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Sorry, what did you say? Living with dysarthria (unclear speech) after stroke

 evidentlycochrane.net/living-with-dysarthria-after-stroke/

Claire Mitchell

26/01/2017



In this guest blog, Annette shares her story of living with dysarthria after stroke and Claire Mitchell (@ReaDySpeech), Speech & Language Therapist and author of a newly updated [Cochrane review on dysarthria](#), explains the findings.

Annette's story

Two and a half year check-up today. I'm in good health. I should be feeling great. BUT, any mention of my dysarthria had me reaching for the tissues. I've finally got my head round my wobbly post-stroke body. I can't get my head around my wobbly speech.

A stroke 2 years ago left me with dysarthria (sounding as though I've drunk a few pints too many; reduced intelligibility; difficulty forming words; an inability to increase volume and pace). I am a 64 year old female. Pre-stroke, a bit of a social butterfly ... and a talker! I am a changed person since developing dysarthria. I prefer being alone and in familiar places.

Dysarthria's effects are many, and profound. Why draw attention to my speech difficulties? If I stay home and keep quiet I can pretend that I'm 'normal'. I hate my new voice. It's not mine. Why put myself through the embarrassment of watching people straining to hear or understand me? Why put myself through the mental fatigue of constantly having to repeat myself?

But friends tell me I'm lucky to be affected so 'mildly'. Mildly??! Yes, my speech could be worse, even non-existent, but the emotional and psychological effects of dysarthria make it impossible to consider myself 'lucky'.

'Lucky' is a life without dysarthria.

I try to avoid the mental and physical effort required to form words – my mouth dries; my throat tightens; my tongue tires (weird). I want to go home. I want to be silent. That isn't me. Well, it isn't the 'me' of 2 years ago.... I force myself to socialise but any excuse to escape and I'm off. I even avoid engaging my nearest and dearest in conversation. Tiring, upsetting and frustrating, the reality of dysarthria smacks me in the mouth every time I attempt speech. I can be in bits with the effect dysarthria has had on my life.

the reality of dysarthria smacks me in the mouth every time I attempt speech

As a divorcee bringing up a child on my own I was used to standing on my own two feet. Now I feel vulnerable because of the restricted communication which my dysarthric speech places on me. I rely on other's patience to hear me out. In my experience people generally (wrongly) associate dysarthria with low or impaired intellect because it isn't 'normal'.

Adapting to the physical restrictions of stroke was painfully slow but the long term emotional effects of my speech problems seem to get worse, not better. I seem unable to accept the change. I want further improvement but I don't know if that's possible or how to achieve it. I had my standard 6 weeks of speech therapy but I want more, I would be willing to try anything. I avoid interactions... misunderstandings affect me emotionally. I'm a tough old bird but I could cry when I have to repeatedly repeat myself. I just withdraw.

Before my stroke I occasionally worked as a TV extra. The agency said I could return whenever I felt ready. Physically, I've been ready for months but my confidence to speak has evaporated. Others may view my dysarthria as 'mild' but its effects have been (and still are) devastating and stifling. Dysarthria has a stranglehold on every aspect of my life. I've always worked and been financially independent but now feel this opportunity is no longer open to me.

Dysarthria is imprisoning, limiting my life to the people and places that I know. I would no more engage in a new friendship or relationship than fly. Dysarthria has robbed me of the confidence to try.

Why put my head above the parapet and risk being shot?

Stick with what I know.

It's safer.

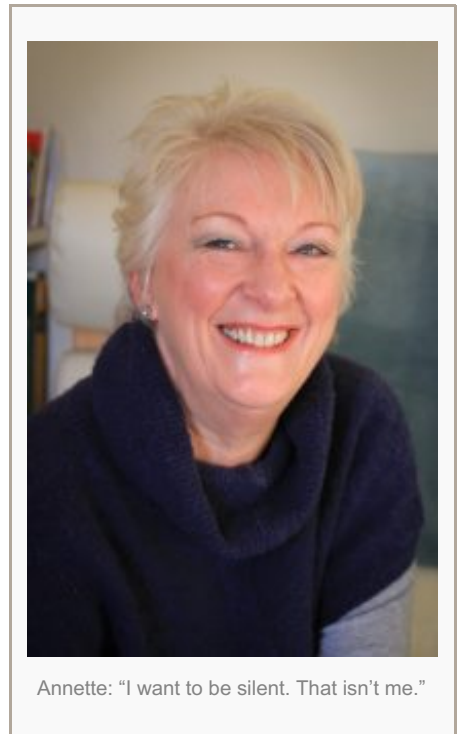
It's also uncharacteristic (of me).

Dysarthria has created a psychological barrier which I am struggling to get over. Dysarthria has robbed me of confidence. I now prefer to avoid speaking. I do my best but it's exhausting. I just want to go home and be alone and quiet.

What's the evidence for dysarthria treatment after stroke or non-progressive brain injury?

Annette's story is a powerful reminder for clinicians and researchers of the impact dysarthria can have and highlights the importance of rehabilitation research.

In this updated [Cochrane systematic review](#) we wanted to find out if there is evidence that any dysarthria treatments work. We found surprisingly few trials (5) with small numbers of patients (234) and almost all participants were post-



Annette: "I want to be silent. That isn't me."

stroke.

None of the included studies had sufficient numbers to answer the question about whether dysarthria intervention works. We still don't know the benefits or risks of intervention and it is important that people with dysarthria continue to receive rehabilitation according to clinical guidelines. Our final conclusion for this review is that there have been no definitive trials focussed solely on dysarthria.

What more do we need to do?

Research into dysarthria has clearly been neglected over the years and this seems inadequate when considering the impact on people such as Annette. This review shows we urgently need better quality trials with bigger numbers of patients to find out more about dysarthria treatments and consider patients' views on interventions and how we measure change.

What does Annette think about the research?

we don't yet know what works best for people and we need to find out

"In a strange way it was heartening to discover that so little research has been done on dysarthria. It gave me hope that with further research people like me might move on with a useful and meaningful life. It is not saying nothing works it is saying we don't yet know what works best for people and we need to find out.

I feel that dysarthria has severely restricted my recovery. Ongoing research is required into something which affects recovery so profoundly. Even slight improvements would improve the quality of my life drastically through increased confidence and self-belief."

The lack of evidence around dysarthria treatment after stroke prompted Claire to look at how treatment could be developed. She is Chief investigator of the ReaDySpeech feasibility study which is looking at whether a computer programme can be used in a randomised controlled, multi-centre trial for dysarthria treatment after stroke. Annette is currently acting as a research advisor for the ReaDySpeech study and was asked to comment on the Cochrane systematic review from a patient perspective.

Links:

Mitchell C, Bowen A, Tyson S, Butterfint Z, Conroy P. [Interventions for dysarthria due to stroke and other adult-acquired, non-progressive brain injury](#). Cochrane Database of Systematic Reviews 2017, Issue 1. Art. No.: CD002088. DOI: 10.1002/14651858.CD002088.pub3.

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