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SUBMISSION TO SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE ENQUIRY INTO THE SOCIAL AND ECONOMIC IMPACT OF COMMUNICATION AND SWALLOWING DISORDERS

Background

Towards the end of July 2013 I suffered a cerebrovascular accident (CVA; stroke) of the left middle cerebral artery, resulting in damage to the left fronto-parietal area of the brain with incursions into the insular cortex. This resulted in a mild weakness of the right arm and very mild swallowing defects. The principal issues however were an inability to speak ("aphasia"); an inability to read or write; difficulty with calculating or anything to do with numbers; short term memory deficiencies; and a significant cognitive deficit.

I was hospitalised for 5 days during which time a variety of diagnostic tests were performed, and I was also visited by the hospital's resident speech pathologist on three occasions. She did a basic assessment of my deficits, suggested some measures which I could undertake to effect some initial improvement in my condition, and referred me to a speech pathologist in private practice in my local area.

I was already aware of the importance of early intervention in both speed of recovery and ultimate outcome with any form of brain injury. I undertook a programme of twice weekly visits to the speech pathologist, in the company of my partner, beginning the week following my discharge from hospital. I continued this protocol for approximately three months.

The input of the speech pathologist in terms of the speed and ultimate degree of recovery was incalculable. She pointed out to me that the ability to move the mouth and tongue in order to articulate words was only a small part of aphasia. Prior to this stage of speech formation, there is finding the vocabulary to express an idea, getting the grammar and syntax right, making the sentence coherent, and coming up with the right sounds to form the words. She was able to very accurately diagnose the particular areas where I was having most difficulty at any particular time and initiate therapy directly targeting those areas.

With her significant experience in dealing with stroke victims, she was also able to astutely assess my psychological and emotional state during my recovery and suggest methods for dealing with any problems. The speed of onset and severity of clinical symptoms with a CVA inevitably has a significant impact on the emotional well-being of the patient, as well as the patient's carers. Of particular relevance to an aphasia patient is the notion, widespread in the general public and of particular concern to me personally, that someone who has difficulties in communicating is assumed to have an intellectual disability.

In addition my speech therapist suggested exercises and strategies with which to address memory and cognitive deficits. She advised both me and my partner on what I was likely to experience during the recovery phase, and provided strategies to deal with issues such as significant fatigue. She gave me guidance on the best way to return to my daily activities in a graded way so that I met multiple successes during my recovery.

One aspect of my experience is realising how little the general public knows about stroke. My partner, who is a well-educated professional with two University degrees, previously thought that a stroke was a form a heart attack. As a result of my recent experience I have become acutely aware of the need for a more directed and strategic public education campaign to increase awareness of stroke.

I have a physically, emotionally and intellectually challenging job in my work as a veterinary surgeon. The speech therapist was very much aware of my intention to return to work and other normal activities as soon as possible, and she always kept that goal in mind during therapy. I am very fortunate to have started working on a part-time basis a little over four months following the stroke, much sooner than generally expected, and have high hopes of returning to a full-time position within the next few months.

The contribution of my speech therapist has been invaluable in achieving my goal of recovery and a return to being a fully functioning member of the community, and I was in the fortunate financial position of being able to afford her services at a frequency which she considered ideal. A couple of months after my stroke, I attended a stroke forum run by the Stroke Recovery Association NSW. As well as papers by clinicians and researchers, there were a number of presentations by stroke victims. With the knowledge that early intervention is paramount to the ultimate result, I was shocked to discover that a number of people present, who were reliant on the public health system, had to wait six weeks or more before having access to a speech therapist or other rehabilitation service providers. It would seem a reasonable assumption that in many cases the disabilities they still suffer would have been less had they access to more prompt rehabilitation. The delay must have an enormous impact on the physical, emotional, and psychological well-being of individuals. In addition the economic impacts, both in terms of a significant delay or complete failure to return to work, and continued reliance on the public health purse, must be significant.

Recommendations

In view of these observations, I encourage members of the Senate Committee to consider the following when making recommendations to government:

- An increase in expenditure on public education on stroke and aphasia.
- Funding of dedicated stroke medical teams in emergency rooms of every major hospital in the country.
- Funding of rapid intervention for stroke victims in the form of publicly-funded access to speech therapists and other rehabilitative practitioners.
- Funding of ongoing provision of speech therapy and other rehabilitative services on a ongoing basis dependent on individual patient needs.

Yours faithfully, Pamela Short