

Imprints of the mind

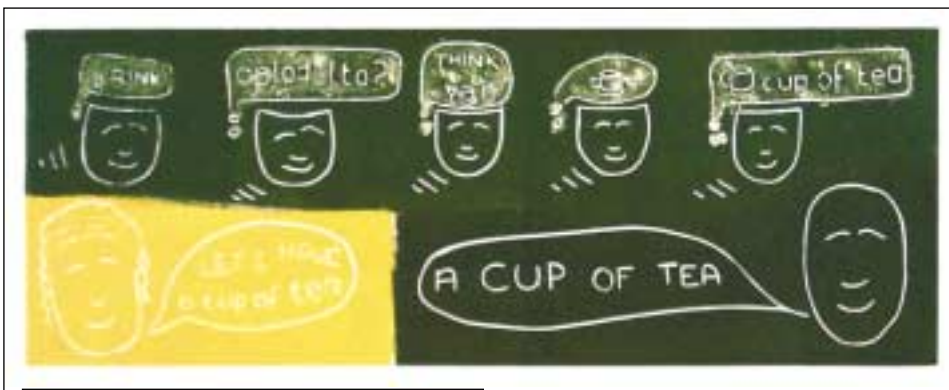


Figure 3 Len Agley - Limits on activity

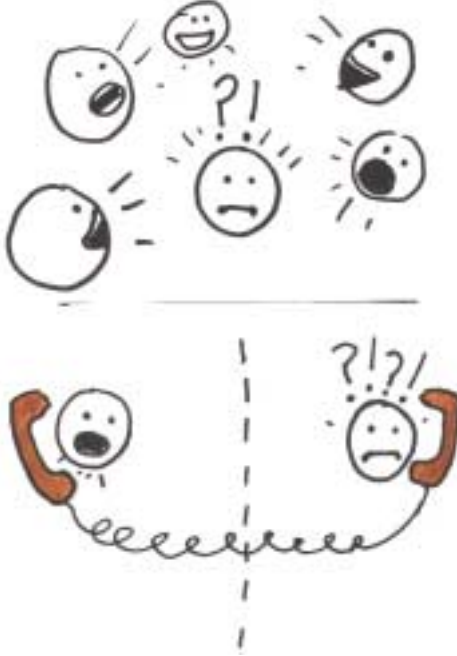


Figure 5 Len Agley - untitled view of reading



Figure 2 (above) Ron Devine: A cup of tea
Ron demonstrates how quickly his wife, or other non-aphasic people can say "Let's have a cup of tea."

Figure 4 Limits on participation



[Speech and language therapists need] persistence. Have to know that no matter how it don't look very good, got to keep going and look at ways of making use of words to look at how the people look at words in their head, because we've all got ways of looking at words.

It's nearly two years since **Ron Devine** had his stroke. Like all the participants in the Expression project, he has come a long way but hopes to go much further. Three weeks into a new job, Ron's life - and that of his family - was turned upside down when he took ill at the wheel of his car not far from his home.

Ron's daughter persuaded him to admit to me that he hated speech and language therapy. He remembers having to find one word and not liking it, preferring the later homework such as puzzles. *I couldn't believe I couldn't do this. After a while I thought, wait a minute, this has happened, so you just have to do it. I didn't particularly like it but thought it would do me good. Patsy [Ron's wife] kept me going. In the beginning, you cannot tell people at all. There's not enough speech therapists to keep going until you're never going to get any better! New people come through needing the services.*

Figure 6 Len Agley: New Discoveries



Early in 2001, six service users with aphasia, two speech and language therapists, an artist and an illustrator teamed up to work on an expressive arts project. The results have gone way beyond what they envisaged and have the potential to benefit a far wider group of people. Here, *Avril Nicoll* meets four of the participants in 'Expression' to hear their unique and often surprising stories about life, change, services, aphasia - and speech and language therapy.

Read this

if you want to

- work collaboratively
- know what users really think
- help people express themselves

As a charge nurse with the frail elderly, Ron was acutely aware that standards of nursing care fell way below what he would have expected. He remembers being handed a razor and being told to shave. As he was not given a mirror, normally used an electric shaver and had just had a stroke, the result was predictably bloody. Ron also felt the humiliation of not being able to express something as basic as needing the toilet, even if someone happened to be around at the time he needed.

... went to go out of my bed ...and I forgot my - my legs werenae working [laughs]. The reason was 'cos they hadn't given me a bottle and I'd never seen anybody and when you canna - canna talk so you canna tell them - if you see somebody going zh-zh-zh-zh [gestures and sounds people buzzing about all over the place], they canna stop - they've got to be able to see you before you can say "I need you" - I needed the toilet, and I just had to go out to try and get it - and I didn't!

Ron is pleased to learn that Ninewells Hospital in Dundee is at long last to get a specialist stroke unit. He contrasted his experience in Ninewells,

and the experience of other people he knows, with the Centre for Brain Injury Rehabilitation at Royal Victoria Hospital, although he didn't at the time agree with their assessment that he had 'potential'. Reflecting

on how his experience makes him view what happened when he was on the other side of the fence as a charge nurse, Ron is very positive.

Actually, I think I thought I had been - because of what's happened - that what I was doing now - oh, the wrong way - that I had been nursing them in the way that I would wanted to be. But you have to have enough nurses to do it - and they didnae have it at Ninewells. Even when you did - phew - it was "hello" and "cheerio". They didn't know how to stop and listen what you need.

In contrast, the rehabilitation centre had an individualised programme and activities were organised for the whole day. At that time in a wheelchair, Ron resented being so dependent on other people for his mobility and found this had a huge limiting effect on his communication and ability to make decisions. He still finds it difficult to believe that he could have made so much recovery in his movement and talking given the

extent of his initial difficulties.

Ron suffers a great deal of pain and continues to find the reversal of roles with his wife hard to bear. He works hard on his computer; figure 1 shows part of two descriptions, done a few months apart, of how his stroke occurred. Interestingly, Ron explains his aphasia using a computer analogy:

I look at my — screen, the screen that I get - and I use this for everything but some people don't have one. Some people think it's in their chest and they feel their words are stopped.

Figure 1 Ron - 'A Stroke Happens'

- January 2001

I held taken to car and always I saw somewhere can to push to can path and him told I going the ambulance and I going person still me seating and but I forget some.

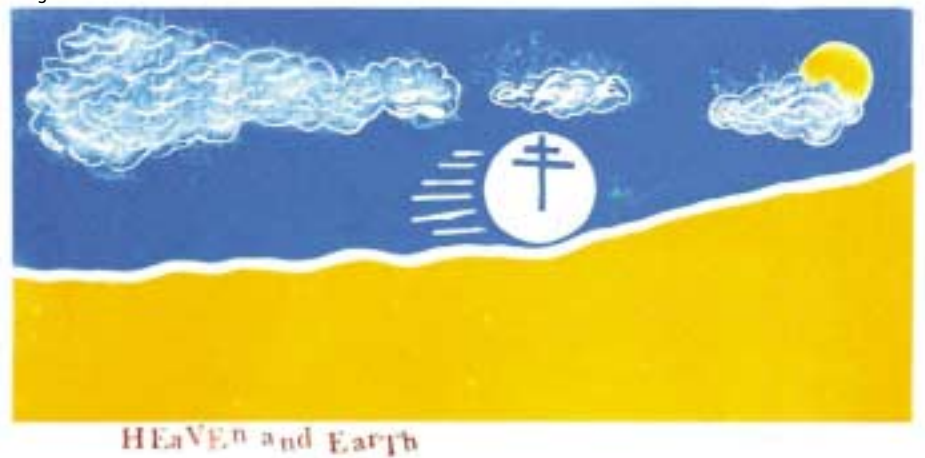
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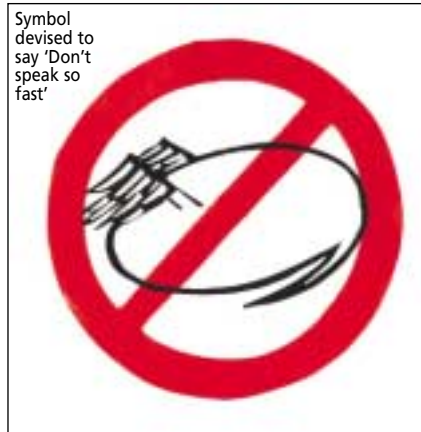
I found myself getting out of the car, unable to do anything but stand there. Someone came down the path of a house and called to me, asked if I needed help and he helped to pushed me against the car before I fell down.

Figure 7 Helen Gowland: Dying to Whoosh



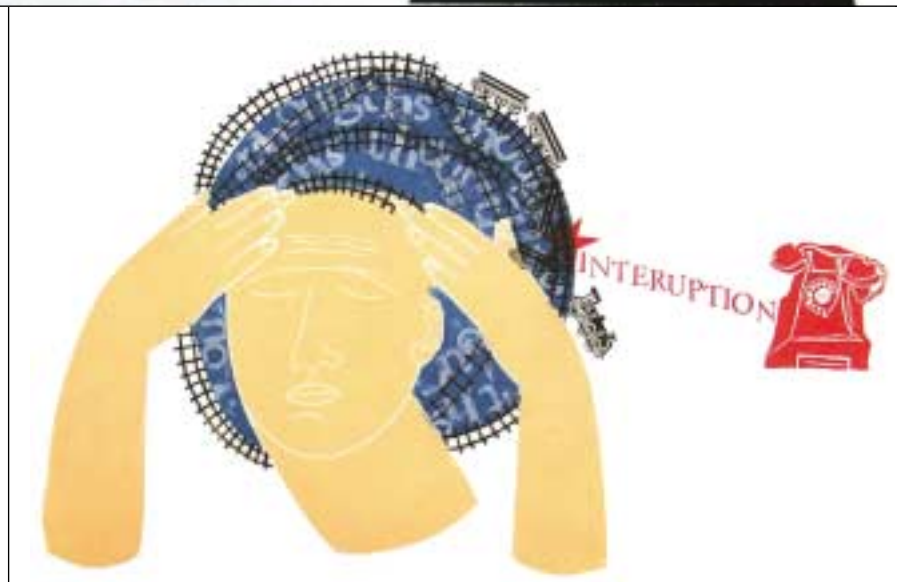
Figure 8 Madeleine Nedelec-Lamb: Heaven and Earth





Symbol devised to say 'Don't speak so fast'

Figure 9 Illustrations by Christine Farrell



◀ Ron talks slowly but fluently, focusing carefully on the point he wants to make and using humour to help him deal with highly personal and emotional issues. His illustrations in the *Expression* project reflect his feeling of being present among a group of people but not being part of the communication, and his recognition that the greatest difference between his communication now and before his stroke is timing (figure 2).

Collaborative venture

Expression is a unique collaborative venture between a group of service users with aphasia, speech and language therapists, an artist, and an illustrator. The use of art as a communication medium following aphasia is growing (see, for example, Sacchet et al, 1999) but the aims of this project were far wider. Over five Saturday sessions of printmaking at an art college, each lasting 5 hours, the group constructed new representations of aphasia in order to:

1. make aphasia visible and more understandable
2. increase awareness of what it means to have aphasia
3. show wide-ranging competencies of people who have aphasia
4. address different aspects of identity (for example; personal, social and collective.)

Taxis and lunch were provided and visual reminders were posted and telephone calls made between sessions. Visual and written summaries of the workshops were also made to facilitate communication about the sessions with family and friends.

Ron had previous knowledge in that he had at one stage been a printer, but **Len Agley's** experience of art was confined to his school lessons. Although he found them enjoyable, he says he was very bad! Len admits to having had a sense of fear about the proposed group but, having discussed it with his wife, felt he would try it and, if he didn't like it, he just wouldn't go again. However, he immediately loved it, built up a strong bond with the rest of the team, and says they would all go to *Expression* anytime. Len gestures expansively as he describes the feeling of inclusion which came from participating.

Same people altogether - similar but different, like being pals. The people helping too were awfully good. That first year I wouldn't have gone because at that time I was thinking I would still be alright - doing a lot to try to help myself. The worst thing was coming to, "you're not going to be the way you want" - you've got to change your head's way. Even now, it's hard.

Len, who exudes a quiet strength, covered a large area of North East Scotland as a service engineer with Comet. He took ill when he was at a customer's house and seems to have been a victim of a catalogue of health service failures. His family feels very let down by the system and his wife points out that, even now, as aphasia is a 'hidden' disability it is not afforded the same respect as other more visible ones. Len would like the

opportunity to tell his story to someone in authority, and for them to listen and learn from it, so that it never happens to anyone else.

It took a long time for Len to accept that he was not going to be able to do all the things he did before. This was a lonely time for his family who had taken that fact on board much more quickly.

It's hard because, before that, I thought I would do anything I wanted to do. Squash, running, bike - I can do it now, but I'm numb up my right side.

Speech and language therapy lasted two years. Len believes he could have gone further with it but, in common with the other participants interviewed, is philosophical about it, recognising that services are under pressure.

Part of the *Expression* project involved the participants keeping a sketchbook where they visually recorded things of importance to them. Suggestions for what they might collect included magazine cuttings, postcards, photos, words, colours and images as well as sketches, doodles and collages of their own. The World Health Organisation principles of impairment, activity, participation and well-being provided a structure, but had to be made meaningful.

Looking first at impairment, Len was asked: What doesn't work? What it feels like? What feels wrong? Why won't it work? Where does it feel wrong? Adding red to a figure of a man, he coloured the right side and around his head. Around a postcard of someone holding their head with a cloud-like question mark, lightning and rain above it, and the question 'what's it all about?', Len explains

I know what I want to say but it comes out all wrong!

Why does my head hurt?

Why do I not feel my right arm or leg?

Limits on activity, on what Len can do, are in figure 3. Figure 4 shows his response to the participation question; the restrictions on his life, involvement, engagement and attainment. Trying to communicate within a group causes confusion and alarm, as does being one half of a phone conversation. Len's humour comes through in pictures of his faces associated with his football team Dundee United - upset, depression and frustration! The serious side to this is addressed by a picture of his face in a box set apart from this, showing isolation. Len goes to the games and is part of the crowd - but not a participant in the same way he was before.

Feelings are explored under the banner of well-being, with Len's a mixture of the negative (helpless, inadequate, frustration, emotional) and positive (more relaxed, more time, accept illness, grateful for help.) Reading and writing are skills he misses

people get huge enjoyment from being creative. Some naturally gravitate towards computers, paints or pastels, and colour or humour

greatly, as shown by the print in figure 5.

Len's print *New Discoveries* is also a mass of allegory which very much reflects how Len felt at that time. The ship *Discovery* (berthed in his home town of Dundee) is pictured along with the *Discovery* space shuttle. As Len explains, *They didn't know what was gonna happen with them. And same as...That's where I was before. And that eh that changed now what I was thinking. You were going up. And eh, going up.*

If you look closely at figure 6, you will also see a lump on the head of the person with the sad face to signify the brain injury. Chris Kelly, artist on the *Expression* team, comments that *New Discoveries* may have a certain naiveté in execution, but the quality of the final print is such that it becomes a sophisticated piece of storytelling.

Ready to reflect

Chris explains how the sketchbook and the World Health Organisation model provided a structure and context for personal reflection by a group of people who were ready to reflect. Getting things out into the open stopped the aphasia from being such a personal burden. Dealing with any example of aphasia in a very public way meant that they could be discussed by the group and worked up into visual representations by the students and illustrator Christine Farrell.

Having expected to find most of the participants' experience of aphasia revolving around the head and the spoken word, the facilitators were surprised to discover aphasia was actually experienced far more holistically. In the first session, one of the speech and language therapists presented a narrative of aphasia, that "it's like coming into a filing cabinet and finding that a group of thieves has played mischief and created disorder." But as an example it was irrelevant, as they didn't identify with it - the participants were more involved with images of being outside of the conversation, whether due to mobility problems or sitting amongst a group of people who were not aphasic.

Helen Gowland's experience of aphasia is not in her head at all. Enthusiasm for life, hobbies, family, friends and work bubbles over as Helen explains where the feeling of whoosh! comes from (see figure 7, *Dying to Whoosh.*)

I said, it's right in here [points to heart] but you just cannot...get it in here [motions up to mouth]. I know EXACTLY what I want to say. Well, it's much, much better now - because, if you say something to me, or I want to say something, you'll say it and I'll know what I meant to say. But I know it's there [in me], but it's in here [points to

heart], and this is why I not in here [points to head], this is why I'm not mad this is why I'm saying it's in my heart, because it's just here [points to heart] or.. just wait a wee minute..[walks fingers towards heart] it can be in there [other area of chest] or there [other area of chest].

Helen is adept at using a variety of methods - writing the first few letters of words, asking for a model of a word, finding key words in her book, asking for time - to help with communication. Her aphasia is the result of a brain haemorrhage and operation two-and-a-half years ago.

I was a physiotherapist and I absolutely LOVED being a physiotherapist - just fabulous. Like you do as well [being a speech and language therapist]. And I got three girls, and a husband. And everybody's fantastic. And all of a sudden - I was sitting at telly about 9 o'clock and I was watching TV - Joo-Jools Holland - and I love him - and that's the last thing I know, I can remember.

Not allowed to enter rehabilitation until a month later, Helen remembers a pretty awful time. She hated sitting about in her night clothes, and cried to get home, but her daughters had to keep telling her she couldn't. Gradually Helen was able to go home for three day weekends when she enjoyed having a good laugh with her friends. This continues with get-togethers for coffee and a group of women meeting up every month for a curry at somebody's house. When I asked whether her friends had known anything about aphasia, she said no and added,

In fact, neither do physios either. Because it's completely different because physios are all about this bit [points to body] and that's been hard for physios to think about what's happened.

Helen now takes a popular exercise session once a week at a club for the elderly, cooks and sews,

and has new hobbies of belly dancing and Tai Chi. She has recently started counselling as she describes her speech and language therapist as 'wonderful' but explains that, afterwards, you ask 'what else? what about ME?' Helen believes there is insufficient speech and language therapy which means it cannot continue for as long as people would benefit from it. She is now active in the local Speakability group which is planning to take its campaign for more therapists to the Scottish Parliament. In common with Ron, Helen didn't much care for 'what's

that?' naming tasks, but says

I love, "Today we're going to Edinburgh with my daughter to get a _____" - MUCH better.

Two of Helen's daughters are at university, one at St Andrews, the other at Oxford. Helen is frustrated that these place names are particularly elusive and, although she is rather concerned that other people might get impatient, is persistent in getting them 'from here to here' through visualisation so she can 'whoosh'. Helen makes use of all her senses to make up for things she cannot enjoy

If you get the opportunity to see the *Expression* exhibition, do go.



◀ as much as before; for example, by smelling books she cannot read. She can manage recipes but important tools such as shopping lists are an ongoing problem. Although her spoken words are firmly in and around her heart, Helen doesn't have a strong sense of where written words are - she just doesn't know.

Helen had tried a Chest Heart and Stroke group but she didn't like the noise and found the volunteers overbearing. In contrast, she describes *Expression* as

Absolutely fantastic, the most wonderful thing I've done. Start with something small - shape, colour, a little bit more, realise oh! I can do a bit more than that.

The grading of the printmaking skills from basic to more complex was overseen by Christine Farrell. Her previous experience, including a residency working with women and children at the Transport Museum in Glasgow, has shown that people get huge enjoyment from being creative. Some naturally gravitate towards computers, paints or pastels, and colour or humour, depending on their age, individual preferences and mood.

Excitement of the moment

Monoprints were done by drawing on paper that was on top of glass covered in ink. When the paper was pulled back, the image was in reverse. In contrast, lino cut is a block print with ink applied to a surface that has been cut. The design and print workshop at the art college has old, cast-iron presses and a history and smell associated with it which increase the excitement of the moment when the finished article is revealed.

The physical element of the process - the balance required to pull the press, the fine control to cut the lino - was enjoyed by all participants.

Madeleine Nedelec-Lamb is unable to use her right arm following her stroke but is particularly persistent. A facilitator held the lino and turned it every time to ensure she made the cuts away from herself, using the weight of their hand to prevent the lino from slipping. Madeleine describes *Expression* as

Probably the best help I've ever experienced in that field. Well, for a start, I didn't know what I was doing. I still didn't know what I was doing. The others knew what they were doing but weren't able to express things clearly, but I didn't know why I was there, what I doing - I knew I wanted to do it because they were nice to you - they had time - you were not a burden - it's like you were a normal person, you weren't a burden.

Of the four participants interviewed, Madeleine has the most spiritual approach to a life which has not been easy. She has persistent pain from arthritis and headaches but has learnt peace and patience, and found her determination not to give up comes from being a mum to her sons, James Paul and John Michael. She is very grateful for all the support she has from her family. For example, she describes her own mum as 'worth

her weight in gold' and tells how John gave up his career to look after her.

Happiness a lot easier to find since. I feel grateful that I am almost chosen to be here and at least talking, not in the manner that I would like - I would love more expressions to be able to... but, yeah. My day isn't long enough. I used to be often bored before, I was always keeping myself busy - probably too energetic, or too hyper. I think I just appreciate being. It's hard - it takes me so long just to do little things - it's taken me so long to do little things whereas before you would do them in a second.

Madeleine describes the relief of being in respite care where she doesn't have to do what seems like one task to us but means ten to her.

I didn't have to buy the food, I didn't have to prepare the food, cook the food, I didn't have to set the table, serve it, didn't have to - em - take the plates away, I didn't have to wash up.

Madeleine's print (Heaven and Earth, figure 8) describes her struggle but says 'nice things' to her - her dad who died when he was 42 is up there, as is her brother John who died at 50. Madeleine herself 'nearly made it' when she was 50. Madeleine found it difficult to conceptualise her picture, and to understand what she was meant to be doing until it was actually finished.

Speech and language therapy is something else Madeleine says she didn't understand until it was finished. She would like to do more but with something she is interested in and which inspires her rather than 'words for words' sake'. Madeleine's father was with the Free French and she remembers the language being spoken around the table with onions and mustard, crusty bread and good cheese long before these became trendy. She would love to re-learn French, but is finding she needs more help than the tapes and books she has offer her and is further hampered by the physical challenge of turning pages.

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Madeleine has ongoing problems with reliability of transport which severely restricts her independence and ability to take part in groups. She is participating in the local Speakability group but, in addition to transport issues, finds the level of paperwork a problem. For so many daily living tasks she feels she needs just a little extra help. She hopes to get a computer again in the future so she can make use of facilities such as e-mail which is far easier for her than writing and folding a letter, putting it in an envelope, sticking a stamp on it and posting it.

Madeleine sets high standards for herself. She likes to have notes to compensate for the memory difficulties she finds so debilitating and frustrating to read, and to use several different words to describe the richness of her experience. She understands why people say 'oh, I forget things too' but is eloquent in explaining what she really needs. *Often I don't talk because... FAR too fast - not clear enough or slow enough. I need words repeated. If I was in a discussion NOW, I would love to express myself better - would love to do it the way I did before. [I need] one-to-one, very*

clear, slow, not in a hurry, not getting job done and on you go. 'Cos everybody is in a hurry and - eh - it's far easier for me if things are slower.

Power

The *Expression* project has enabled all these participants to communicate their experience of aphasia. At every stage, facilitators were enthusiastic, encouraging, observing, discussing and taking notes. By turning the power over to the participants to create something unique reflecting their personal experience (examples in figure 9), the possibilities are infinite. Over the next few years, Christine Farrell plans to extend this work with other people with aphasia so that it will benefit a wider audience. She envisages a package of illustrations being produced to be used by speech and language therapists with people with aphasia and their families at different stages of the process of coming to terms with it.

If you get the opportunity to see the *Expression* exhibition, do go. The enthusiasm, inclusion, confidence and humour associated with it is there for all to see, and the bond between the facilitators and participants mutual.

As Madeleine says, *I couldn't believe how nice they were. They said we had benefited them - wow! It made you feel so - you're not a number, it's like you're a person again - and they had the time for you.*

References

Sacchet, C., Byng, S., Marshall, J. & Pound, C. (1999) Drawing together: An evaluation of a therapy programme for severe aphasia. *International Journal of Language and Communication Disorders* 34 (3).

Acknowledgement

Avril Nicoll would like to thank Christine Farrell, illustrator, Chris Kelly, artist and Laorag Hunter and Lynsey Paterson, speech and language therapists for their assistance in gathering information for this article. Special thanks go to Len Agle, Ron Devine, Helen Gowland and Madeleine Nedelec-Lamb, *Expression* participants, for sharing their very personal experiences so that others with aphasia may benefit - it was a privilege to meet you all. ■

Reflections

- Do I know how the therapy I offer makes people feel?
- Do I appreciate that a communication difficulty is felt more holistically by clients?
- Do I prioritise people for therapy at the right time for them?