

How I encourage community participation (2): “Actions not words”

Shortly after being made redundant from his job as a welder, **Colin** had a stroke which left him with mild motor difficulties and moderate aphasia. Speech and language therapist **Rebecca Allwood** and occupational therapist **Jane Terry** reflect on the factors that enabled him to embark on a journey back to work in spite of his communication difficulties.

READ THIS IF YOU WANT TO

- USE A GOAL SETTING APPROACH
- WORK IN A MULTIDISCIPLINARY WAY
- SUPPORT ACTIVITY AND PARTICIPATION

Returning to work is often a long-term goal for younger people who have had a stroke. The National Stroke Strategy (DH, 2007, p.34) cites the finding of the Stroke Association and Different Strokes (2006) that three quarters of affected younger individuals want to return to work. It also recognises that employers and voluntary organisations require training so they can support the process.

The National Clinical Guideline for Stroke (2008, p.103) gives advice on supporting people to return to activities or work:

- Every person should be asked about the vocational activities they undertook before the stroke.*
- Patients who wish to return to work (paid or unpaid employment) should:*
 - *have their work requirements established with their employer (provided the patient agrees)*
 - *be assessed cognitively, linguistically and practically to establish their potential*
 - *be advised on the most suitable time and way to return to work, if this is practical*
 - *be referred to a specialist in employment for people with disability if extra assistance or advice is needed (a disability employment advisor, in England).*

The Community Stroke Team (Citihealth, NHS Nottingham) supports people to return to or undertake new activities, including paid or unpaid work if this appears to be realistic. The team provides multidisciplinary medium to long-term rehabilitation and advice for people with a stroke and their carers. It works alongside other agencies such as the YMCA, Stroke Association and Aphasia Nottingham (a local self help group), and also offers stroke awareness training. Alongside occupational therapy, speech and language therapy and physiotherapy, we have a mental health nurse who supports people and carers with the emotional side of having a stroke and rehabilitation. We also have generic assistant practitioners and rehabilitation support workers who carry out programmes of rehabilitation under the supervision of the

Figure 1 Colin's Communication Profile

I had a stroke in April 2008.

Due to the effects of the stroke:-

- **I sometimes have difficulty saying what I would like to say.**
- **I sometimes get stuck on words.**
- **I sometimes say words that I do not mean to say.**
- **I can mostly read single words but I have difficulty reading sentences.**

I can:-

- **Understand everything that is said.**
- **Think normally and make decisions.**

Ways to help:-

- **Give me time to find the words I want to say.**
- **Take things slowly.**
- **Do not pretend to understand what I am saying - check with me.**
- **Do not give me a lot of information to read.**

health professionals. Rehabilitation centres on patient-led goals which are reviewed and updated regularly. Outcome measures are recorded using the East Kent Outcome System (EKOS) (Metcalf, 2010).

Colin

One of our clients, Colin (now aged 63), had a left hemisphere stroke in April 2008, and was referred to us around four months later. His stroke caused a mild motor apraxia and right sided weakness. The main effect was a moderate expressive aphasia characterised by word retrieval difficulties. Colin initially required a lot of support to express himself in conversation, and had acquired reading and writing difficulties.

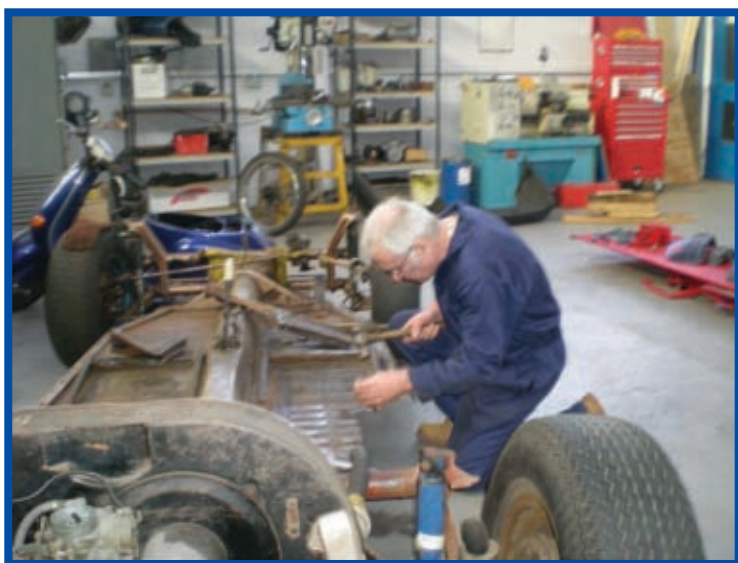
After a period of residential intermediate care, Colin returned to live on his own in a complex of flats near the city centre. The team worked with him to achieve his early goals, which related to important everyday activities such as shopping and using public transport.

- Speech and language therapy focused on
1. strategies for effective communication
 2. impairment based work to improve
 - word retrieval
 - reading comprehension.

Colin began to use communication strategies such as gesture and talking around the word. There was some improvement in conversational language but his aphasia remained a challenge when meeting new people. His



Colin working at Wheelbase. The top left photo shows him in discussion with Rebecca and Jane.



reading improved to comprehension at sentence level, and he was able to write important information such as his name and address.

As Colin continued to improve we began to discuss longer term goals. Just prior to his stroke, Colin had been made redundant from his profession as a welder. In December 2008, as part of the goal setting discussion, he expressed an interest in returning to work. Following this we had a joint session with Colin to identify goals that would begin the process. These were to:

- attend an interview at a volunteer agency with the support of speech and language therapy and identify suitable volunteering opportunities
- identify the challenges of returning to a work environment
- be able to explain his communication difficulties and identify the support strategies that he finds useful
- begin the return to driving process
- sustain a regular commitment to a social activity.

We felt that a period of volunteer work would give Colin a good experience of what it would be like to return to regular work but would also allow him to be flexible with his hours and to build up his skills and confidence

slowly. His main challenge to returning to work was his communication difficulties and it was important that whoever he was placed with had a good understanding. Returning to driving and sustaining a regular commitment to a social activity require routine, motivation, increasing independence and commitment, and these qualities are all important in working life.

Real life

We arranged an interview at the local Volunteer Agency in Nottingham. This was a challenge for Colin. Much of it was word based, for example he was required to search computer databases for work opportunities and to respond to direct questions from the interviewer. The experience also highlighted the jump between conversation in therapy sessions and in 'real life'. Colin had been forthcoming in talking about his communication difficulties during therapy but had difficulty explaining them in this new situation.

Having reflected on this, we developed a communication profile (figure 1). Colin could use this to help explain his communication difficulties to new acquaintances. It would also offer them strategies to support Colin's communication.

We explored the volunteer opportunities together and Colin chose Wheelbase, a motor

charity project supporting young people at risk of crime and social exclusion. His role was to work on old motor vehicles, initially breaking down parts and cleaning them, with the aim of restoring the vehicle. Colin started volunteering at Wheelbase once a week and was allocated a supervisor / mentor. Although Colin was working in a quiet workshop away from the main project, he was still required to interact with his colleagues.

Around this time Colin was also assessed by the DVLA (Driver and Vehicle Licensing Agency) as able to return to driving. He got a car, which increased his general confidence and independence.

After a few weeks of settling in, we met with Colin and his supervisor to set some workplace based goals. These were to:

- begin a graded return to a motor task (initially breaking down and cleaning parts from a car, progressing to re-assembling and welding)
- be assessed for competency to weld
- access an email account and read a short email each week
- ask for support with reading when required
- update his CV and add the communication profile to inform potential employers

- f. use the communication profile to explain communication difficulties to a colleague
- g. identify services to support return to paid work
- h. attend Work Directions / Pathways to Work interview with the speech and language therapist.

These carefully structured targets enabled Colin to build his confidence and to experience success with each small step achieved. These goals integrated functional occupational and speech and language therapy rehabilitation as well as developing skills required for return to work.

Colin's mentor at Wheelbase described the difference in Colin from the beginning of his volunteer placement: "The biggest thing for Colin was that he wanted to talk to people but he didn't think they would listen. When they did it gave him confidence." He added, "The first time he turned up he had no car, it was difficult to engage in conversation and physically he seemed awkward. Now, what was it you said the other day [referring to Colin losing his temper about something not going right], you tried something, got irritated and used natural language; the words were just there. I was impressed at how natural the speech was. It may as well have been anyone else who worked here."

One-to-one speech and language therapy continued, concentrating on 'question and answer' scenarios and strategies such as having important information written down.

Following discussion with Colin about his communication difficulty and helpful strategies, he began to interact more and we noticed a significant improvement in his conversational language. Colin also commented that, "It's improved things because I can talk to people. Anything I want I know I can go and ask. I just get on with it".

Opportunities

Colin continues to set and achieve new goals. He has overcome the initial barriers in returning to the workplace and now sees that paid employment is a realistic option. Colin is becoming more independent in establishing his role and seeking out opportunities to develop himself further.

This volunteering placement has benefited Wheelbase as well as Colin. Staff are more aware of the effects of stroke and how to support people with communication difficulties. Colin's mentor says, "He's a nice bloke, good to have around and I've learnt something from him being here. In helping Colin to learn things I've had to find new ways to teach." We hope Wheelbase will offer similar opportunities to other people and share their experience with other voluntary groups and employers.

There is a drive to support people with disability back into work. National services such as Pathways to Work and Disability Employment Advisers have been useful in giving us information about what is available for Colin in terms of opportunities and financial support.

Our experience at the Volunteer Agency and at the Wheelbase Motor Project highlighted again a lack of awareness among the general population of the effects of stroke, especially aphasia. Colin's communication profile helped to explain that he was not just 'forgetting' words and that his 'speech' difficulties did not affect his ability to think and make decisions. There is a need for specific training for employers and voluntary services to improve their awareness of the effects of stroke and to improve their confidence in supporting people in the workplace. In the Community Stroke Team, we recognise it is our responsibility to provide this training, and we have developed a training package that can be offered to potential employers and outside agencies. We aim to deliver this training 3-4 times a year and hope to link in with the volunteer agency. Although general training is important, this experience has also taught us the importance of specific support and training for places which are supporting a person back into work.

As well as being valuable to Colin, the multi-agency and interdisciplinary approach means we have developed our skills and learnt from each other. For example, we have an increased awareness of the challenges of a communication difficulty in returning to an activity and also of the importance of making use of retained ability and working in a graded approach to build skills and confidence.

The key learning outcomes for us are in figure 2. As Colin says, it is about "actions not words". Although this article describes one client's journey, it encapsulates the philosophy of our team in offering a service that crosses professional boundaries to achieve patients' goals and recognise their full potential. **SLTP**

References

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Resources

- Wheelbase Motor Project, www.wheelbase.org.uk
- Search for Pathways to Work, Disability Employment Advisers, and information about returning to driving at www.directgov.uk/disability

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Figure 2 Our key learning outcomes

- **There is a need for lifelong access to stroke services as documented in the National Stroke Strategy (DH, 2007) to support long term goals.**
- **Teams must be aware of the need for support as people's needs change and develop over time, and to have a robust system to enable people to re-access services.**
- **Services should be commissioned to reflect evidence based research for stroke rehabilitation.**
- **Aphasia is not just a speech and language issue. Involvement of occupational therapy and other agencies has been key in recognising Colin's retained abilities and offering a graded approach to return to work.**
- **We need to provide stroke awareness training to services that may not be directly related to stroke.**



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REFLECTIONS

- DO I WORK IN A WAY THAT SHOWS I UNDERSTAND APHASIA IS MORE THAN A SPEECH AND LANGUAGE IMPAIRMENT?
- DO I RECOGNISE THAT ABILITY IN A THERAPY SESSION MAY NEED EXTRA SUPPORT IN A REAL LIFE SITUATION?
- DO I CHANGE THE FOCUS OF MY THERAPY TO REFLECT UPDATED BEST PRACTICE GUIDELINES?

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