

Missing presumed dead: communication, identity and reconnecting with life after stroke

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Acknowledgements



different **Strokes**

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‘Missing presumed dead’



Facts and figures

- Up to a third of people with stroke have aphasia
- Depression common – 33% (Hackett et al, 2005)
- Approximately 25% of people living with stroke are under 65

- Recent improvements in early stroke care
- Post hospital support remains poor
- Only 24% rate psychological support as good or very good
- (National Audit Office, 2010)

My life is very, very narrow'

- Social exclusion at personal, interpersonal, societal level (Parr, 2007)
- Barriers to participation – physical, communication, information, infrastructural, attitudinal, temporal (Pound et al,2007; Howe et al, 2008)
- 'Identity theft' (Shadden,2005)

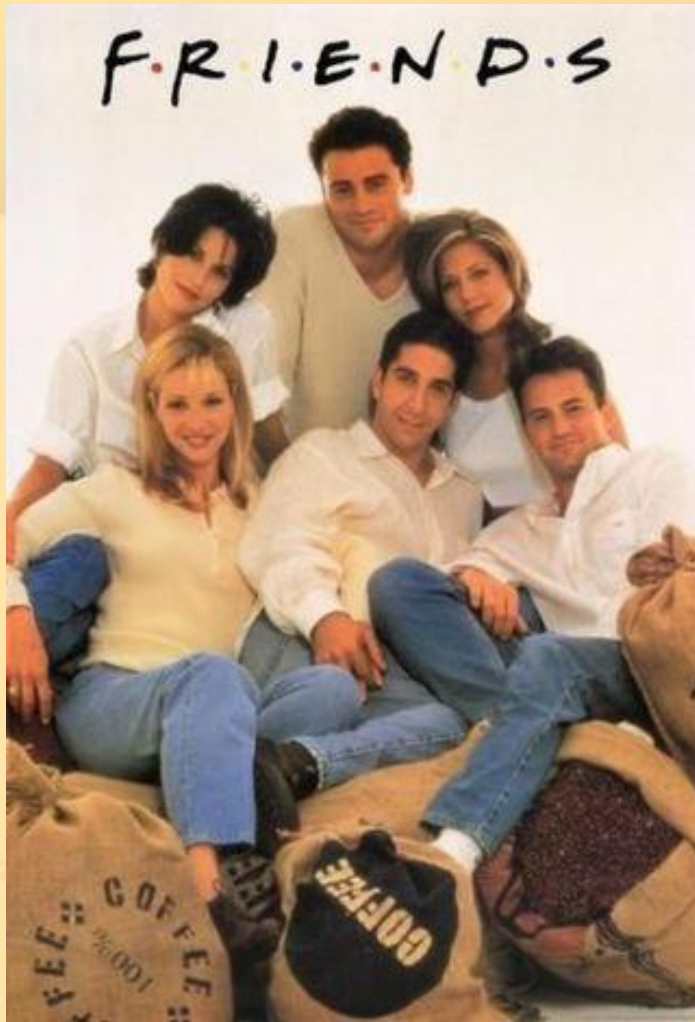
Social support and networks

- Social networks shrink –
 - 30% of people with long term aphasia no friends at 1 year;
 - 64% reduced friends; more frequent contact with family not necessarily related to higher HRQoL!

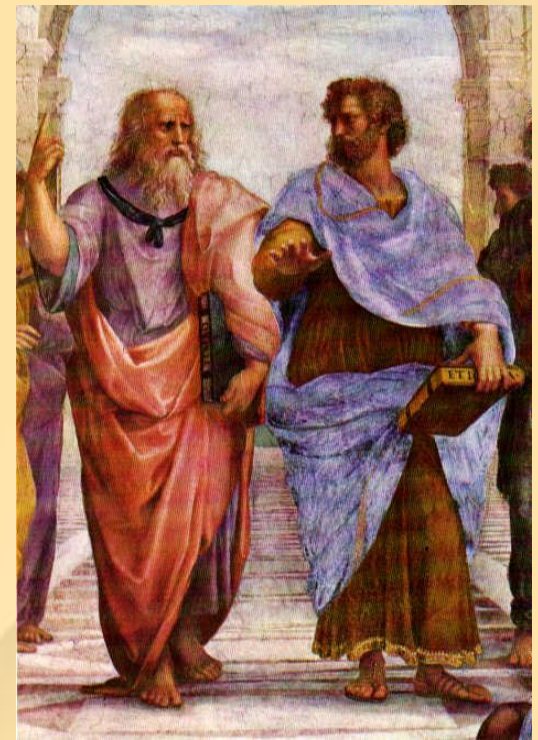
(Hilari and Northcutt, 2006)

- Stroke severity and loneliness at baseline related to higher psychological distress at 6 months

(Hilari, et al, 2010)



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The impacts in summary ...

- *'I couldn't speak, couldn't read, I couldn't write, erm numbers, I couldn't understand'*
- *'I lost my speech, my wife, my job, my home'*
- *'People don't understand ... it tears ...it rips out your core'*
- *'exiled...we are 'other'...not the same'*
- *'Asphasia isreally, really, hard work'*

My stroke – Medical facts

- Medical history
 - Born a heart murmur or
 - “Stenosis Aortic Valve”
 - 1995: Mechanic valve (Aortic heart valve)
 - 2001: TIA Very mild stroke
 - 2006: Stroke (“Broca’s Aphasia”)
 - 2007: Epilepsy

My aphasia

- Broca's Aphasia
- No full Sentence
- Little words forget and problem bigger words
- But language may also be the source of cognitive failures
- Stability of linguistic meaning and about the use of analogy, metaphor, and allegory
- Straight talk important; colloquialism hard

My life

- Family, Work, Interests
- Personality (Big Five)
 - **Openness to Experience:** imaginative, independent, and interested in variety.
 - **Conscientiousness:** Organized, careful, disciplined.
 - **Extraversion:** Retiring, sombre, and reserved.
 - **Agreeableness:** soft-hearted, trusting, and helpful.
 - **Neuroticism:** calm, secure, and self-satisfied

Changes

- Impacts of stroke and aphasia
 - Family
 - Work
 - Everyday life

“Don’t understand!”
(thinking)

Changes to Being

- 'I am' first words
 - Cogito ergo sum
(I think, therefore I am)



- René Descartes

Not dead but not here

- Cognitive fog - in my head



- Fog – other people can't see me

The veil of ignorance

A veil (Descartes – Hobbes, Rousseau, Locke, and Rawls) between you and the world

In the original position, however, representatives of **citizens** are placed behind a "**veil of ignorance**", depriving the representatives of information about **the individuating** characteristics of the citizens they represent. Thus, the representative parties would be unaware of the **talents and abilities**, ethnicity and gender, religion or belief system of the citizens they represent.

- Aphasia masks talents and people

Evolving rehabilitation

Communicating
slowly

The
basics –
eating
walking
sleeping



Finding a
way through
the fog –
more holes,
less fog

'Communication therapy'

Language
therapy

Roles, identity,
meaning

Supported
conversation

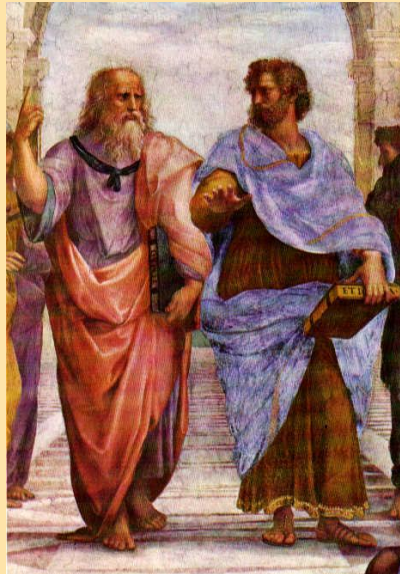
Doing,
being, becoming,
belonging
(Wilcock 1998; Hammell
2004)

Barriers to
inclusion

Communication
Access

Friendship, philosophy and rehabilitation!

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



Friends of value – best friends, soul mates e.g. Best man, partner

Friends of utility – colleagues at work, volunteer work

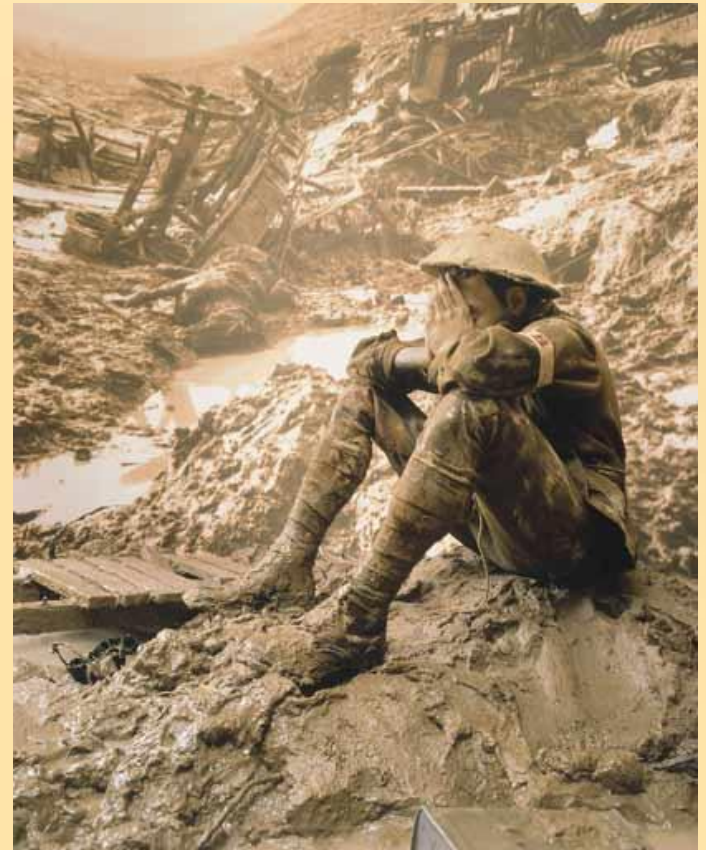
Aphasia, identity, inclusion – Take home messages

- Don't write people off – importance of hope, aspirations, futures
- Really try to understand aphasia and its impact
- Not just a language impairment it 'exiles' you to a different place

- Attend to communication access and barriers to equal opportunities and active citizenship
- Attach more importance to relationships that allow people to address barriers and rebuild identity – families, friendships, peers, colleagues
- Think about time and timing – fog may last for some years, reconfiguring identity is an ongoing, dynamic process

'I'm not dead I m still here'

- Thank you for listening
- More information about long term support ...



- **Connect** – www.ukconnect.org



- **Sign up to our Facebook page–**

- <http://www.facebook.com/pages/Connect-the-communication-disability-network/239609287191>

- **Different Strokes**



- www.differentstrokes.co.uk

- www.bmycharity.com/DifferentStrokesNorthampton

- **The Stroke Association**

- www.stroke.org.uk