

# **‘My friends are my anchors’: friendship and aphasia**

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# Acknowledgements



- Advisors with aphasia
- Supervisors
- Interviewees



*different* **Strokes**

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# About the project

- Preliminary research question:
- How do people with aphasia (of working age) define and talk about friendship?
- How can people with significant language impairment engage in qualitative research?

# What is aphasia ?

- A language impairment typically following left hemisphere stroke
- 250,00 people with aphasia in UK
- Approximately one third of those who survive stroke
- Changes in communication, identity, social participation and inclusion

# The experience of aphasia ?



Reactions of self – internal world

Reactions of family and friends – social world

# Why friendship?

- Importance to younger people with aphasia
- Prioritised by project advisory group
- Friends are good for your health
  
- Topic largely neglected by health and social care services and medical model bias of most stroke research

# What happens to friendships after stroke and aphasia?

- Social networks reduce in size
- Social activities reduce in number
- Family relationships change e.g. increased frequency of contact
- Hilari & Northcott (2006); Cruice et al (2006); Davidson et al (2008)
- Research typically prioritises quantitative change and provider perspective

# Stroke and aphasia research

## Barriers to relationship /friendship

- Communication barriers
- Depression and psychological distress
- Poor awareness of aphasia and what to do
- Transport and physical impairments
- Loss of work and leisure activities
- Financial barriers
- Temporal barriers

(Parr 2004; Northcott & Hilari, 2011)



# Methodology

- Participatory Action Research
  - Looking, thinking, acting (Stringer, 1999)
  - ‘the intent of participatory action research is to accent the processes of collaboration and dialogue that empower, motivate, increase self esteem and develop community solidarity (McArdle and Reason, 2006)
- Advisory group keen to prioritise *action* and relevant benefits to people with aphasia

# Project stages – current data

Interviews x 12

Age range 20-60; 2 -20 years post stroke

## Exploratory

how younger people with aphasia define and talk about friendship

## Innovation

Developing and testing a range of creative friendship products

## Evaluation

Evaluating the impacts of the friendship products for a wider group of people with aphasia

Advisory group meetings x 10

# Methods

- Issues in interviewing people with aphasia
- Issues in gathering phenomenological data
- Techniques used in interviewing – ‘supported conversation’
- Props and resources – pen and paper, pre prepared images, diagrams, word lists, additional time
- 3 dimensional verification – on line, follow up member checking , advisory group review

# Findings - Who are your friends?



Grant

Emily



Sarah

# Who are your friends?

Work friends

Family –  
partners,  
cousins, aunts,  
children

Carers, therapist,  
support workers

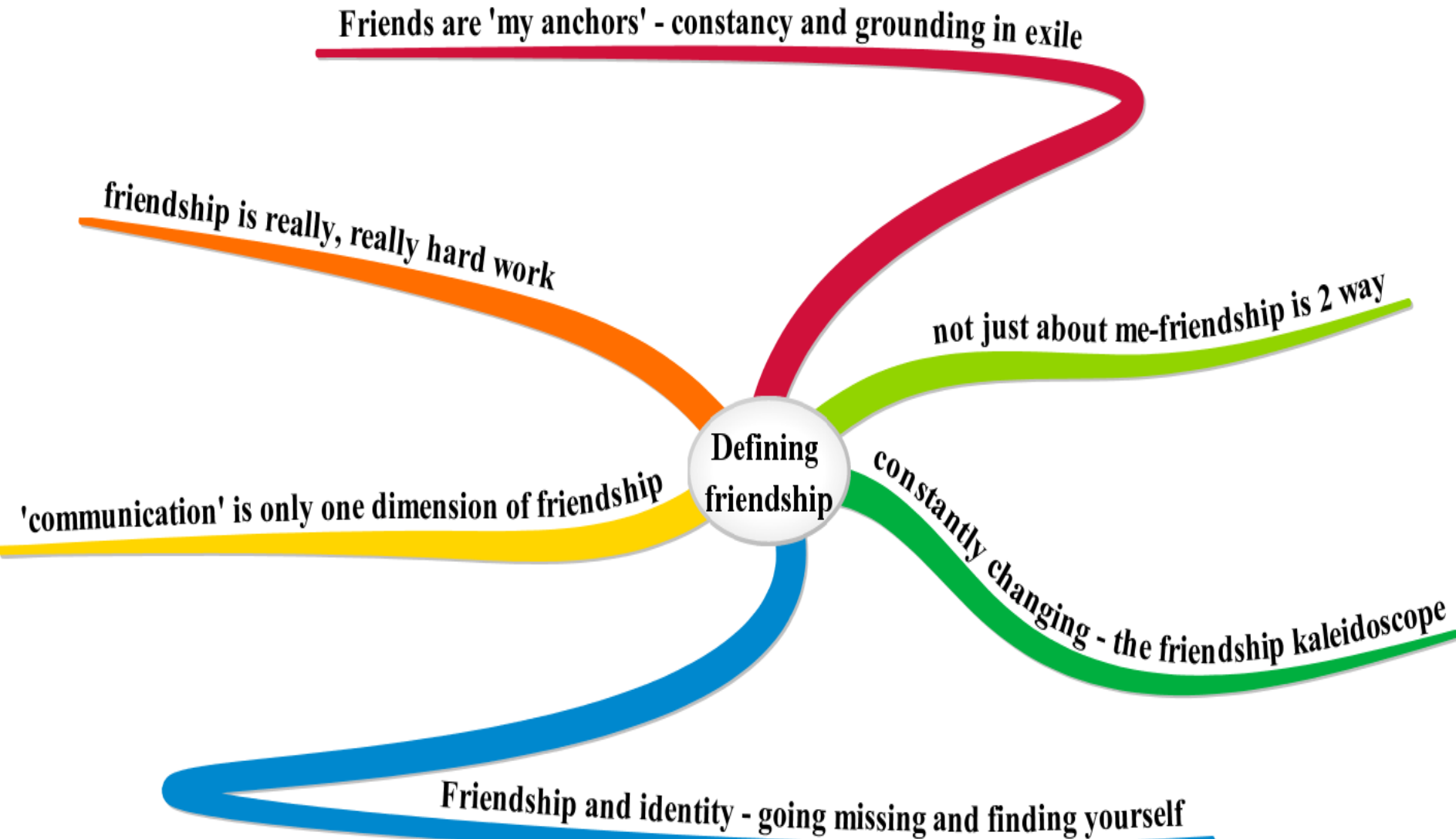
Self

People with  
aphasia, 'fast  
friends'

Old friends –  
school, university,  
family history etc

New friends –  
volunteering,  
clubs, activities

# Findings - overview of themes



# 'My friends are my anchors'

- Aphasia as disembodiment and social exile;
- Friends ground and anchor you
- CP: Could you say a bit more why these [hand over stones] friendships are important?

B: Erm, [clears throat], erm, okay I told you about erm, .. they are an anchor [hand on chest] for me, erm, when something ... erm, kind of disturbing happens to me erm, that I .. erm, erm, my confidence goes [holds chest] or erm ooh [flutters fingers on chest] erm, erm, erm, feel unsteady. Then I think of erm, them [laughs] and ... [laughs] their voices saying okay, if I told them this what would they say back? ' (Binda, age 49, 18 years post stroke )

# 'My friends are my anchors'

- 'I have a carer on the Tuesday and she is a really good friend because I see her every single Tuesday. Erm, and because I see her every Tuesday she is a very good friend to me. I think I talk to her about the kind of things that maybe upset me or, ...erm, confuse me a bit. So she is very good'  
(Katie, age 57, 6 years post stroke)



# Friendship and identity

- Losing your core ; identities imposed by others ;
- rebirth and spiritual journeys
- importance of collective identity
- ‘And slowly I had an identity by erm, an open space by choosing, choosing erm, erm, a friend and choosing an activity outside, well outside my family, my protective net. So the, the, erm, I feel [clears throat] erm, that’s why friendship is so crucial. Erm, erm, it’s so crucial in order to get, you know, what am I about?’ (Binda)

# Friendship and identity

- [CP: What gets in the way of friendship?]

K: yeah it is me. Because in the first three years I wasn't anybody to be with. Whereas now I feel I do have a friendship to believe in. It is erm ... I believe that I can be a friend to Dawn, can be a friend to Penny, to Daphne

CP: you had three years where you feel ... three years where you feel that you couldn't be a friend? Why is that?

K: because I didn't know myself. Erm ...I wasn't friends to anybody. (Katie)

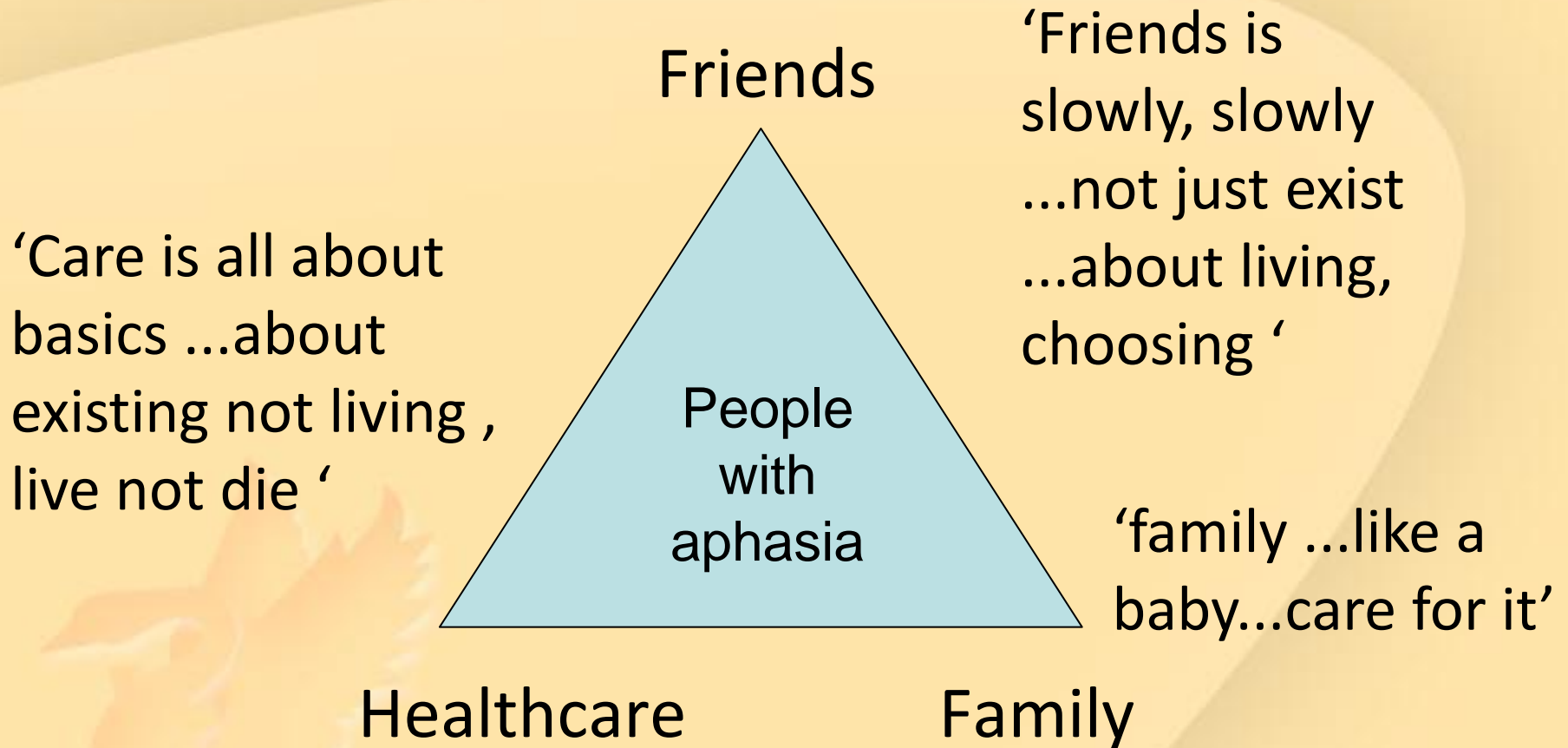
# Friendship is 2 way

- Power , protection , balance, reciprocity
- Altruism & contribution; peer relationships
- ‘I, I ..try not to be with a rescuer. Erm .. *pity*, erm, erm, *pity* is shown by erm, a person who’s a rescuer . Fuck off! ‘ (Binda)
- ‘Well a person is only a friend if they can open up everything to you. When I first had the stroke nobody was allowed to tell me anything’ (Katie)

# Friendship is 2 way

- On a conversation it's not about erm, its not always about me [laughs]. And its not like an interview, erm, its a conversation. So I want to hear things about you too. And erm that's what I feel makes a good friendship as well. Erm [laughs] reciprocity' (Priya, 24, 2 years post stroke)
- Commenting on successful, sustained friendships: 'Equally. E-equal...e-equal...e-equal...my friends and me [nodding, hand hovering over friendship stones]' (Sarah, 60, 10 years post stroke)

# Themes and relationships



# Challenges of study

- Hidden and diverse population
- Recruitment predominantly from support groups not most isolated individuals
- Inclusion of people with very severe aphasia
- Identifying meaningful 'Actions' – relevant friendship 'interventions'

# Conclusions

- Friends and friendships are largely neglected in rehabilitation
- Friends have the potential to ground people with aphasia, help them to make sense of internal and external worlds
- Friends and friendships provide alternative opportunities for reaching out – beyond ‘rescuing’ or ‘throwing a lifebelt then you’re alright’

‘You know, through *aphasia* erm, we are so isolated. I mean, I erm, I’m not now but I was erm, we are so isolated and ..friendships are a very, very, er ..an ..absolute part of our relation. ..Er, erm, we need to relate.’ (Binda)

Thanks for listening