

Being there

An investigation into the social participation of people with aphasia

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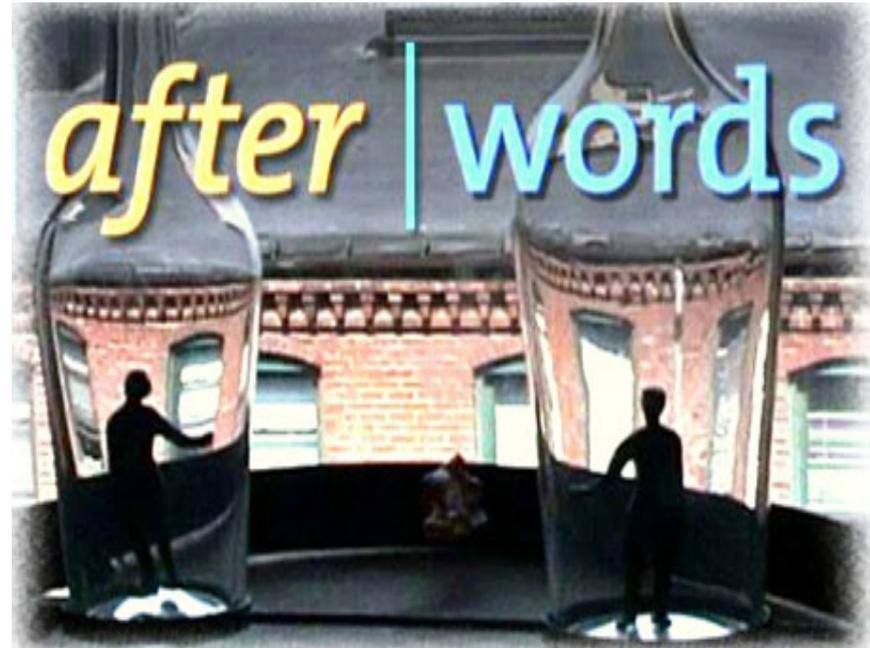
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Aphasia

What does it mean when you can't catch your world in words?

- How would you feel?
- What would your life be like?
- Would you still do the things you want to do?



Social participation

`Participation is the performance of people in actual activities in social life domains through interaction with others in the context in which they live`

Four social life domains are included:

- **Domestic life**
- **Interpersonal life**
- **Education and employment**
- **Community, civic and social life**

Dalemans, R. J. P., de Witte, L., van den Heuvel, W., & Wade, D. (2008). A description of social participation in working age people with aphasia: a review of the literature. *Aphasiology* 22(10), 1071-1091.



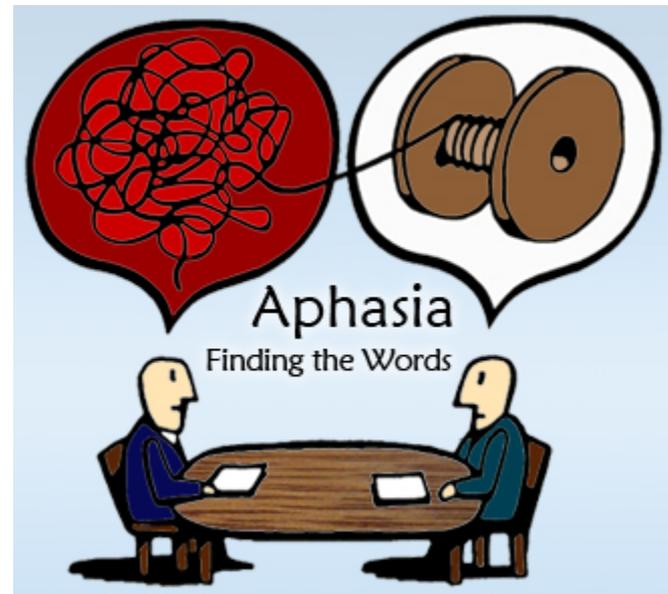
Social participation through the eyes of people with aphasia



How do people with aphasia and their central caregiver experience social participation and which factors influence this?

Qualitative study

- Keeping track of pre-structured diaries
- In-depth interviews
- Focus group interview



<http://www.uthealthleader.org>

Participants

	age	time po(y)	rs FAST	z-score	compreh.	expressi	reading	writing	Marital status	children	employment pre-stroke ¹
1. Liv ²	48	2,1	12	-0,9	3	4	3	2	married	son	housewife
2. Rita	56	7,7	27	1,43	8	10	5	4	married	son, daughter	Precision production, craft and repair occupation E.666
3. Bert	49	3,6	19	0,19	7	7	3	2	married	son, daughter	Professional and technical occupation, A.229
4. Mia	55	5	22	0,65	6	9	5	2	married	4 sons	housewife
5. Jos	57	1,4	26	1,27	10	8	5	2	married	daughter, son	Transportation and material moving occupation G.804
6. Roos	45	3	29	1,74	10	10	5	4	married	daughter	Professional and technical occupation A.106
7. Hans	58	9	24	0,96	9	7	5	3	married	none	Service occupation, except private household K.434
8. Stan	71	11	12	-0,9	6	3	3	0	married	3 daughters	retired
9. Roel	65	3,9	22	0,65	7	6	5	4	married	2 sons	Sales occupation C.256
10. Tom	55	3	10	-1,21	5	2	3	0	married	2 sons	disability pension
11. Sally	69	5	19	0,19	4	8	5	2	married		housewife
12. Jef	66	4	24	0,96	7	8	5	4	married	3 sons, 1 daughter	Transportation and material moving occupation G.814
13. Sara	52	8	26	1,27	10	8	5	3	divorced	2 sons	Professional and technical occupation A.095

¹ Occupation as classified using the U.S. Standard Occupational Classification System: Major Occupational Groups (MOG)

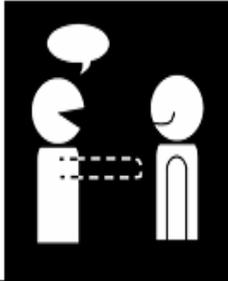
² The names of the persons with aphasia are changed to insure anonymity

Diary

Keeping track a diary during two weeks

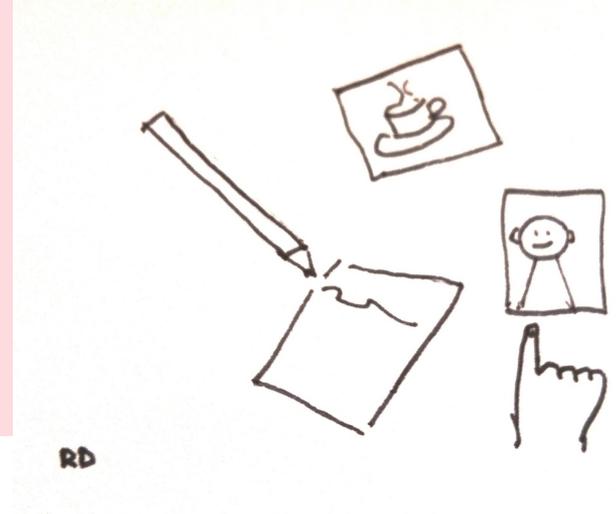
What did you do today?
How well did this go?

- Using a structured outlined lay-out
- Augmentative communication by using pictograms to be placed in the diaries
- Separate space in the diary for the caregiver to express his perspective
- Including the caregiver as an assistant for the person with aphasia

visual structured diary		
Monday	Activity	Performance
	Domestic life	
		
	Relationships	
		

Interview

- Interviewer, interview-assistant, person with aphasia and caregiver present during the interview
- Use of audio-tape
- Addressing the person with aphasia first
- Use of pictures, photo`s, drawings, pen and paper



Focusinterview

- An aphasia-friendly report before the focus-group interview
- PowerPoint presentation
- Discussion with conversation rules
- Encourage people with aphasia to express themselves

Member check

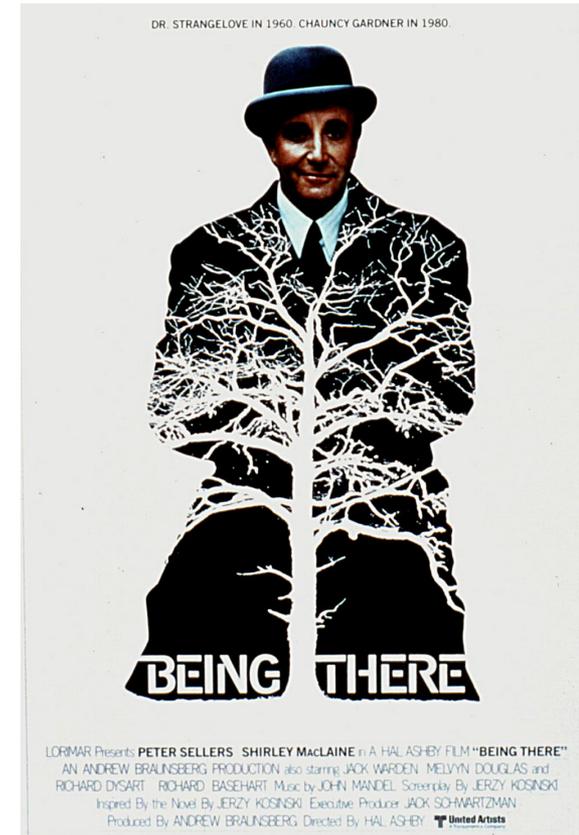
Figure 2: example of a sheet supporting the focus interview

Interpersonal: Knowledge

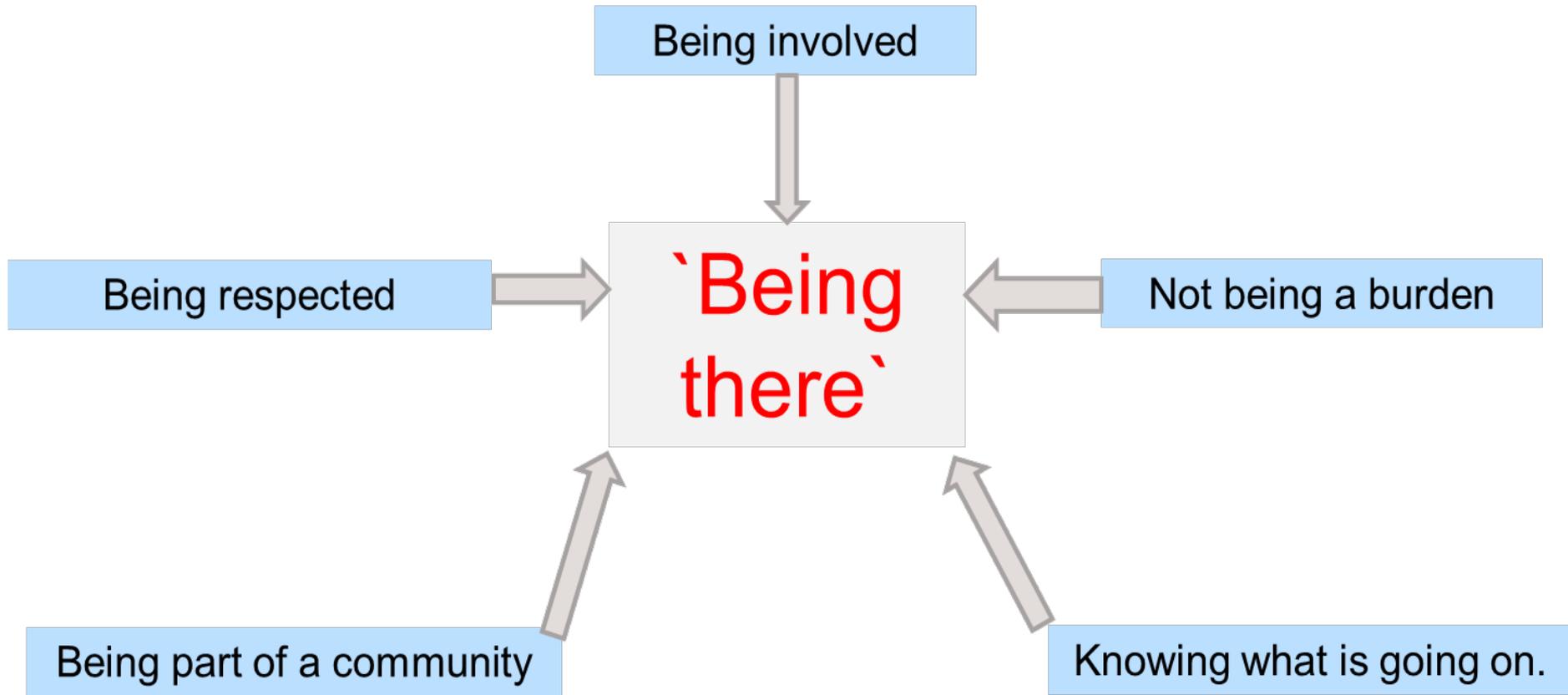


Results: Social participation through the eyes of people with aphasia

- Great variation in number of social activities
- Doing things and performing activities is not as important as being there
- People with aphasia do not think in terms of social participation
- People with aphasia want to have a feeling of `being there`

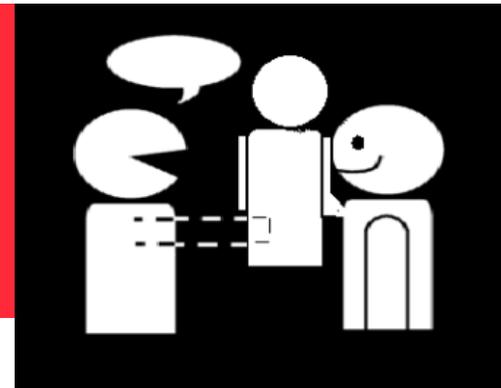


`Being there`



Being there`

feeling engaged, being involved



- People with aphasia often **feel isolated** and not **involved**.
- People talk to the central caregiver about the person with aphasia in presence of the person with aphasia.

“Roos: No, they do not talk to me. We are standing around a table and euh, yeah I just stand there, but I do not belong.”

Being there`

Do not want to be a burden

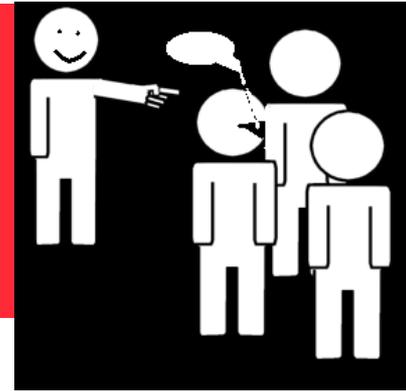
- People with aphasia often feel they are a burden to others and therefore stop doing activities

"Rita: They were like, euh, you do not have a problem, come on. To cheer me up. I want to be there, but I euh...it does not work like that...the dizziness and euh the awfull fatigue... at a certain moment I am really exhausted and then I have to leave them behind. Then I say, just go shopping, I will stay here. But, yes perhaps that's my own fault."



Being there`

knowing what is going on

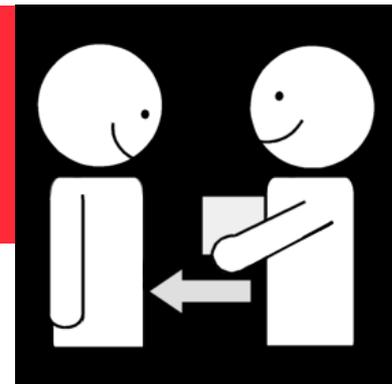


- People with aphasia are often unable understand conversations because they **need more time** or because the others were **talking to rapidly**.
- They could **not participate** in discussions because they did not understood what was being told.
- They reported that **they wanted to know what was being said** so that they could **join** the conversations.

Being there :

be a part of a community

- A lot of people with aphasia stop working.
- A lot of people with aphasia **want to be a part** of the community.
- They want to **contribute** and have a **meaning**.



"Interviewer: What would you rather do?"

Roel: I was here, you know (points out to the printing office).

Interviewer: You want to work in the printing office?"

Roel: yes!"

` Being there ` :

being respected

- People do not treat them as normal
- People think they are crazy
- People do not take into account the feelings and wishes of people with aphasia



`Being there` : influencing personal factors

Personal factors

- Motivation
- Perseverance
- Physical and psychological condition

`Partner Bert: he just tries, you know. We were on holiday and I wanted to go to get a sandwich. He came back and laughed. He said: they thought I was an Italian. But, you got what you wanted, I said. Bert: Yeah, I just ignore it. They have to take me as I am.`

Communicative skills

- Use of communication boards
- Use of short sentences
- Use of gestures

` Being there ` : influencing social factors

The role of the central caregiver

Aspects of the communication partner:

- Knowledge
- Willingness
- Communication skills



` Being there ` : influencing environmental factors

Facilitating:

- Quiet environment
- Familiar environment
- Living in a village

Hindering:

- Many distractions
- Limited access

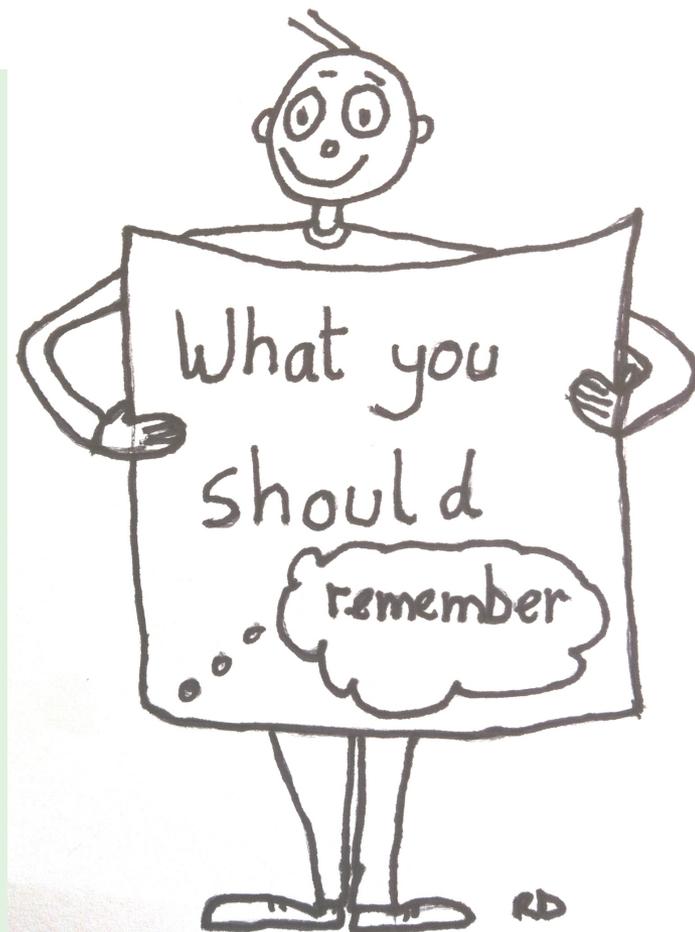


Take home message

- **Respect** the person for who he is
- Be more **aware** about the consequences of aphasia
- **Prepare** people with aphasia and his direct environment to these consequences
- Look **beyond** the boundaries of your profession
- Keep in mind that people with aphasia want

to `BE THERE`

and support them in achieving that



Everybody is a genius.



But if you judge a fish by its
ability to climb a tree, it will
live its whole life believing
that it is stupid.

Albert Einstein.

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