Exploring experiences of friendship and aphasia: A workshop

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Friendship and Aphasia Research Group
Acknowledgements
About the session

• Frameworks for thinking about living with aphasia
• Philosophy of Friendship
• Friendship and Aphasia Research Project
• Practical approaches to working with friends
Working with relationships

Professional practice
How do you respond to issues of social connectedness and social isolation?
What are your worries and challenges?
‘Individuals with adequate social relationships have a 50% greater likelihood of survival compared to those with poor or insufficient social relationships. The magnitude of this effect is comparable with quitting smoking and it exceeds many well-known risk factors for mortality (e.g., obesity, physical inactivity).’ (Holt-Lunstad, Smith & Bradley Layton, 2010)

Friends are good for your health!
Friendship and current policy themes

- Wellbeing & human dimensions of healthcare
- Self-efficacy & self-management
- Older people & loneliness
- Social capital & strengthening communities
Caring & Wellbeing – A lifeworld led approach

Evidence from head, hand and heart

A theory of suffering & wellbeing

What constitutes humanising/dehumanising care?
(Todres et al, 2009; Galvin & Todres 2013; Dahlberg et al, 2008)
<table>
<thead>
<tr>
<th>Forms of humanisation</th>
<th>Forms of dehumanisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Takes account of feelings, mood, how things are on the inside</td>
<td>As if you are invisible, labelled, just an object</td>
</tr>
<tr>
<td>Insiderness</td>
<td><strong>Objectification</strong></td>
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<tr>
<td>Having a say; free to make choices</td>
<td>Passive recipient; no say in decisions; done to</td>
</tr>
<tr>
<td>Agency</td>
<td><strong>Passivity</strong></td>
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<tr>
<td>Treated as unique person, as an individual</td>
<td>Labelled; in a group; all assumed to be the same</td>
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<tr>
<td>Uniqueness</td>
<td><strong>Homogenisation</strong></td>
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<tr>
<td>Connected to other people; sense of belonging</td>
<td>Isolated and alone with your experience</td>
</tr>
<tr>
<td>Togetherness</td>
<td><strong>Isolation</strong></td>
</tr>
<tr>
<td>Understanding what’s happening; the whole &amp; the parts</td>
<td>Lost; hard to make sense of events and condition</td>
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<tr>
<td>Sense-making</td>
<td><strong>Loss of meaning</strong></td>
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<tr>
<td>Finding continuity; connecting past, who you are now and future hopes and dreams</td>
<td>Unfamiliarity of events; no continuity or connection to who you are</td>
</tr>
<tr>
<td>Personal Journey</td>
<td><strong>Loss of Personal Journey</strong></td>
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<tr>
<td>Comfortable, relaxed, familiar, ‘at home’</td>
<td>Displaced in a strange place, unfamiliar culture</td>
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<tr>
<td>Sense of Place</td>
<td><strong>Dislocation</strong></td>
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<tr>
<td>Linking mind &amp; body &amp; connection to the world</td>
<td>Focus on body &amp; symptoms; fixing a body part</td>
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<tr>
<td>Embodiment</td>
<td><strong>Reductionist view of the body</strong></td>
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Framework for Humanising Care (after Todres et al, 2009)
<table>
<thead>
<tr>
<th>Traditional Rehabilitation</th>
<th>Lifeworld led rehabilitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Task focus</td>
<td>Experience focus</td>
</tr>
<tr>
<td>Thoughts</td>
<td>Thoughts and feelings</td>
</tr>
<tr>
<td>Individual</td>
<td>Relational/ community</td>
</tr>
<tr>
<td>Privileges rational knowing</td>
<td>Privileges implicit, embodied knowing</td>
</tr>
<tr>
<td>Patient learning</td>
<td>Mutual learning</td>
</tr>
<tr>
<td>Person-centred, patient focus</td>
<td>Human-centred, focus on shared humanity</td>
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<tr>
<td>Doing</td>
<td>Being and doing</td>
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<tr>
<td>Certainty, straight lines</td>
<td>Uncertainty and ambivalence</td>
</tr>
<tr>
<td>Focus on possibilities</td>
<td>Possibilities and vulnerabilities</td>
</tr>
<tr>
<td>Dominant restitution narrative</td>
<td>Multiple narratives</td>
</tr>
</tbody>
</table>

From Pound, Ellis-Hill and Mojsa, 2015)
Wellbeing

Doing

Being

Becoming

Belonging

Occupations fostering belonging, connectedness, and contribution

(Wilcock 1998; Whalley-Hammel, 2009; 2014)
Your friends & friendships

Who are your friends?

What’s important for you about friends & friendships?

How have your friendships changed over time?

How & why do you neglect/nurture your friendships?
Meanings of Friendship
Aristotle’s categories of friendship

Friends of pleasure – doing things together e.g. playing tennis, holidays

Friends of utility – colleagues at work, task collaborators

Friends of virtue/excellence – best friends, soul mates
Philosophy and friendship

- Soul friendship (Montaigne)
- Mirror vs secrets view (Cocking & Kennett 1998)
- Caring friendship (Kierkegard)
- Politics and friendship (Aristotle & Cicero)

Potential benefits of an increased focus on friendship ...
- Happiness and wellbeing
- Identity and Personal growth
- Support
- Citizenship
Medicalisation of friendship?

- Diminished social networks after stroke and disability

- Changed relationships and the need for social support

- ‘Friends and family’ ...or family and an occasional friend
About our project

Participatory action research

How do **working-age adults** with aphasia define, experience and **understand** friendship?

Ways to **support** people with aphasia and their friends to **sustain and develop** friendship.
The process of participatory action research

After Stringer, 2007

- Democratic
- Collaborative
- Relational
- Sustained reflection on power
- Process and outcome
Participants

- 40 + people with aphasia in total

- Participatory Action Research Group – co-researchers with aphasia (8)

- 1 to 1 interviews (12 + 16)

- Event participants (30)

- Age range 18-65

- Approx one third participants - severe aphasia

- Approx one third single and/or living alone
Study Methods

Phase 1

Exploratory
12 x in-depth interviews

Phase 2

Innovation
2 Friendship Events

Evaluation & Elaboration
16 semi-structured interviews

22 Research Group meetings + additional face to face and virtual meetings to develop products, talks
Who are your friends?

‘Best friends...the three amigos...falling behind...a rocky road to get their friendship back’

‘fast friends’

My cousin

Ex work colleagues

Friends from school

Flora ... my carer
Findings: Who are your friends?

Work friends

Old friends – school, university, family history, activity etc

Family – partners, cousins, aunts, children

Carers, therapist, support workers

‘Fuck off friends’

Self

Community friends – neighbours, residents, church, pub

New friends – volunteering, clubs, activities

People with aphasia, ‘fast friends’
Findings: What happens to friends & friendships - overview

• Remain the same

• Changes in quantity – friends disappear; make new friends

• Changes in quality

• Changes in priority
Stories of change – different narratives
The Forest of Friendship

Friendship & Identity: going missing & finding yourself
- 'fast friends' & peer support
- rebirth
- resisting imposed identities

creativity: doing friendship differently
- flexible friends
- technology & friendship
- getting out & doing things

Friendship is really, really hard work'
- managing other difficulties
- managing reactions of others
- managing emotions
- making the effort

Communication is only one dimension of friendship
- communication changes & challenges
- the role of communication support

'My friends are my anchors'
- loyalty & constancy
- trust
- belief

Time, time, time
- tempo of conversation
- time & recovery
- friendship & the life course

humour & hanging out
- pets
- just being
- role of humour

'more than me': friendship is 2 way
- power, balance, equality
- making a contribution
- reciprocity

Pound, 2013

the Forest of Friendship model
‘My friends are my anchors’
‘My friends are my anchors’

Space to be vulnerable

Trust
Belief in you

Sacred Monsters, Sadler's Wells Theatre

Loyalty, constancy, grounding
I have a carer on Tuesday and she is a really good friend because I see her every single Tuesday...I talked to her about the kind of things that maybe upset me or I am confused me a bit. She’s very good’ (Katie)

‘I think of my friends as my anchor (...). My anchors’ 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

‘My friends are my anchors and I’m an anchor to my friends ...a circuit ...A large part of me is aphasia ...I kind of don’t budge ...so my friends come to me if they want to, you know ... kind of listening more ‘
‘My friends are my anchors’

My friends are my anchors, do not judge, just there!

My friends are my keys. out from isolation, from exile!
We have fun together, even when confidence goes.

My friends are my anchors!
(Ireland, 2011)
Friendship and Identity

- Reconfiguring identity
- 'Fast friends' & peer support
- Rebirth
- Resisting imposed identities

Friendship & Identity: going missing & finding yourself
‘My family were great and everything ...but my friends were like fresh air’ (Priya)

‘in the first three years I wasn’t anybody to be with... ...because I didn’t know myself ...erm I wasn’t a friend to anybody’ (Katie)

‘My family honestly does not understand the concept of friends...they don’t see the importance of my friends’ (Binda)
‘Professional people and family they give you a lifebelt and cuddle. But friends give you a space and time to express yourself. They understand you, they know what you like and not like – what make you tick. They can transform your life and confirm your identity’ (Barbara)
‘Fast Friends’ and peer support

‘the importance of the *peer* support ...has been *enormous*! the benefit has been far greater than any drugs or ... ... Erm, it’s so important. It is, you go you can relax. You don’t, you know, you can *be yourself* whatever you are now. You know, you can be that person. *So important.* It’s made such a difference to my life’ (Derek)
Friends and biographical continuity

- Life thread model (Ellis-Hill et al (2008))

Frayed life threads post-stroke
From Ellis-Hill et al, 2008
Frayed life threads; life threads joining up
From Elllis-Hill et al, 2008

The role of friends in mending frayed threads, weaving new biographical stories, creating narrative coherence? (Shadden et al, 2008; Barrow 2014)
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Friendship & aphasia
- just being
- role of humour
- pets

Creativity: doing friendship differently
- getting out & doing things
- flexible friends
- technology & friendship

'Friendship is really, really hard work'
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Communication is only one dimension of friendship
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Time, time, time
- 'more than me': friendship is 2 way
- power, balance, equality
- making a contribution
- tempo of conversation
- friendship & the life course

'My friends are my anchors'
- loyalty & constancy
- trust
- belief

Pound, 2013

the Forest of Friendship model
Any changes in your friendships after stroke & aphasia?

What are the challenges?

What has worked well with friends?
Friendship is hard work.
Hard Work

No speech is not everybody cup of tea
Old friends came to my home
but could not talk to them,
was horrendous, enormous effect.
HARD WORK!

Doesn't see them too much,
they are busy with everything,
That is HARD WORK too!
Creativity: Doing friendship differently

- Getting out & doing things
- Flexible friends
- Technology and aphasia

Creativity: Doing friendship differently

Friendship and aphasia
"I would say it’s (the internet) almost a life saver actually...if I had my stroke in thirty years ago my life would be, erm well ...it would have been horrible. Couldn’t have done much...and people won’t understand what the problem is’ (David)

Friendship and technology
Humour and Hanging out
Animals are very important as friends, more so after a traumatic injury, they are non judgemental...and are totally reliant on you for their wellbeing, so the sense of achievement for providing for them is enormous’ (Derek)

‘I come out with words that are laughable...amusing...all my friends without aphasia...we scream with laughter at words that sound the same...that for me is an important aspect of relationship...humour’ (Binda)
Friendship & aphasia

'Time, time, time'

'My friends are my medicine'

'Two way traffic'

'more than me': friendship is 2 way

power, balance, equality

reciprocity

making a contribution

tempo of conversation

time & recovery

friendship & the life course
Two Ways!
Two dimensions, my friends and me,
Friendship is not only about me.
Two ways!
They talk seventy percent and I talk thirty percent!

Friends can open up everything to you,
to the darker side.
But love share humour,
laughter together.

We have a vision , so
THANK YOU
Friendship possibilities raised in our study

Access
Information
Participation
Identity
Friendship in practice

• What do you do currently to include friends?

• What are the **barriers** to greater involvement?

• Look at the **diagram** – any ideas for addressing the themes raised in the research? How could you involve friends more?
What could you do to involve friends more?

in one or more of the following...
• Assessment
• Goal-setting
• Therapy and support
• Information
• Advocacy
• Community life
• Giving and skill sharing
• Wellbeing
• Other
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Pound, 2013
- Some people feel **lost** after a stroke
- Friends can help you ‘**find yourself**’
- '**fast friends**' with **aphasia** can be really helpful

**Getting out**
- **Technology**
- **Be flexible**

**Acknowledging what’s hard**
- **Keep going**

**Creative communication**
- **Friendship beyond words**

**Loyal friends** - 'there through thick and thin’
- Friends who **believe in you**
- Friends you can **trust**

**‘just being’**
- **Pets**
- **Having a laugh**

**Opportunities to give**
- **Skills swap**

**Time to talk**
- **Time to recover**
- Friendship is **always changing**

*Friendship research group, 2013*
Ideas from people with aphasia
Actions for ...people with aphasia

• Talk to peers with aphasia – what has helped them stay in touch with friends
• Make an effort
• Get out of the house
• Let people know early on e.g. send a card
• Take time out from rehabilitation – prioritise relationships too
• Don’t make assumptions about negative reactions – check whether self or other exclusion
... for family members and friends

• Family are hugely important but friends are important too - Don’t exclude friends
• Use your own communication skills to act as a bridge e.g contacting and arranging meetings
• ‘Don’t take it personally’ if people with aphasia get upset. ‘Lighten up!’
• At first try visiting in pairs
• Be flexible – try new ways to hang out together
• Inform yourself and your family but also equip friends with information about stroke and aphasia
• Stay in touch with your own friends – for your own wellbeing and as an important friendship resource to the person with aphasia
... for service providers

• Don’t ignore or exclude friends
• Ask about friends in initial interviews and follow ups; consider those most at risk of friendship loss
• Help people access peer support and persevere if people aren’t keen early on
• Give friends information too
• Offer more information and education about relationships
• Remember family and friends are not ‘all one lump’
Reflection

• What has the session made you reflect on?
• One thing you might try out, do differently?
And finally a few warnings

• ‘Don’t medicalise friendship’

• ‘Friendship is not a tick box exercise’

• ‘Friendship is not the same as ‘social support’, its about reciprocal relationships’

• Friendship is an exploration not a programme
• More about our project
• www.friendshipandaphasiasia.weebly.com
Selected Bibliography

• Friendship and Aphasia Research Group website . www.friendshipandaphasia.weebly.com
• Rotherham, A, Howe, T and Tillard, G (2015) ‘We just thought this was Christmas: perceived benefits of participating in aphasia, stroke and other groups. *Aphasiology*, DOI: 10.1080/02687038.2015.1016887