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**STROKE SURVIVOR EXPERIENCES
THAT POSE CHALLENGES TO
CARERS**

**EUROPEAN LIFE AFTER STROKE FORUM
– WEBINAR SERIES –
SHINING A SPOTLIGHT ON STROKE**

**3RD WEBINAR: LIFE AFTER STROKE: CARING FOR
THE CAREGIVER**

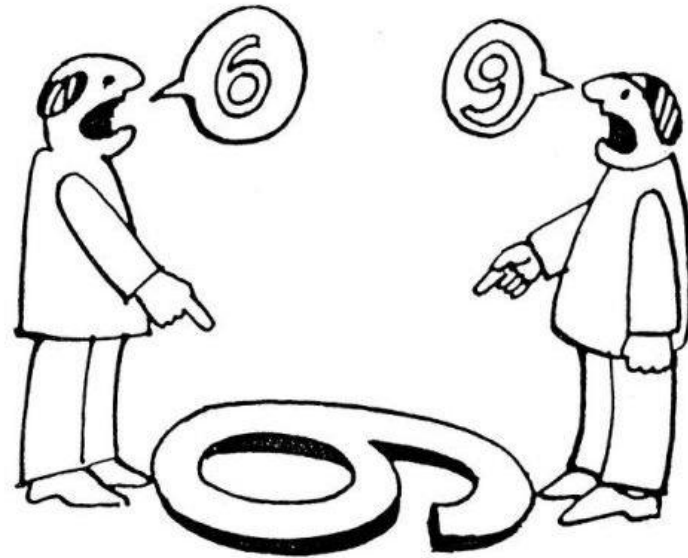
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Carers may find themselves in conflict with stroke survivors for several reasons.

One particular reason is the discrepancy between what caregivers feel the stroke survivors' cognitive problems are and the stroke survivors' own perception and awareness of their deficit and its severity.

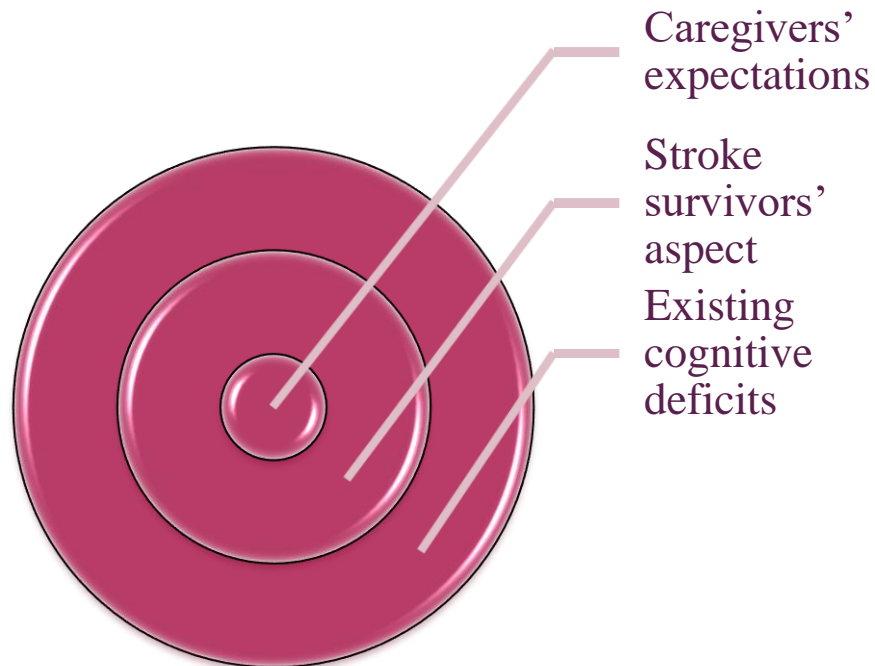


This discrepancy may generate, especially in the long run, several problems that will negatively interfere the outcome of rehabilitation, and, ultimately, with each interested party's well-being and quality of life.



Caregivers should be made aware of the multiple possible causes of conflicts of this kind.

A mismatch in the evaluation of the stroke survivors' problems, may stem, with very negative consequences, from both the stroke survivors' cognitive deficits and the caregivers' expectations.



Caregivers should know that lack of awareness of the cognitive deficit is a common consequence of brain damage.

The cause may be related to either:

- premorbid personality or
- the type of brain lesion

confounding the two leads to serious problems!



Surely the premorbid personality of the person with stroke has an influence:

the overoptimistic may remain such even after stroke, the depressed...etc...

but attributing unawareness to premorbid personality (or to changes to it) may be a serious mistake, easy to commit, since caregivers may have known the patient for long time and feel they can rely on that knowledge...(they may be right...)



Certain types of lesions are especially likely to lead to an awareness deficit

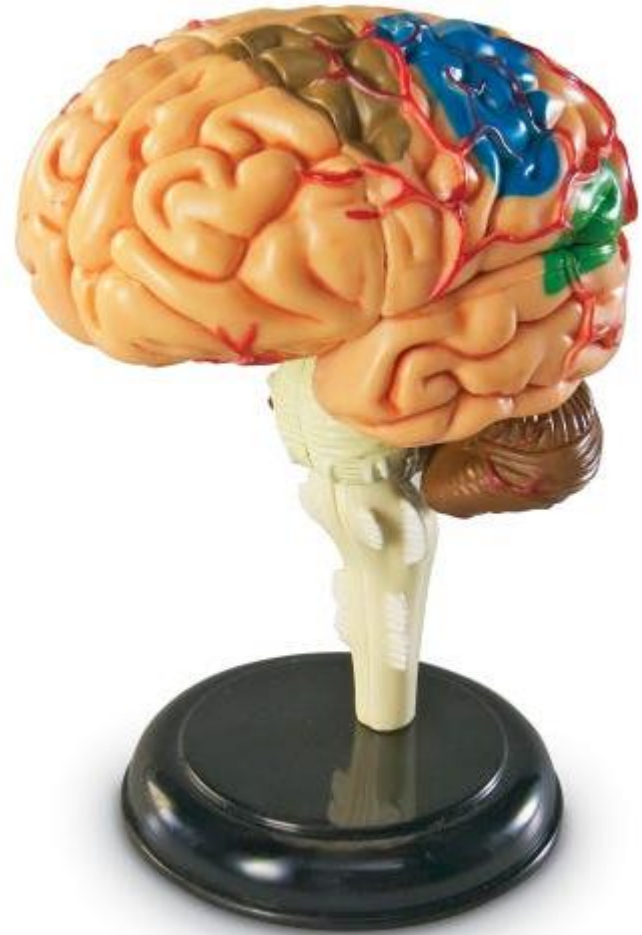
e.G. Stroke survivors with...

- right posterior lesions may ignore space, even their own body parts,

- left posterior lesions with aphasia may not realize they have comprehension deficits,

- frontal lobe lesions may be unaware of violating social rules...

this is not known to the large majority of caregivers, who must be told.



Caregivers should be made aware of the fact that lack of awareness of the cognitive deficit is a very common consequence of brain damage.

They should also know that the awareness deficit may be subtle, and therefore hard to spot, while sometimes, on the contrary, it may manifest itself as conspicuous, hard to win, delusion.



Stroke survivors may either overestimate their abilities, or, sometimes (as much importantly) underestimate them because of authentic cognitive deficit or depression.



It has also been shown that stroke survivors (magnifying what happens in the elderly) may overestimate their premorbid performance, thus being unhappy of a perfectly good performance.

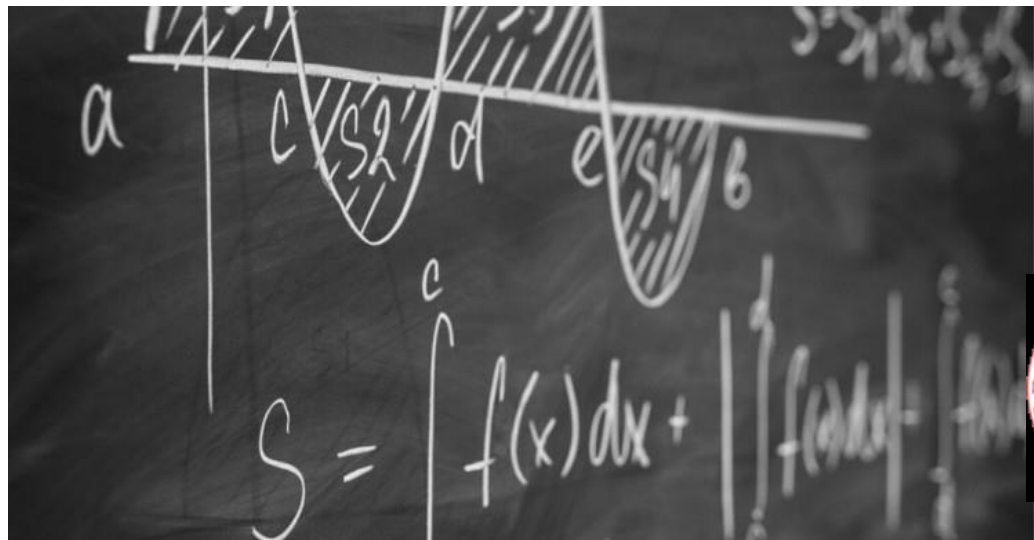


Caregivers may want to know that the pattern of spared and affected abilities may sometimes be counterintuitive.

For example:

- stroke survivors may overestimate their math abilities,

but they may still be able to make sensible financial choices.



Caregivers too may overestimate or underestimate the stroke survivors' abilities.



This may lead to problems:

- not being aware or deny important deficits, especially soon after stroke (e.G., Minimizing the impact of aphasia “he/she lets her/himslef understood”...)

Or

- denying the patient's ability (that may be spared) to take important decisions.



Caregivers should be made aware of these problems and provided with tools to help them.



These tools may be the results of questionnaires given to both the stroke survivors and the caregivers, emphasizing the discrepancies; caregivers may also benefit from knowing what objective measures of stroke survivors' cognitive functions reveal, which may be different from the caregiver's own intuition.



Caregivers should be told that a discrepancy between objective results and their intuition is very common.

They should not worry or feel guilty about this fact.

It is just important information they may consider: ultimately they may rely on their own judgement.

If you are doing your best,
you are doing enough



Thank you



References:

Proios, H., Tsakpounidou, K., Karapanayiotides, T., Priftis, K., & Semenza, C. (2021). Aphasia and Math: Deficits with Basic Number Comprehension and in Numerical Activities of Daily Living. *Journal of the International Neuropsychological Society*, 1–13. Advance online publication. <https://doi.org/10.1017/S1355617720001368>

