasia

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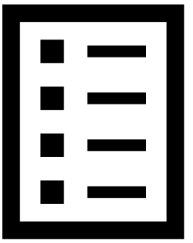


## Disclosure statements

- The **SUPERB trial** was funded by **The Stroke Association**
  - Priority Programme Award on Psychological Consequences of Stroke (PPA2015/03)
- **Katerina Hilari**
  - Receives a salary from **City, University of London** (financial)
  - Is on the Board of Trustees of **Aphasia ReConnect** (non-financial)

# Outline

- Psychological consequences of stroke and aphasia
- SUPERB trial findings
  - Feasibility
  - Acceptability
- Clinical outcomes
- Qualitative – views of people with aphasia



# Psychological consequences of stroke and aphasia



# Depression and anxiety after stroke and aphasia



- Prevalence of depression in **stroke 31%** for all stroke survivors (Hackett et al., 2014)
- **Persistent 29%** even 10 years post stroke (Ayerbe et al., 2013)
- Prevalence of depression **for people with aphasia: 43% to 70%** (Kristo & Mowll, 2021)
- People with aphasia **7.5 times more likely** to exhibit depressive symptoms than those without (Zanella et al., 2022)
- Anxiety post stroke and aphasia: **44%** (Morris et al., 2017)
- **High distress / depression** early post-stroke and **loneliness and low satisfaction with social network** -> predictive of depression later (Hilari et al., 2009)
- High distress / depression one of strongest predictors of **reduced quality of life** (Hilari et al., 2003; Hilari et al., 2012)

# National Guidelines

## UK National Clinical Guideline for Stroke (2016; 2023)

### *Recommendations*

- Services for people with stroke should **offer psychological support to all patients** regardless of whether they exhibit specific mental health or cognitive difficulties
- All members of the stroke MDT should be **trained and engaged** in supporting those with psychological problems following stroke.

## **NATIONAL CLINICAL GUIDELINE FOR STROKE** for the United Kingdom and Ireland

2023 edition



[www.strokeguideline.org](http://www.strokeguideline.org)



## And yet...

- People with aphasia are often **excluded from mental health interventions** due to their communication difficulties (Baker et al 2019) **and from trials** on the effectiveness of psychological therapies for post-stroke depression (Allida et al., 2020)



## Bringing all this together...

Addressing **wellbeing is a priority** for people with aphasia.

*Depression matters:* increased incidence of depression

- Reduces effects of rehab; impacts on long-term outcome; leads to higher mortality rates

(Ferro et al., 2009; Hackett et al., 2008)

*Depression is persistent*

- Need interventions that **promote wellbeing and adjustment** with stroke and aphasia and may prevent depression

(Baker et al., 2018 SLR)







## The **SUPERB** trial (NCT02947776)

Level 1 intervention

for those with **no mood problems** or **low mood**

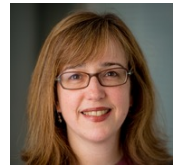
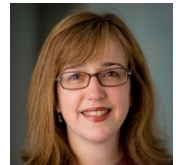
support PWA at a **time of increased need** - discharge

Led by Clinicians - Speech & Language Therapists

**Delivered by people with aphasia**

## SUPERB trial

- Exploring the **feasibility** of a definitive phase III RCT for Supporting wellbeing through **PEeR Befriending** (SUPERB)
- Hilari K (CI), Marshall J, Simpson A, Thomas S, Flood C, Northcott S, McVicker S, Goldsmith K



# SUPERB team



- Dr Nick Behn – Trial Manager
- Dr Becky Moss – Researcher, Befriender Trainer
- Ms Katie Monnelly – Qualitative Researcher
- Dr Abi Roper – Researcher
- Dr Sally McVicker - Befriender Trainer & Supervisor

## Consultants with aphasia



## Befriender group



## User group



# Peer befriending

- Peer befriending is social and emotional support **provided by people with experience of a condition** to others sharing a similar condition to bring about a desired social or personal change.
- Peer befrienders, who have achieved improvements in their own condition, offer **acceptance, respect, empathy, support, companionship and hope and share experiences and ideas about how to cope.**
- Evidence (systematic review and meta-analysis):
  - moderate but significant **positive effects of befriending on depressive symptoms** [SMD=-0.75] (Mead et al., 2010)
  - In neurological conditions: **positive outcomes in health, confidence and self-management** (Aterman et al., 2023)

# Why peer-befriending?



Capitalises on the skills of people with aphasia



In toolkit of clinician's resources / packages of care



Getting out of the house



Readiness for groups

**usual care**



**30**

**+ peer befriending**



**30**

**6 visits**

# 10 befrienders







## **Training**

5-6 hours across 2-3 days



## **Supervision**

Monthly group sessions

Individual as and when needed



**4 months**  
**10 months**





**depression**

**wellbeing**

**participation**

**community integration**

**friendships**

# Feasibility

Rate of consent

Rate of recruitment

Recruited to target

Proportion who

consent ✓

Withdrawals ▼

# Participants

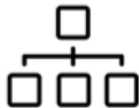


Variable	Usual n=28	Peer n=28
<b>Aphasia severity</b>		
<i>Very severe/severe</i>	7	7
Moderate	2	3
Mild	19	18
<b>Mobility</b>		
Wheelchair user	6	6
No wheelchair	22	22
<b>Gender</b>		
Female	14	13
Male	14	15
<b>Age</b>	69.7 (13.4)	70.5 (13.7)

~~N=62~~ consented

~~N=10~~ Peer befrienders, 8 female

# Acceptability



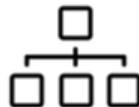
**study processes**



**outcome measures**



**researchers**



**peer befrienders**

# **Clinical Outcomes**

**for people with aphasia**





# Outcomes

12

depression screen  
(GHQ-12)

baseline

baseline



3

+ peer befriending



usual care

0



# Outcomes

12

depression screen  
(GHQ-12)

10 months

10 months



3



+ peer befriending



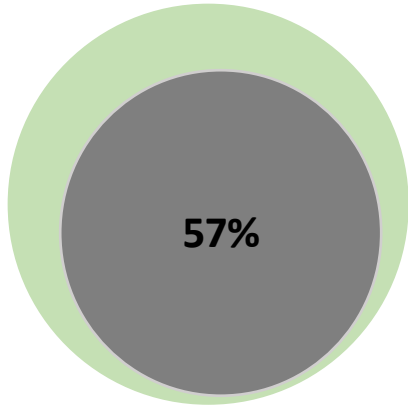
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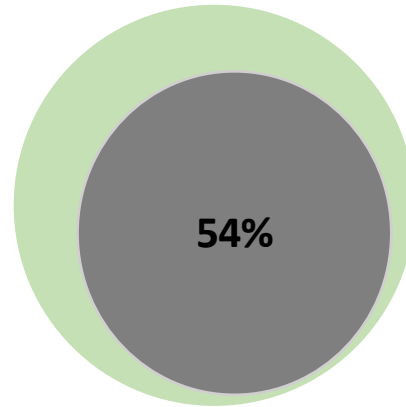
usual care

# GHQ-12 categorical - Baseline

- Usual care arm

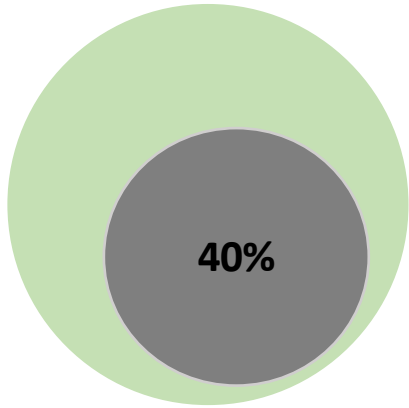


- Peer arm

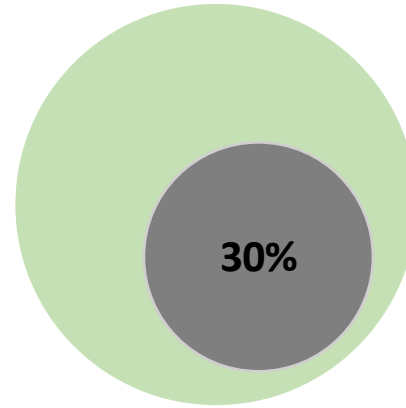


# 4 months

- Usual care arm

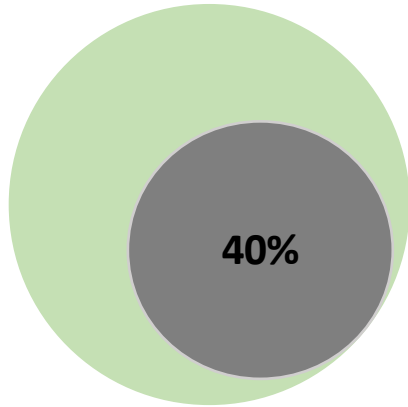


- Peer arm

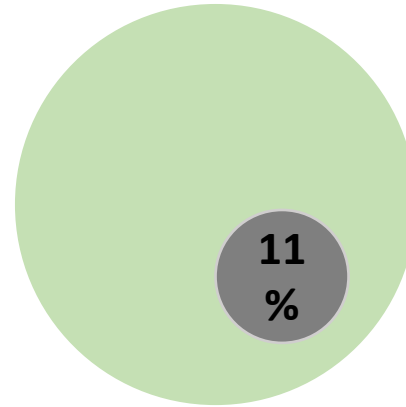


# 10 months

■ Usual care arm



■ Peer arm



88% decrease in the odds of caseness on the GHQ-12 [0.12 (0.01, 1.01)]

# Qualitative findings

An illustration showing a woman on the left with her hand on the shoulder of a man on the right who is covering his face in distress. Two speech bubbles are positioned above them. The background is light beige with small white specks.

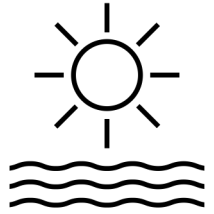
**10 peer  
befrienders**

**10 people  
with aphasia**

# **Befriender's experience**



## Positive aspects



- Training
- Group supervision and peer-support
- One to one supervision
- Visits
  - Sharing stroke stories
  - Chatting
  - Going out e.g. coffee shop
- Close bonds
- Humour
- Common, shared experience
- Relationship: two way and reciprocal

*'The best thing is that I like happy and they satisfied with me that I've been there, they feel good about theirself, and I feel good about myself, yeah, that's the best thing.'* (Zainab)

*'I love it because also it benefits me, erm, it's a bit of a challenge... open the door and see who it is. I know I've got someone behind me... I feel secure in that way.'* (Joyce)

## Challenges



- Logistics e.g. negotiating complex journeys, scheduling appointments
- Managing unexpected incidents, witnessing befriender's distress
- Challenging communication environments
- Repeated cancelled visits or a befriender not engaging

interesting  
rewarding

secure  
challenge



pre-stroke self  
renewed appreciation

# **People receiving visits - their experience**

## Befrienders

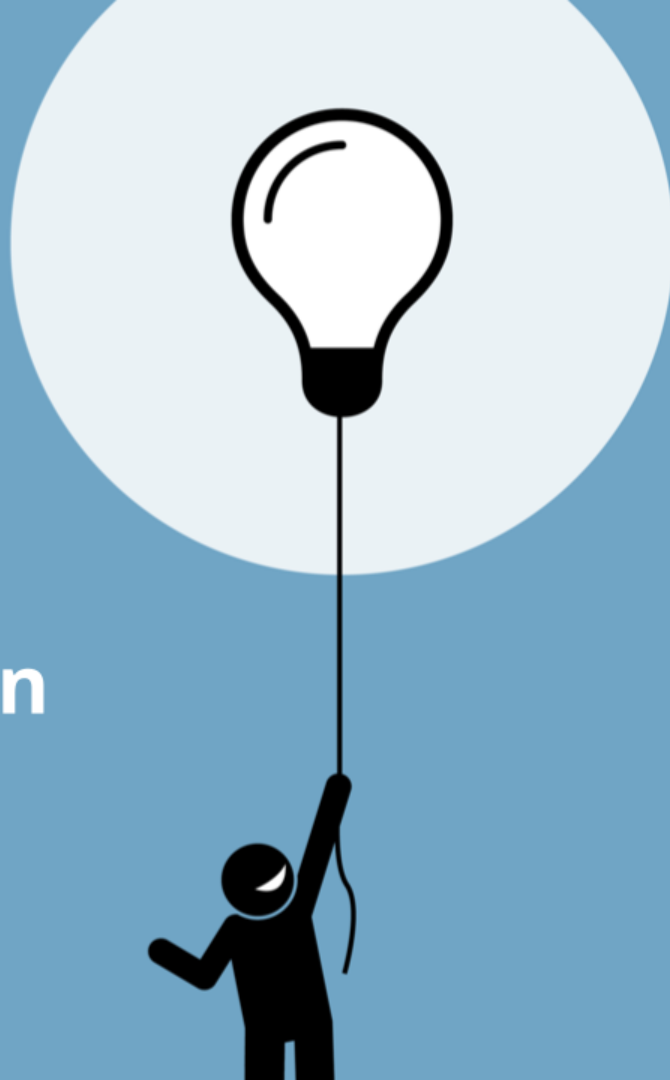
- ✓ Chatty
- ✓ Sympathetic
- ✓ Patient

## Visits

- Planning visits straightforward
- Overall endings were ok
- ✓ People felt the **scheme had benefitted them.**



**inspiration**



**future  
recovery**

**Unanimously agreed they would recommend peer-befriending**

**emotional  
well being**





**they are experts**

**they have been through the same path**

**so they are the best people to talk to**

**It gives you the confidence and hope that  
people have been through it that you can  
also go through it and be perfect**

**it's not the end of life**





**living well with aphasia**

**making a difference  
helping others**

**make sense of  
their aphasia**

# Summary and conclusions



## SUPERB peer-befriending scheme

✓ Feasible and acceptable

→ Need to monitor the wellbeing of the befrienders

→ Training

→ Supervision and support

✓ Clinical outcomes: preliminary evidence of benefit of the befriending intervention in terms of depression

✓ Positive experience: both parties found it helpful and valuable – they would recommend it to others

Need for preventive / early stage interventions – peer-befriending may be a useful add-on to service provision

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**Thank you**



# SUPERB information, papers, videos

