

MacKenzie, C., Paton, G., Kelly, S., Brady, M., & Muir, M. (2012). *The living with dysarthria programme for post-stroke dysarthria*. Paper presented at European CPLOL congress, The Hague, Netherlands.

Dysarthria is a common sequel to stroke but has attracted little attention in intervention outcome research. Management directed at psycho-social effects rarely has been addressed in dysarthria outcome research and few descriptions are available to guide practice.

The life effects of dysarthria might be addressed in a group situation, providing opportunities for natural interaction with a range of communication partners,<sup>i</sup> discussion of experiences, problem solving and peer support. As main communication partners, the negative impact of dysarthria may extend to caregivers,<sup>ii</sup> and their inclusion in dysarthria management is advocated.<sup>iii iv</sup>

We designed a novel group intervention programme, *Living with Dysarthria*, for people with chronic dysarthria after stroke and their main communication partners, and piloted it twice, with different participants. The programme, of eight once weekly two hour sessions, led by two speech and language therapists (SLTs), comprises three inter-related key components central to the concept of *Living with Dysarthria*: a) education, b) peer and professional support, c) communication practice. Research questions addressed were: 1. How operationally feasible is the programme?; 2. How do participants perform prior to and at the conclusion of the programme on measures of quality of communication life (QCLS)<sup>v</sup>, speech intelligibility (SIT)<sup>vi</sup>, communication effectiveness (CEM)<sup>vii</sup>, (CES)<sup>viii</sup>, general wellbeing (GHQ-12)<sup>ix</sup>, knowledge of stroke and dysarthria<sup>x</sup>?; 3. What are participants' views of the programme, expressed via anonymous questionnaire and focus group discussion?

**1. Operational feasibility:** Our target of programme completion by 16 people with dysarthria (PWD), set with fair confidence from preliminary review of case records in the two recruiting hospitals, serving large populations, was not met. Despite energetic contact efforts and a 6 year case scrutiny, only 12 PWD and 7 family members (FMs) were recruited. 9 PWD and 4 FMs completed the programme. Attrition was due to ill health or return to work. Both PWD and FMs were positive about the smaller group size, which they thought facilitated discussion and individual attention: views endorsed by the SLTs. All preferred the community centre location to a hospital situation. While preparation time was high, future use of the *Living with Dysarthria* programme is practicable.

**2. Outcome measure performance:** The assessor was not involved in the therapy. SIT and CEM were rated by listeners blind to assessment point. QCLS, SIT, and CEM applied to PWD and CES, GHQ-12, SSKT to FMs also, for which measures PWD and FM scores were handled together, to maximise N. Notwithstanding small participant numbers, score changes were in a positive direction for all measures. Effect sizes ranged from 0.17 (just below small effect) to 0.46 (just below medium effect). Although type 2 errors are common in significance testing of small groups, for speech intelligibility (SIT) and knowledge of stroke and dysarthria (SSKT), significant post programme changes were present ( $p = 0.05$ ). The smallest effect size (0.17) was seen in the quality of communication life measure (QCLS), but a ceiling effect is likely in this measure, not designed specifically for the dysarthric population.

## Performance data for before (A1) and after (A2) programme assessment

	N	A1 median (range)	A2 median (range)	Z; p value; d
QCLS (80)	9	67.0 (50.5 – 78.5)	72.0 (54.0 – 79.5)	-0.71; p = 0.48; d = 0.17
SIT (100%)	9	92.4 (54.3 – 99.4)	94.55 (61.06 – 99.39)	-1.96; p = 0.05*; d = 0.46
CEM (7)	9	5.89 (2.11 – 6.89)	6.11 (2.22 -6.89)	-0.98; p = 0.33; d = 0.23
SSKT (20)	13	12.0 (5.0 – 18.0)	15.0 (5.0 – 19.0)	-2.00; p = 0.05*; d = 0.39
CES (32)	13	21.0 (15.0 – 28.0)	23.0 (16.0 – 28.0)	-1.07; p = 0.28; d = 0.21
**GHQ-12	13	12.0 (7.0 – 18.0)	11.0 (4.0 – 14.0)	-1.48; p = 0.14; d = 0.30

\*significant at p =0.05; \*\* score decrease represents improved status

**3. Participant views:** All 13 completing participants returned anonymous evaluation questionnaires comprising 11 statements with a strongly disagree/disagree/neither agree nor disagree/agree/strongly agree response scale, and several questions about programme improvement. Excepting one response for each of three statements, all responses were 'agree' or 'strongly agree'. Participants considered they knew the programme aims, sessions met expectations, were stimulating, of appropriate difficulty and pace, relevant to living with dysarthria, provided enough practice and feedback, and were a good way to learn more about dysarthria. The SLTs were thought to be well prepared and helpful and participants thought they would be able to use what they learned. Few suggestions for improvement were made, the most common being a wish for more sessions (2 FMs and 4 PWD). 1 FM and 2 PWD would have liked longer sessions. 3 PWD though the sessions should be more difficult but 2 thought they should be less difficult. 3 PWD and 1 FM suggested the content covered should be increased but 1 PWD thought this should be decreased. Thus the programme as presented suited the majority.

All participants also contributed to one of three post-programme focus group discussions facilitated by the Principal Investigator, who had not been involved in the sessions. Nvivo software assisted coding and analysis of the audio- recorded data. As with the anonymous evaluations, feedback was consistently positive. The programme was regarded as enjoyable, stimulating, interesting and useful. Participants felt well involved and commended the flexible approach. New learning about stroke and dysarthria was appreciated and in some instances disseminated to others. Some facts had been 'tough to hear'. Activities were thought varied, well paced and of appropriate difficulty, and assessment suitably challenging. Some participants fitted home practice into their routine, but this was difficult for others, especially if living alone. Many benefits were voiced, including meeting needs, learning and insight, humour, peer and professional support, speech improvement, confidence, continuation of therapy, involvement of family and having a resource folder for future practice. There was disappointment that the programme had ended and a wish for further support. Views on group size, session length and frequency accorded with anonymous evaluations.

### Conclusion

The *Living with Dysarthria* programme was very well received by both PWD and FMs, all of whom considered it beneficial. Although recruitment was lower than planned, both participants and SLTs thought that larger groups would be disadvantageous for discussion and individual needs. The test performance data suggest modest gains, especially in stroke and speech knowledge and speech

intelligibility. Further data should be collected on response to the *Living with Dysarthria* programme.

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<sup>i</sup> Elman R J (2007) *Group treatment of neurogenic communication disorders: The expert clinician's approach*. San Diego: Plural.

<sup>ii</sup> Long A, Hesketh A, Bowen A (2009) Communication outcome after stroke: a new measure of the carer's perspective. *Clinical Rehabilitation*, 23, 846-856.

<sup>iii</sup> Yorkston K M, Beukelman D R, Strand E A, Hakel M (2010) *Management of motor speech disorders in children and adults*. Austin: Pro-Ed.

<sup>iv</sup> Duffy, JR 2005 *Motor speech disorders: Substrates, differential diagnosis and management*, 2<sup>nd</sup> edition. St Louis: Elsevier Mosby.

<sup>v</sup> Paul, DR et al (2004) *Quality of Communication Life Scale*. Rockville: ASHA.

<sup>vi</sup> Yorkston K, Beukelman D, Hakel M (1996) *Speech Intelligibility Test*. Lincoln: Communication Disorders Software.

<sup>vii</sup> Mackenzie C, Lowit A (2007) Behavioural intervention effects in dysarthria following stroke: communication: effectiveness, intelligibility and dysarthria impact. *International Journal of Language and Communication Disorders*, 42, 131 -153.

<sup>viii</sup> Donovan N J, Velozo C A, Rosenbek J C (2007) The communicative effectiveness survey: Investigating its item-level psychometrics. *Journal of Medical Speech-Language Pathology*, 15, 433-447.

<sup>ix</sup> Goldberg D, Williams P (1988) *A User's Guide to the General Health Questionnaire*. NFER: Windsor.

<sup>x</sup> An expanded and Scottish adapted version of the Stroke Knowledge Test (Sullivan K, Dunton N J, 2004, Development and validation of the Stroke Knowledge Test. *Topics in Stroke Rehabilitation*, 11, 19-28) was devised by the research team.