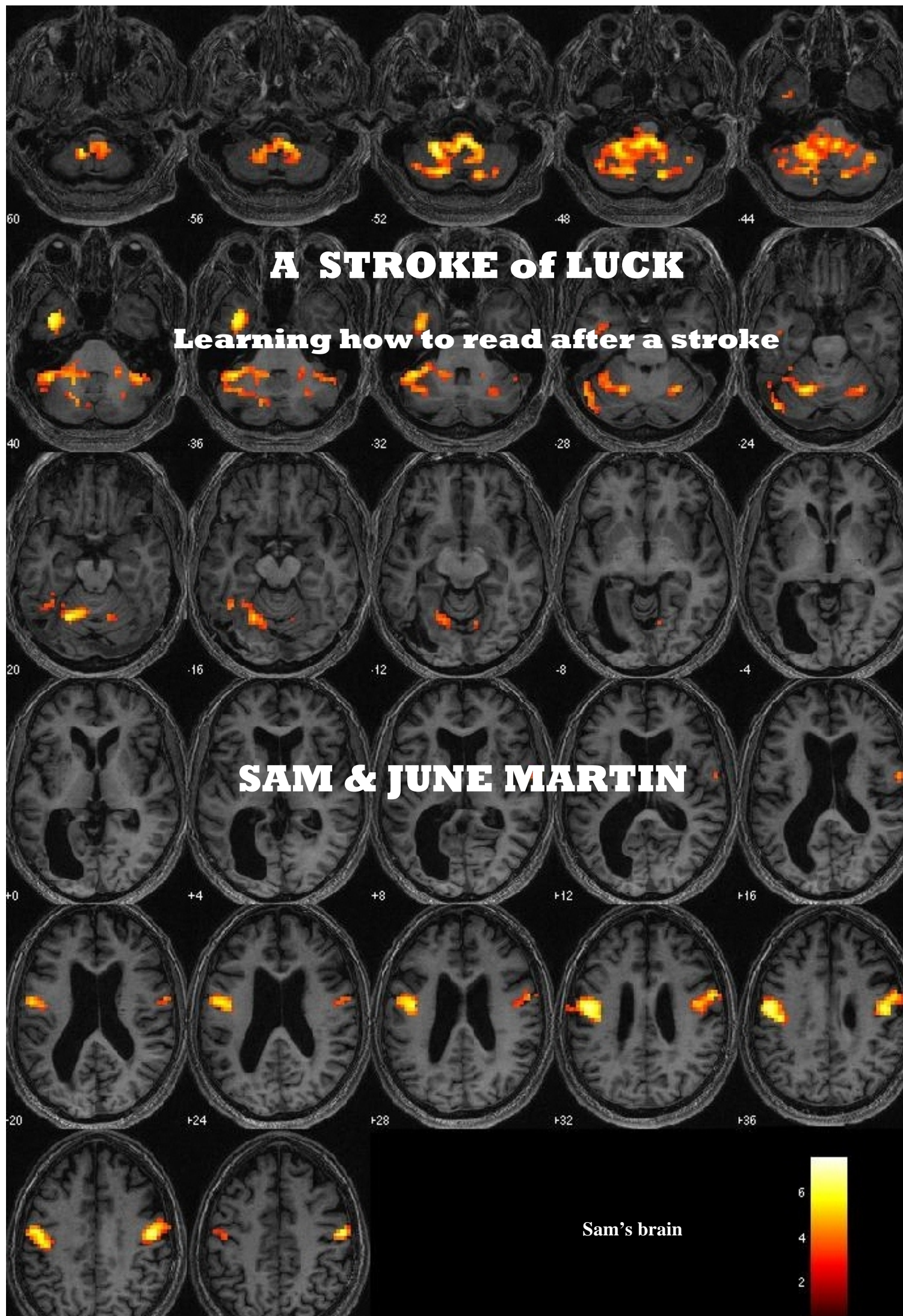


A STROKE of LUCK

Learning how to read after a stroke

SAM & JUNE MARTIN



Front Cover: The fMRI images shown on the front cover were kindly supplied by Suz Prejawa a member of the Predicting Language Outcome and Recovery After Stroke team at UCL. The coloured areas represent the areas of the brain that are active when doing single tasks such as looking at words or saying words.

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Acknowledgements

I thank members of the research staff at the Predicting Language Outcome and Recovery After Stroke, known as PLORAS, at University College London for their help and interest, particularly, Suz Prejawa for providing the coloured image of my own brain in action taken in a functional MRI scanner, and Louise Lim, who kindly provided valuable editorial suggestions on the text and Rachel Browne, who has helped website links. I also thank Paul Montgomery of the Stroke Association in Belfast for assistance with setting up the Justgiving donation link.

I am grateful to all the staff in Dr Wiggam's ward in the Royal Victoria Hospital in Belfast, N. Ireland, who during my week's stay helped to give me confidence to face the future.

When back home, the attention and support of the Occupational and Speech Therapists from the Community Stroke Team in The South Eastern Trust in N.Ireland, is greatly appreciated during the first few months of my recovery and especially Alison Bell for drawing my attention to the novel on-line Read-Right Therapy devised by Dr A. Leff.

Immediately on my arrival home from hospital, my cousin Derek Capper, supplied me with numerous 'baby books' which helped me relearn the alphabet and simple words like 'if' and 'it'. Also, after June and I had finished the text of this book, he carefully edited and greatly enhanced the entire manuscript.

Finally my greatest thanks must go to my wife, June. Her constant love and support and patience over the last two years has been vital. Also her strong and dedicated school-teacher's understanding of the importance of the daily routines of teaching, learning and testing, has been the core basis of my recovery. I know now why she was such an excellent teacher and is loved and respected by her students around the world.

Sam Martin
2013

Preface

In late 2011 my husband, Sam, suffered a stroke resulting from a cerebral haemorrhage. Fortunately the physical effects were minor but he lost the ability to read. When he got home from hospital on the 19 November 2011 he could only recognise a few letters of the alphabet and very few 2 letter words. Fortunately over the last 2 years he has recovered quite well and enjoys reading again.

This short book is the story of his recovery which has been greatly assisted by the use of an innovative computer-assisted therapy and the realisation that his reading problems involved two distinct defects each of which required different types of therapy along with an enormous amount of personal help and teaching by me. Our story '*A Stroke of Luck – learning how to read after a Stroke*' will be of interest to stroke survivors and their carers and to health professionals who are involved in reading and communication disorders.

In a recent publication by the Stroke Association – "*UK Stroke Survivor Needs*" (December 2010), it is stated that "problems with ...reading were reported by 23% (almost a quarter) of respondents."

While great progress has already been made in research into the needs of sufferers in the acute stage of stroke, the problem of reading was described as one "of those needs that was not always assessed in clinically focused studies of stroke outcomes", and 34% of those with reading problems reported that their need was "unmet".

It is with this finding in mind that we feel this booklet should make a valuable contribution to what the survey demands – i.e. "increased research efforts into long-term outcomes, needs and methods of meeting needs," to "ensure that progress is made in strategies to manage the long-term consequences of stroke".

June Martin

Foreword

By Dr Alexander Leff

Patients' stories are always fascinating to me and I think that recounting and sharing them helps both the storyteller and others who have been affected in a similar way. Although very much a personal journey, this story contains many aspects that will be familiar to anyone who has had a stroke: from the dawning realization that something 'serious' has happened, through interactions with the health service (both the acute phase and waiting in the community for follow-up therapy), and most importantly, through a recovery trajectory that is positive and still ongoing.

My main academic focus is in neurological rehabilitation, or, in layman's terms, understanding how patients with brain injury can be helped to recover over time. While some of this recovery may be 'spontaneous' and due to physiological factors over which we have little current control, the majority of recovery takes hard work, with the need to practice the right thing at the right time over and over again, and bucket loads of patience.

Sam's stroke caused two main problems with his reading: a generalized problem recognizing individual words (pure alexia) and slowed text reading due to his visual field defect (hemianopic alexia). The behavioural therapies for these two impairments differ. Sam has worked really hard on his reading, and to good effect, but as his story makes clear, not all forms of therapy were equally good for him and he had to work out what worked best for the pure alexia component of his reading problem. I'm very glad that an occupational therapist and speech therapist were able to point him towards the web-based therapy tool I have set up for patients with hemianopic alexia with funding from The Stroke Association: Read-Right. This therapy is a strategy-based therapy, that is, it doesn't improve the underlying problem (visual loss) but rather uses undamaged brain regions that control eye movements to compensate for the visual loss. It is heartening to see it have a beneficial effect in even a single case, but in fact many patients have benefited from using this site.

When it was being set up, I don't think anyone envisaged that the internet would be used to improve people's health. The simple message is that behavioural therapy following stroke works but much time is needed to effect change, in other words: "practice makes perfect". The main issue in neurological rehabilitation at present is insufficient access to specialist therapists' time. Developing evidence-based therapies that can be used by patients over the internet seems like an obvious solution to me.

Finally I'd like to pay tribute to June. Not everyone with a stroke has a family member or friend to help them on the road to recovery, but stroke almost always affects more than one person and her dedication to Sam's reading rehabilitation certainly played an important part in getting him better so quickly.

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Foreword

By Dr Ivan Wiggam

Recovery after stroke is a complex process that requires a thoughtful, determined and informed approach. Central to this is the ability to accurately identify the patient's problems and then implement appropriate strategies to deal with these. This is by necessity an individualised process in which both diagnosis and treatment are continuously refined by careful ongoing observation.

The old adage “listen to your patients – they are giving you the diagnosis” (René Laennec) has rarely been more clearly demonstrated than in the story of this patient – Professor Sam Martin. This personal account of Sam's reading difficulties after stroke and his journey to recovery provides an excellent description of both pure alexia and hemianopic alexia, together with a practical approach to recovery.

Maimonides, writing over 800 years ago, insisted that “medical practice is not knitting and weaving and the labour of hands, but it must be inspired with soul and filled with understanding and equipped with a gift of keen observation”. Soul, understanding and observation are at the heart of this story. Whilst none of us can ever share completely the feelings of another, the mere effort of trying to do so undoubtedly enriches us all. I wish to thank Sam and June for their willingness to share their story. Those who read it will be both educated and inspired.

Dr Ivan Wiggam,
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Chapter 1

The Key to my Future.

It all began on the Thursday evening 12th of November 2011. My wife, June, and I were in bed and I had been reading my current novel *Ultimatum* by Matthew Glass, and then around midnight, having kissed June 'Goodnight', I settled down to go to sleep. Suddenly I felt a severe pain above my left eye. I assumed that it was the onset of a migraine headache and June quickly fetched me an aspirin. I swallowed it with a little water but then immediately fell asleep lying on my right side, although the pain had eased and had moved over the top of my head and down the back of my neck. I'm not certain that I did not actually faint and I did not wake until 6.00am in the morning. My headache had vanished and I was able to get up and go to the toilet. Although I had been sick while in the toilet, I was not stumbling about in any way and was able to get back into bed and soon went to sleep again. I woke around 8.00am and got up as normal, putting on my dressing gown, making a mug of coffee and accompanying our dog, Tory, briefly around our small garden. However, when I sat down for breakfast, I suddenly felt nauseated and was violently sick and had to return to bed. I continued to be sick at intervals during the next four or five hours. Throughout Friday I slept a lot and was continually disturbed by very strange repetitive dreams. June later told me that while my diction, on waking, was normal (not slurred) I was talking very strangely about my dream which I confused with reality, as I kept insisting that she had experienced this weird dream with me. She didn't know whether to laugh or to cry - or to call a doctor at once, so abnormal a phenomenon the whole scenario was to her, but I told her I was confident I'd get over this episode without recourse to a doctor! In any case, by the evening I was able to take some very light food (blancmange and brioche toast with honey and tea,) and slept well on Friday night.

On Saturday morning I felt much better. I was up and about for short periods throughout the day and during the afternoon I watched some rugby on TV. I noticed that I did not see the right-hand side of the picture correctly as I could not see the red dot on the top right of the screen without bending round to my right. At 9.00pm we decided to watch the Swedish film, *Wallander*, which had subtitles. All day I had been aware of something not being right about my right eye, and no matter where I sat I could not see the full width of the TV screen. The right hand side was blocked out for me and I also complained about the subtitles, which I could not read as they moved too fast for me. I thought I had strained or hurt my right eye, but later in the evening when I went to bed and began to look at my novel, I found to my horror that I could not read at all. The scramble of letters on the page meant nothing to me, no matter which eye I used. I knew at that moment that my problem was much more serious than merely having had a migraine headache. I then had a sleepless night realizing that I probably had had a minor stroke. On Sunday morning I immediately tried again to read but could not understand anything on the page.

After breakfast, June and I composed and sent an e-mail to my GP describing what had happened. Fortunately, Dr Keith Steele picked this up immediately and called us on the telephone. He advised me to go immediately to Accident and Emergency at the Royal Victoria Hospital in Belfast. We arrived at the A & E around 11.45 on Sunday morning, and while June was parking the car, I went to the reception desk to sign in, but was immediately directed to the Eye Clinic on the ninth floor. When I left the A & E, I realized that I was very disorientated and had no idea how to get to the Eye Clinic. Fortunately, when June returned from parking the car, she found me sheltering from the

rain near the front door of the hospital. June guided me up to the ninth floor where we were told that the Clinic would close at 1.00 pm. However, a young doctor read the copy of the letter which I had sent to my GP and recognized that I had used the words 'unable to understand' and immediately said that my problem was not merely to do with my eyes and I should go back to the A & E. In fact the round trip to the Eye Clinic took us nearly an hour and we eventually saw the triage nurse at the A&E at around 1.30 pm. We then sat in the waiting room until early evening and eventually saw a doctor at around 7-8 pm. We had some difficulty in convincing her of the severity of my main visual problem but eventually she agreed to admit me to a hospital bed. At around 9.00pm I found myself in bed in an inpatients' ward.

The next morning I saw Dr. Wiggam who arranged a CT scan and told me that I had had a 'bleed' on my brain and that I was very lucky that I had not more extensive problems. On Tuesday evening, when a bed became available, I was transferred to ward 7, the Stroke ward, under Dr Wiggam's care.

For the next seven days I was given the greatest care and attention that any one could wish for while in hospital! Blood tests, heart tests, physical tests, eye tests, reading tests, speaking tests, walking tests of every description, including a challenging obstacle course. In addition I had X-ray, visual field and CT scans and continuous BP monitoring - I got the lot, and the food was excellent as well. But ward 7 was one of the strangest places I've ever been in. I seemed to be the only one who could walk about and none of the other patients in the ward were able to speak to me. I realised that I was very, very lucky. My inability to read was my biggest problem. I could not read the signs on the ward walls. I struggled for hours to work out what the sign over the wash hand basin said. 'HAND HYGIENE' were the first words I made sense of. The young speech therapist was very helpful and gave me lots of exercises to do, but I did lead her astray on one occasion. She showed me a sheet with the alphabet displayed in two long rows, and to her surprise I was able to read out the letters perfectly. Although I was later to realise that I had been only rhyming the letters off by heart rather than actually reading them, and I felt sorry that I had mislead the young therapist. My speech was fine and I could recognise most animals and things but even three letter words caused me great problems. I recall one challenging picture; at first I could not articulate the names of two items in the picture, although I knew what they were. Then I said out loud, "Egypt, Cairo, Giza - the sphinx - and a pyramid".

However I did have difficulty in finding some commonly used words. The morning after my stroke I couldn't find the noun used to denote the dark stewed fruit I took every morning at breakfast. June had to tell me they were *prunes*. Even with this prompt I had difficulty in articulating the word "prunes". It wasn't until the next day that I could pronounce it properly, if I preceded the word prunes by stewed. "*Stewed prunes*" then became relatively easily to me.

The other word I had particular difficulty with was "*aspirin*." "What is the name of that pill you gave me last night for my headache?" I would ask repeatedly and June would reply, "*Aspirin*".

This use of an adjective or qualifying word before a noun I used repeatedly as a coping strategy. For example, I could tell people my consultant was Dr Wiggam when I preceded his name by saying "*High Wycombe*" - a town near where our son John lives.

Taken off the Beta Blockers by the consultant, I started taking Ace Inhibitors. The way I could remember this word was by thinking of *Formula 1 Ace* drivers, and then *Ace Inhibitors* followed quickly.

Towards the end of my stay I was transferred to a side room. However, I spent a lot of time looking at two words on the door, "SIDE ROOM", and tried to work out what they were. It was Friday evening at around 6.00pm, while I was waiting for June to return from dinner, that I finally realised what SIDE spelt. June recalls the delight I

greeted her with, on the final Saturday in hospital. She stated, “Sam had spent about 2 hours working out the meaning of all the 15 words on a leaflet explaining how to get using the mini TV and radio apparatus in his room. This was really a very difficult task which he persisted at for a very prolonged period of time.”

One afternoon when I was ‘presumably off the danger list’, a senior member of Faculty asked me if I would be willing to be a guinea pig in a tutorial with a group of 2nd Year Medical students. Of course, I had to agree and soon the room was full of about a dozen eager students. They were to try and find out what was wrong with me. It was an enjoyable half hour when I interlaced answers to questions with anecdotal stories of my student days, but the only thing they learnt was not to allow the patient to talk too much!!

A few days before being allowed home I was transferred to a side room where I was free from the various tubes and wires and monitors that I had been attached to earlier. On my first night in this private room with the door closed I had gone into a deep sleep. Prior to having the stroke I had been working on my mother’s family history and, now while in hospital, I remember dreaming about my Uncle Sam. *I recall being out of bed and putting on my dressing gown which I thought was a heavy rain coat. I was looking for my Uncle Sam on the Albertbridge Road during an air raid and I opened the ward door into the corridor and went out. A few yards along the road I was stopped by a man, (maybe an ARP warden, he should know the way to the Albertbridge Road) who asked me my name. But then I heard a shout from the end of the corridor, and a nurse whom I recognized came running up to me, took me by the arm and led me back to my room. I had been sleep walking which was the most horrific experience. For some time I imagined that this would be a legacy of my stroke, but a year and a half has passed without recurrences, so perhaps I am lucky again!*

Any large organisation such as a hospital is always at risk of sudden changes of plans and misunderstandings. I fell into this category on what was to be my last night. I had been waiting all week for an MRI scan and had been told that if this scan had not been taken by Friday evening I could go home and arrangements would be made for me to have an MRI scan through outpatients. Also, the results of the final blood test were due late that afternoon, but unfortunately as the sample had to be retaken at around 6.00pm I envisaged that the results would not be back until the following morning so I assumed I would stay another night in the hospital. Fortunately my son Allen, from Aberdeen, was visiting that evening when around 8.00pm a nurse came into the room and told me that the MRI scan would be booked through outpatients and that I could go home but she asked did I need a taxi? Both Allen and I tried to explain to her that my wife had a car and would be coming for me, pending the blood test result. The nurse did not seem to understand us and repeated three times, “Do you need a taxi?” Clearly, her comprehension of every day English was very limited although I would not question her competence in her nursing skills. Shortly afterwards, June and the senior nurse on the night shift arrived and assured me that I would not be sent home in the middle of the night by taxi!

My final memory concerns a delightful nurse from the Philippines who was in charge of giving out the medicine. She had always a very pleasant smile and a wonderful way with words. One evening I had gone to sleep early and as usual had closed the door of my room. I was awakened out of my well earned slumbers by a loud bang! I jumped up in bed and saw in the now open doorway my nurse holding in each hand a cup full of my medicines. She was saying in her delightfully *loud* voice, “Sam, wake up, here’s your bowel medicine!”

Finally, before I leave the topic of Ward 7, I wish to say a big thanks to Dr Wiggam and all the members of his wonderful team, the nurses, the speech, occupational

and physiotherapists, the porters, the catering staff and the cleaning staff, for their kindness, their careful attention and encouragement and of course their friendly banter which kept my spirits up. Of course, my contact with Dr Wiggam and his staff has continued over the past months as they have carefully controlled my blood pressure which has now been stabilised at a much lower level. This, most important of all, is the key to my future.

Chapter 2.

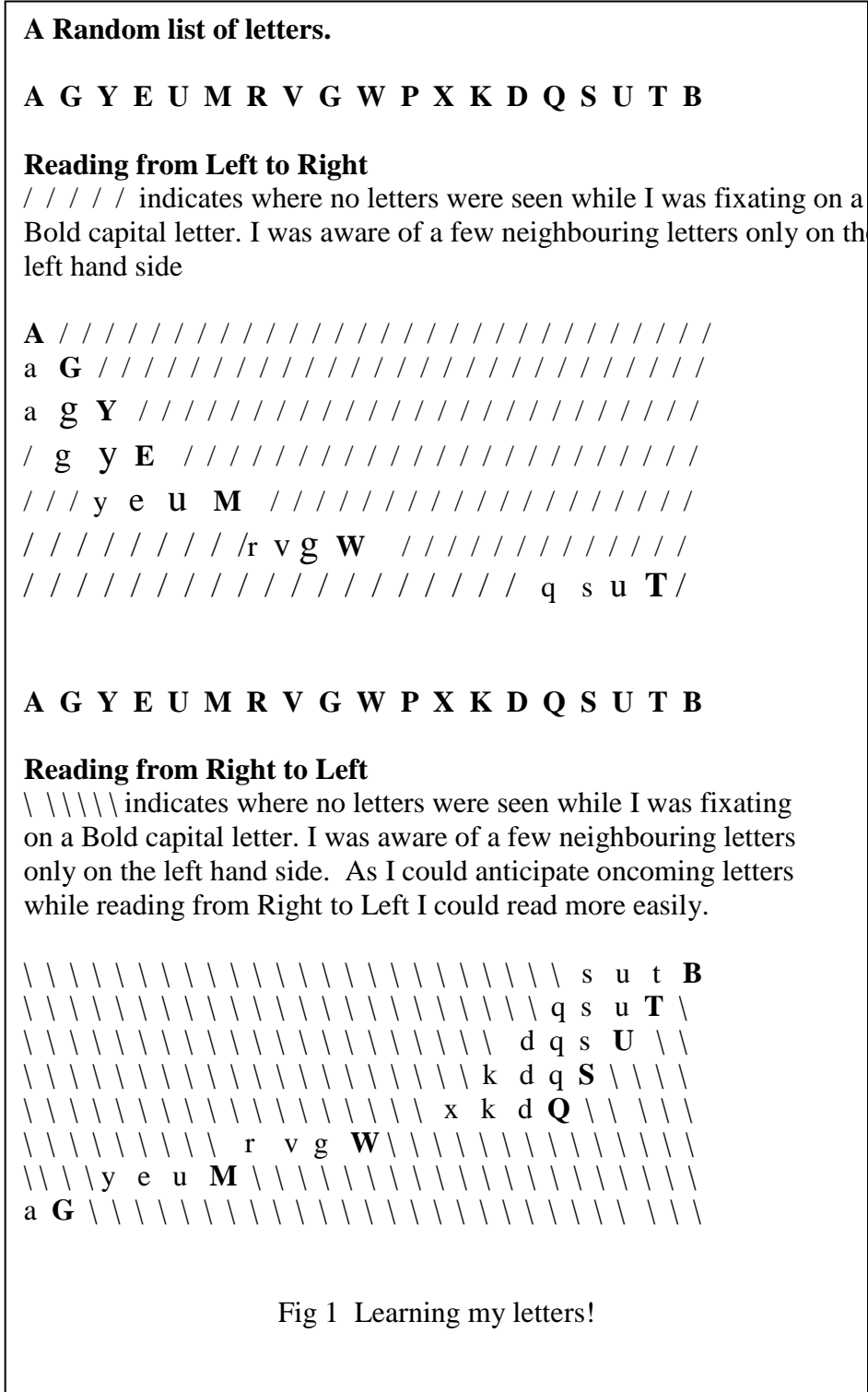
Reading between the Lines

On the Saturday morning the final test results came through and I was allowed home in the afternoon. Of course getting home was great and to be able to walk around our house, to get in and out of the car, to be able to walk our dog, Tory, around the garden, to sit at the table and eat a meal and to look at television made me realise just how very lucky I was. Compared to all those poor patients I had left behind in ward 7 who could neither walk nor talk, indeed I was very lucky. However the fact that I was unable to read very soon came to dominate my thoughts and feelings. All my life I had been a keen reader, always having a book or paper on hand: often while watching television I would be scanning a newspaper to see what was interesting to read more thoroughly later. I realised that a large chunk of my life style had been lost- would I ever regain it?

A young speech therapist had tested my reading ability while I was in hospital, and had been very encouraging and hopeful that I would recover well. She had given me a number of sheets of simple words to study that would keep me busy until a visiting ST would get in contact. Meanwhile my cousin Derek Capper gave me some books used in helping young children to learn to read. Derek was an expert in Phonics and both June and he tried to teach me some basic phonics. I couldn't manage this at all and their silent "e" and magic "t" and the hums and ahs that my grandchildren make while figuring out the words they were reading, sent me 'round the bend'. For a 75 year old who had been taught to read and spell by the frequent and abusive use of the cane, modern phonics is quite useless. More important, this time I realised that although I could say the alphabet by memory I could not recognise many individual letters when they were set in random order. Fortunately, one of the books that Derek had given me contained long lists of random letters and I began to use these to teach myself the alphabet. It was slow work. A few letters were easy and I knew them at sight, but many I found difficult. With a difficult letter I had to rhyme off the alphabet, until I recognised the printed letter. It was as if my brain was responding to my voice but not to my eyes. As I became more proficient I began to be able to read each letter slowly. I realised that I could not really scan along the line, but had to consciously focus, or as the professionals say 'fixate', on each letter before I could decide what it was. I began to read slowly from Left to Right along the line (see Fig 1) and then come back from Right to Left. I became aware that, while reading from Left to Right, and fixating on a particular letter, I did not see anything on the right side, the side I was about to read. However, I did see the images of the nearby letters on my left side that I had just read. Then, when reading from Right to Left, I could readily anticipate the letters on my left side but there was only a blank on my right side. In fact I felt that it was easier to read the letters from Right to Left than from Left to Right.

I called June and she confirmed that she could see the neighbouring letters on both sides of her fixation point and then she timed the reading speeds in both directions and confirmed that I was considerably faster reading from R to L than from L to R. This was a eureka moment - I was back in the lab doing experiments and getting a result that was

confirmed by a colleague. We went to the computer and June helped to write a short note on what we had done as this would be important to show to some experts who could hopefully diagnose what was really wrong with my eyes.



During the following week, in early December, an Occupational Therapist called to see how I was keeping and I mentioned to her what we had done and showed her the notes. She immediately said she knew what this was and mentioned the words ‘*hemianopic alexia*’ and told us that there was an online therapy that might help me. Within a few days she brought us more information about the ‘Read-Right therapy’ website that had been set up by Dr Alex Leff at UCL. Our Speech Therapist who was now also visiting us, helped June to get the website set up so that I could use it.

June and I spent a long time trying to work out how to use it, June reading the text and I trying to understand what to do. However the instructions were very clear and it was not long before we understood how the therapy worked. First you choose a novel from a long list of popular books. Then when the START key is pressed the first sentence of the novel begins to move out along a lane from right to left, (see Fig 2.) The text

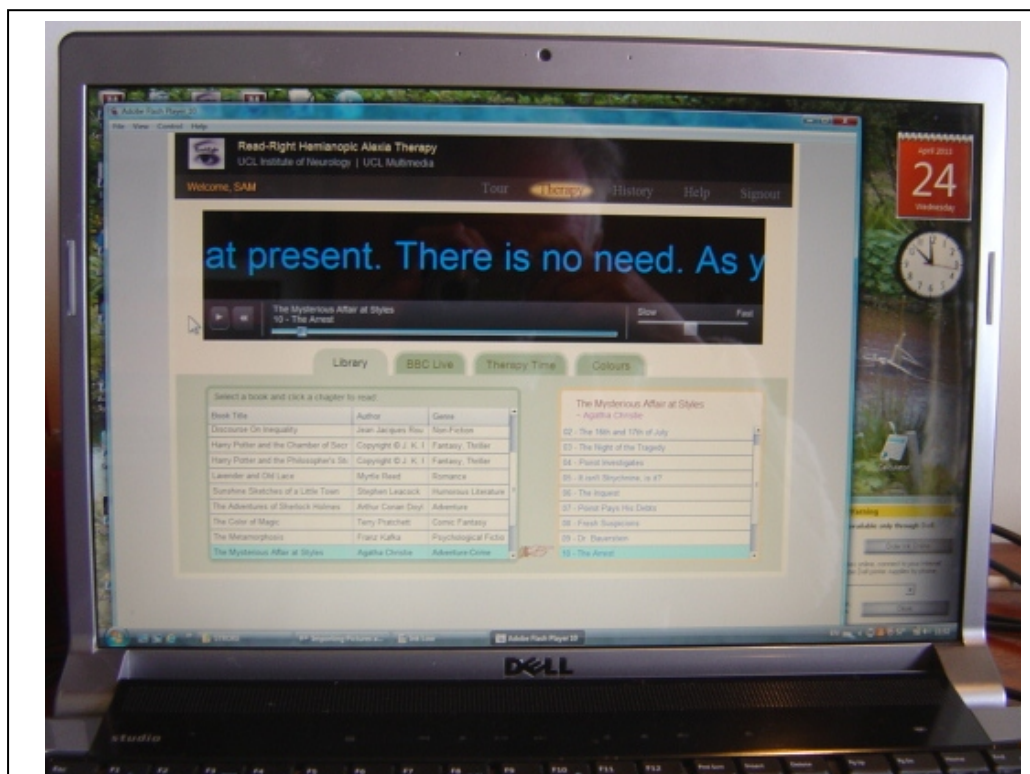


Fig 2. Read-Right Therapy The blue text moves from Right to Left. You can stop/start the movement by pressing the key on the left or increase the speed of movement by adjusting the slide on the right. Try it out on:

<https://www.readright.ucl.ac.uk>

travels at a slow speed, about 10 words per minute and then disappears at the left hand end of the lane. There are a number of settings that will increase the speed up to over 100 words per minute. For me, the slowest speed was much too fast and I could not keep up with the moving words, which seemed to disappear into a tunnel at the end of the lane very quickly. However, before proceeding further the patient has to agree to allow the results of the various on-line tests to be used in the research project. The therapy results from research work that is supported by the Stroke Association. Before starting the

therapy you do three short reading tests and also an on-line Visual Field test and the results of these are reviewed by staff at the UCL laboratories. At this time I was not certain whether this therapy was right for me and decided to contact Dr Leff directly to ask his advice and I sent him an e-mail outlining my situation and the impact my stroke had had on my reading letters from right to left and from left to right. Within a few days he replied saying, "... *I saw a patient in clinic today just like you. In short you have two problems:*

1) Right-sided hemianopia (actually according to your web-based test it may mainly be the upper field that is affected, with some sparing below. Are you better with vision below fixation? That is, if you look at your nose in a mirror, can you see the lower half of your face/shoulder better than the upper part of your face?)

2) Problems with recognising words and probably letters. This condition is sometimes known as pure alexia.

Unfortunately both will impact on your reading. The second problem is more severe and will not respond to the Read-Right website therapy. This problem is the main reason that your text reading is so slow (less than 10 words a minute) and why you cannot manage the scrolling text even at the slowest rate.

The good news is that your stroke was recent, it was a haemorrhage, and you are likely to continue to improve (both 1 and 2) with time.

I'd be more than happy to see you in my NHS clinic in London if that would be helpful, but it's a long way to come..."

This e-mail from Dr Leff was very encouraging as it put me in direct contact with someone who seemed to know about my problems. Neither *hemianopic alexia* nor *pure alexia* had ever been mentioned to me before and dividing my reading problem into two distinct issues that required different types of treatment was a crucially important step in setting me on the way to recovery. Persistent suggestions from June, and other teaching friends and speech therapists about the value of learning phonics and the new methods of teaching children to read and spell, had been causing me severe difficulties and were of no help to me in either reading or spelling. I decided to ban them! Not June and our teaching friends of course, who all have been so kind and generous with their time during my more difficult days.

By the 7th December 2011, only just over three weeks from my stroke, June and I had become sufficiently confident with working the Read-Right therapy that we established a daily work programme that would tackle both of my problems. Firstly, to use the on-line Read-Right therapy to strengthen my eye muscles to help them adapt to my visual field problem and secondly, to learning words and their numerous connections that would help re-establish the neuron networks that link my eyes to the memory bank of words that I knew was still intact. I 'knew' it was intact by the fact that I could speak and think and even type on the computer reasonably well. I had begun to draft e-mails by typing the words by partial touch typing and the help of spell-check. This I could do quite well, but strangely, after a few minutes I found that I could no longer read what I had just written. This phenomenon lasted for some time and is still present to a minor degree, but it gave me hope that my brain banks were still intact and that I only had to grow new neural links, which could be partially achieved by rote learning of words that I did not recognize. It was in this area, that without June's help, I would have been completely lost. I needed one-to-one attention, especially during the initial stages of recovery when my knowledge of common words was very limited. When I had achieved a common word baseline, I began to use the context of the whole sentence in order to

work out the meaning of the difficult word and occasionally spelling the word out loud was also generally successful. After about nine months I envisaged that I could replace June with some sort of computer dictionary that would allow me to type in a word and it would pronounce it. On one visit to UCL, Dr Leff and his colleague Louise Lim told me about an app called 'Speak-it'. This is available for the iPad and is extremely useful and would have been well worth having at a much earlier stage. However I am pleased to say that the app is no longer needed, but I am delighted that June is still here!

So, as already stated, around the 7th December 2011, June and I started our regular classes, 7 days a week.

We chose *A Christmas Carol* by *Charles Dickens* as it seemed an appropriate book to read at that time of the year. In retrospect I would choose a more simple book, perhaps something that a child would read with very simple words. Nonetheless, *A Christmas Carol* was a challenge and good fun and although I had to stop and start the moving text frequently, it did allow us to develop a good routine. June sat beside me with a paper copy of the novel and as I read out the moving text, she wrote down or marked any words I stumbled over or had to stop at. I read for a period of 45 minutes, (to avoid distractions we unhooked the telephone). June had noted the time at start and finish and using the paper copy of *A Christmas Carol* she

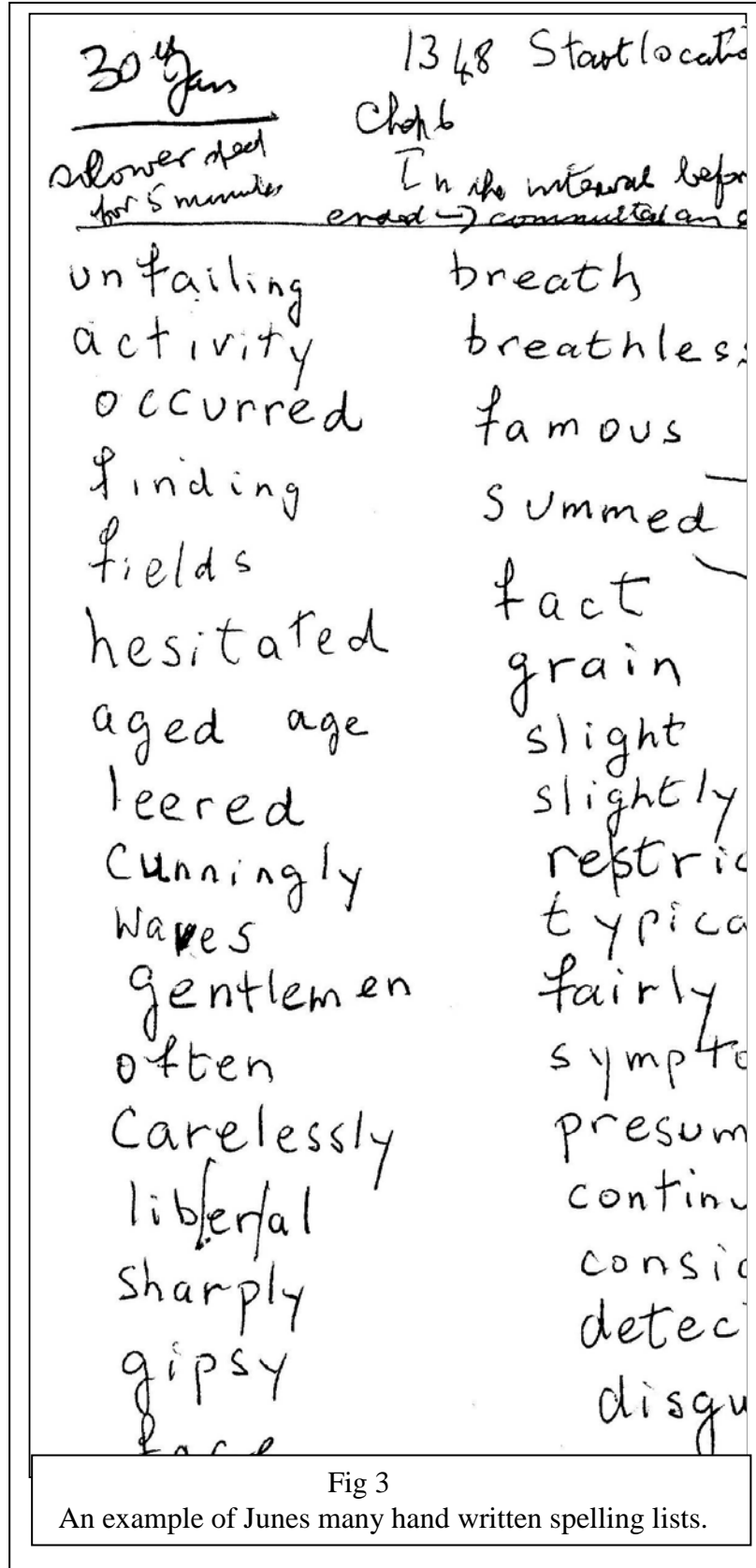


Fig 3

An example of Junes many hand written spelling lists.

calculated the number of words per minute (w/m) that I had read during my 45 minute therapy session. On the 7th December my rate was 7 w/m. After a quiet cup of coffee, June then went over the piece I had read with me using the book, and made sure that I knew all the words. She had written out most of the problem words and not only these words, but lists of related words and groups of words with the same starts and others with the same endings. As the days went past we accumulated stacks of A4 sheets (Fig 3 on page 21) filled with June's lists of my difficult words - and then I had to learn them!

But it was worth it. Every few days I could see my reading speed increase and by Christmas I was reading at around 15 w/m. After Christmas we changed over to another novel, our visiting daughter, Patricia, telling me that Dickens was far too hard. So we chose a novel by *Agatha Christie* called *The Mysterious Affair at Styles* which could be

Read-Right Therapy

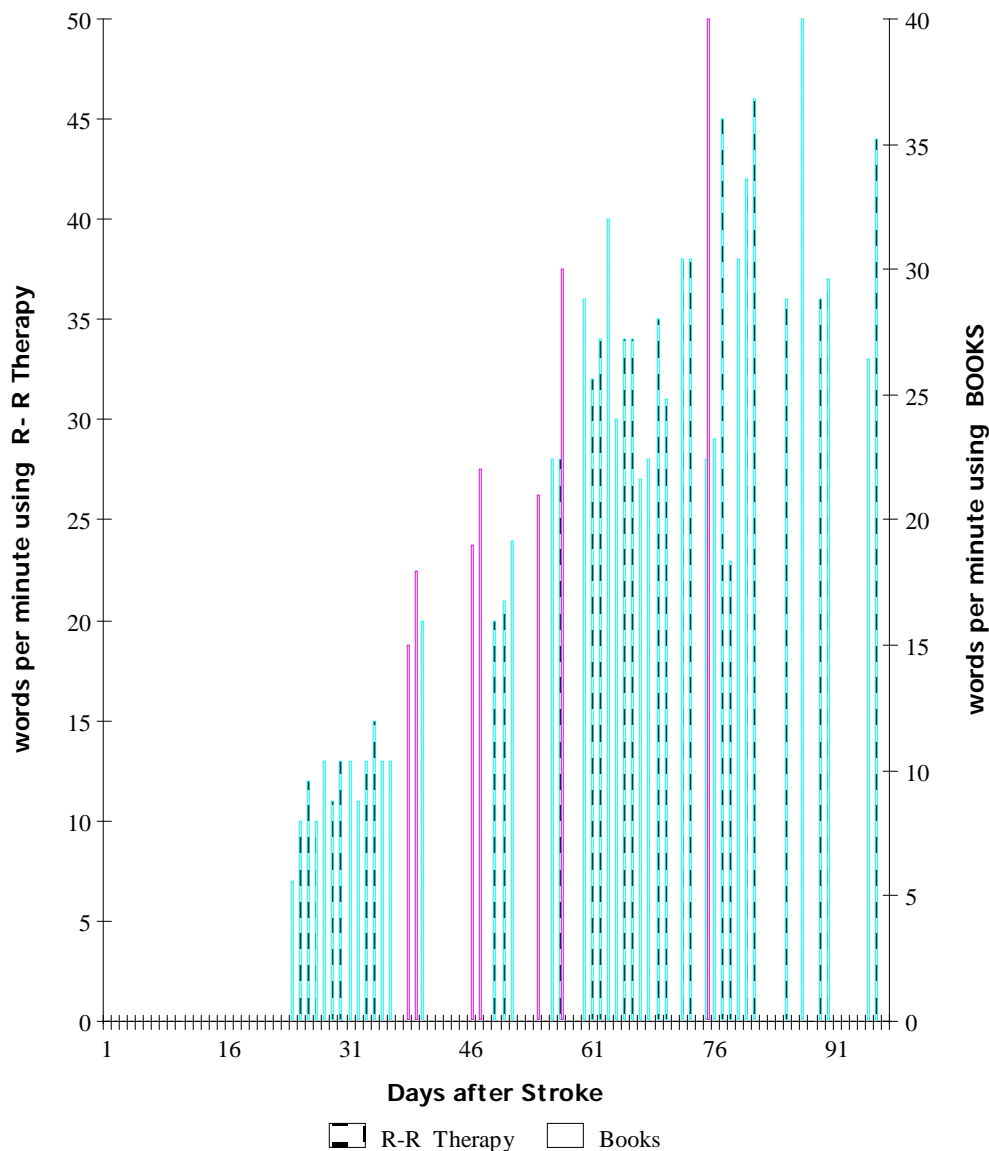


Fig 4. Twenty-three days after my stroke, I started the Read-Right Therapy, the programme was set at the slowest level and I had to use 'stop' and 'start' to keep up with the movement of the words from Right to Left across the screen. I read for 45 minutes and then June using a **book** copy of the novel, calculated the total words read during the 45 minute session and hence my reading speed in words per minute (Blue bars). I occasionally read short passages directly from books and June noted my reading speed shown in the Red bars.

obtained free on Kindle. After a short break over Christmas we continued our routine classes until March, when my reading speed had reached around 30 w/m. (Fig.4).

During March, we took the opportunity while staying with our son, John, who lives near Maidenhead, to visit Dr Alex Leff at his clinic in the Institute of Cognitive Neuroscience at Queen Square in London. He gave me a very thorough visual and reading examination and gave me a clear assessment of my major problem '*pure alexia*' and his message was clear that I had to keep reading in order to improve.

On returning to Belfast in mid-March we reassessed our work schedules and I decided to concentrate more on direct reading of books and to change slightly my use of the on-line Read-Right therapy. It had become clear that although my reading speed had improved at a fairly constant rate during the first three months, it had now levelled off at around 30 w/m. This could be due to the two problems, *hemianopic alexia* and *pure alexia* improving at different rates. I hypothesized that if *pure alexia* was slowing down my reading speed, then this could be tested, by reading on the computer, text that did not contain words that were strange to me. On the other hand, by concentrating on reading books and especially with the help of '*Speak-it*' I would relearn 'strange words' more readily without pressure on reading speed.

My new strategy for work on the computer was to read short passages from the BBC News sections which are available on the Read-Right Therapy library. I could now manage these quite well but did not worry about the time or speed. I also selected a long passage from the Agatha Christie novel that I had read before. This passage was 1650 words long. Although I had already read this passage, I could not rhyme it off. My internal control was to set the Read-Right therapy speed at the high rate and I soon found that I could not keep up with the text as it passed through the short reading lane. In fact my external control was June, who can read fluently at any speed at which I set the Read-Right Therapy. I started reading this passage on the 20th March at a comfortable speed of 50w/m which allowed me to read the whole passage without pressing STOP. I then repeated the reading at slightly faster speeds, noting the time for each run until I had to press STOP. I continued this therapy until the end of May (see Fig 5, page 16) and my reading speed increased gradually but then tapered off at around 90 w/m.

I interpret these results as follows. Firstly, in these tests my reading speed is not being influenced by my *pure alexia* problem but the *hemianopic alexia* caused by a residual Visual Field defect. The increase in reading speed during this latter phase supports the fact that the Read-Right Therapy helps to strengthen and train the eye muscles to overcome at least partially the residual Visual Field defect. It will be interesting to see in the months and years ahead if my optimal reading speed will improve further.

However, since January 2012 I have read a number of large hard back books, including Matthew Glass's *Ultimatum*, Agatha Christie's, *The Mysterious Affair at Styles* (on Kindle), Stephen King's, *11.22.63*, Ken Follett's, *Winter of the World*, and David Quammen's, *Spillover* (a masterful survey of viruses that cause human pandemic diseases), *The End of the Chinese Dream* by Gerard Lemos and *The End of Medicine and the Last Doctor* by Sidney Lowry. Each of the early novels took me approximately up to four months to complete as my reading was very slow because I had to puzzle over each 'new' word and work it out either by its context, or by spelling, or if these failed, by use of '*Speak-It*' or seeking June's help if she was nearby. However, the challenge of tackling these large books was stimulating and to see the number of pages read in a day increase gradually, was an additional reward to the enjoyment of these wonderful books that we humans are so fortunate to have. I am glad to say that between the 28th December 2012 and St Patrick's Day (17th March 2013) I completed *Spillover* and my reading has

improved greatly. I can now read a newspaper and the National Geographical Magazine quite easily, (though still slow by normal standards). I can work out most 'strange' words by association or by spelling it out aloud. I no longer use *Speak-it*, but if June is nearby, I may sometimes seek her help. What would I do without her!

Read-Right Therapy

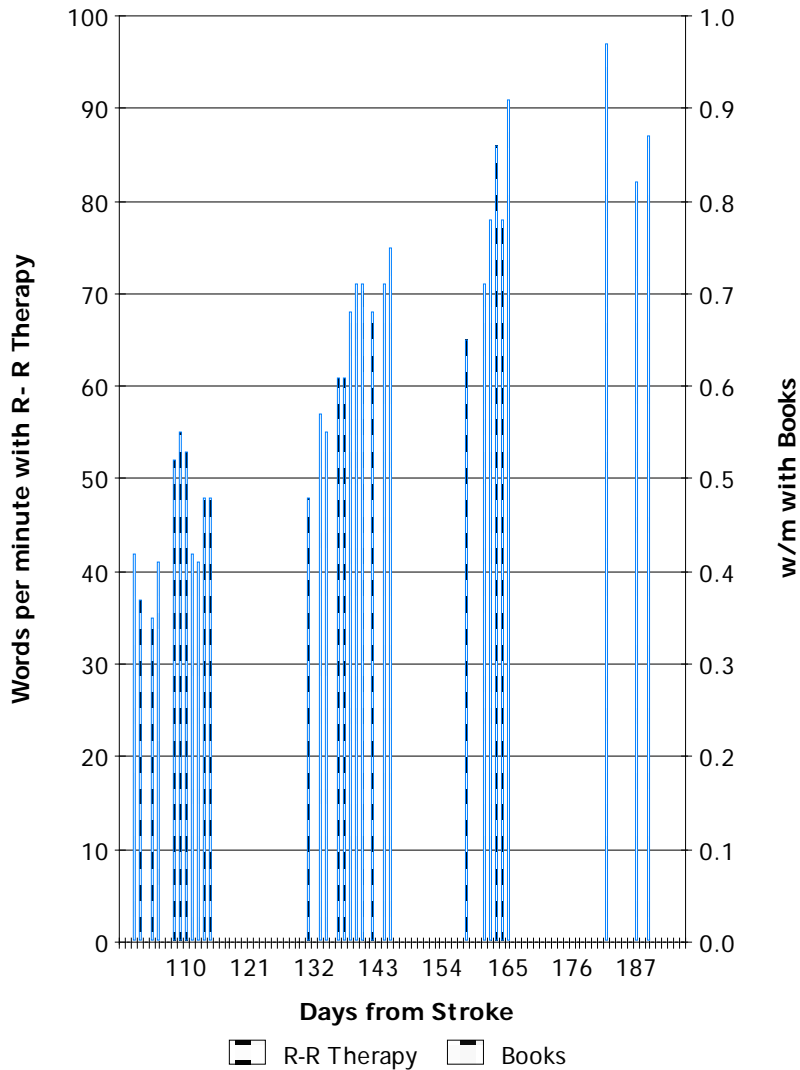


Fig 5. At the end of March 2012 I decided to start reading known text and chose Chapter 10 of *The Mysterious Affair at Styles* containing about 1650 words. This allowed me to avoid my problem of pure alexia and concentrate on improving my hemianopic alexia problem. By not having to stop the movement of the text, I was, over a number of weeks, able to increase the rate of movement of the text up to level seven. However at this setting over a number of months (not shown) my reading speed did not increase further.

During our visit to Dr Leff in early March, he also suggested that I might be interested in a research project that was being carried out in a neighbouring department. He introduced us to Louise Lim, who explained that participating in this research project would not necessarily help me improve, but their monitoring of me over a period of time would help their research programme which is trying to understand the factors that govern the recovery from strokes. I decided to sign up to be a participant in this research project and I can arrange for assessments to be made whenever we visit John's family in Berkshire. In fact this is a very interesting project including intensive speech and language testing and functional MRI scans which will hopefully help researchers and clinicians to understand and improve prognosis and treatment of stroke patients. Further information about this research project, known as, Predicting Language Outcome and Recovery After Stroke (PLORAS) is given in Appendix 1 and in their website

<https://www.ucl.ac.uk/ploras>

Chapter 3

A Review of Sam's Language Problems and Recovery

by his wife and carer, June Martin

Speech therapy while in hospital

During his stay in hospital Sam had spent much time working out the words that were made from the combination of letters, as described by him in Chapter 2.

He also had had a few sessions with the NHS speech therapist who had given him various exercises as described in Chapter 2 and then she had presented him with some worksheets for him to work at on his own. The first ones had pictures with 3 words containing similar sounds and he was to underline the correct word.

e.g. coaster, toaster, rooster – the correct word being toaster.

He did these exercises practically perfectly.

Harder were the sheets containing 24 isolated compound words. Most of these were compound nouns.

e.g. handbag, teapot, necktie etc.

He worked very hard at these, eventually sooner or later understanding what was written. Very often he would get the second component of the word, e.g. “bag”, and had to spell out and think about the first half of the word – “hand”, giving the compound noun, handbag. The 2 nouns together seemed to be using the first noun as a qualifying word. i.e. as a kind of adjective.

This phenomenon would be akin to the coping strategy described on page 2 of Chapter 1 when he found he could articulate certain key words more easily if they were preceded by an adjective or phrase that had some association with the word he was looking for. The “oral” expression was an indication of a certain amount of the “*dysphasia*” problem while the difficulty with the written word was an indication of other language problems, which as described in Chapter 2 we came to realise are termed *hemianopic alexia* and *pure alexia*.

Most often when reading these lists given to him by the speech therapist he would get the right hand side of the compound word first. Then he would try to get the qualifying word (almost equivalent to an adjective). This was the reverse of the way he found words when speaking. (But this probably had something to do with finding that he could read more easily from right to left, when he was experimenting on reading random letters from right to left and from left to right after he had left hospital, as described in Chapter 2.)

There were 2 aspects about these sheets which baffled me. Firstly, I could not reason out why the therapist had given him these lists of random words, many of them quite difficult, and which had absolutely no common thread connecting them, either by sound, sight, meaning etc. I could not find any logical reason for the compilation of these lists! But they had been taken from a reading work book for patients suffering from “*aphasia*” (or “*dysphasia*”) and published by ECL Publications. So obviously speech therapists had found this sort of exercise beneficial for their patients.

Secondly, the fact that in one column of 12 words, *teapot* appeared, and further down the page on the right hand, second column, *teacup* was printed. But Sam

found no correlation between “tea” in both words. Also “uphill” and “pickup” on the same page had no sense of correlation for him!

To his credit, Sam persevered at working at these sheets of words for a number of days. It would at first have taken him maybe up to a full day to work out a page of 24 words, but by Saturday, 26th November he was able to work through a list in approx 20 minutes. Yet the strange thing was when he would read the same list again maybe 20 minutes later, he still had to work out almost from scratch some of the words, although some patterns were becoming more easily recognisable.

Struggling with his language problems at home

On leaving hospital Sam was promised help from the local NHS speech therapist who we were told would very soon contact him.

While we waited for the contact from the speech therapist he worked at the alphabet etc., as described in Chapter 2, and in fact had diagnosed, by himself, his main problem of having the visual defect of not seeing anything on the right hand side of the word or letters he was fixating on as he read.

It was our young Occupational Therapist who actually supplied us with the correct terminology for Sam’s main reading problem. She had been made aware of the problem of *hemianopic alexia* at a conference she had attended. She brought us a scientific paper dealing with research into this problem, parts of which we read and found extremely helpful. She also told us about the Read-Right therapy for the problem which was being offered on line by Dr Leff of UCL. London.

As no speech therapist from the NHS had been in touch by 1st December, almost a full 3 weeks after his stroke and 2 weeks after being released from hospital, I contacted a private therapist who came to the house on Friday 2nd December for an hour session at a fee of £50.

She gave Sam various tests.

Auditory comprehension – fine.

A sample of his handwriting showed there was no difficulty in syntax.

But a test of showing pictures and asking Sam to identify each one, the *Graded Naming Test*, caused some difficulty. He had a score of 11/30.

Our private therapist said this revealed a *semantic* problem. (*Semantics* (dictionary definition) *I.i.e. the branch of linguistics that deals with the study of meaning, changes in meaning and the principles that govern the relationships between the sentences or words and their meanings. 2 the study of the relationships between signs and symbols and what they represent*)

I think this meant the following: if Sam was shown the word *pig* he had difficulty in making sense of the letters. If he was shown a picture of a pig he would know what it was, but might have difficulty in articulating the word *pig*. But once he had mastered the articulation of the word describing the picture, then if he was shown the picture and a group of words including the word *pig*, he was able to match the word and the picture.

There were also problems with spelling and reading words.

She suggested that either she or one of the other therapists should carry out the *Reading Comprehension Battery* test.

The private therapist was also of the opinion that Sam needed more help with his visual problems and our OT had also suggested this and was to arrange an appointment with the orthoptist at Lisburn Health Centre.

The Speech Therapy offered by the NHS

We do understand that the expertise of the speech therapist is in very great demand by the very many stroke survivors in our society. We realise their skills are in no way confined to helping patients to read and speak again after the onset of a stroke. Severely afflicted patients, on their road to recovery, are taught by these therapists many skills, for example how to breathe properly so that they can eventually articulate words and to learn to swallow again so that they are not permanently relying on tubes in order to be fed. Compared to the devastating disabilities of so many stroke survivors Sam's reading disability might be considered of less importance. Yet to be able to lead an independent life people need to be able to read, if only to do their shopping efficiently, to communicate with others on email and by post, to pay bills and to manage their finances. For these reasons we consider more attention should be paid to sufferers of *hemianopic alexia* and *pure alexia*.

However, we were feeling desperate for some professional help and were very relieved when a NHS Speech Therapist, eventually found a slot in her heavy work schedule to come to our house on Tuesday 6th December, (almost 4 weeks after the stroke). On that first visit she activate the Read-Right therapy website on our computer that our OT had told us about. Between then and the early spring the ST visited us on 3 or 4 occasions and finally signed Sam off in early April, after we had visited Dr Leff at UCL. She was pleased and impressed by the way Sam's reading skills had so much improved and wished him all the best for his continuing recovery.

The inefficacy of the phonics and graphemes method for a patient like Sam

Our speech therapist had given Sam various worksheets and she was convinced that the way forward for Sam was to work with "graphemes" and "phonemes".

[A *grapheme* is one of a set of orthographic symbols (letters or combinations of letters) in a given language that serve to distinguish one word from another and usually correspond to or represent phonemes e.g. the "f" in "fun", the "ph" in "phantom" and the "gh" in "laugh".

[A *phoneme* is one of the set of speech sounds in many given languages that serve to distinguish one word from another e.g. "p" and "b" are separate phonemes in English as they distinguish such words a "pet" and "bet".] (definitions from Collins English Dictionary).

The worksheets of words the ST had given Sam included some combinations of letters or *phonemes*, forming *graphemes*, but which were not real words at all. Sam just found these most irritating, meaningless and completely useless in his endeavours to learn to read again!

Being a linguist, I myself had tried to help Sam, by saying, when he had difficulty with a word like "necktie", look it's "n" "ehh" "k" = neck. Or "stick" – it's "s" "t" "i" "k". Alas, this kind of help was of no avail.

Likewise, making patterns of words, containing the same vowel such as:

Cap, cat, bat, sat, sad, glad, proved to be of no assistance. In collaboration with the speech therapist I made copious lists with words beginning with consonants such as *ch, cl, gu, ga, go, ge, gi, th, fr, fl, th, thr, w, br, bl, gl, gr*, etc. and many others with the same vowel sounds but different consonants at the beginning of the word, e.g. *hill, pill, sill*, and *face, lace, space, trace*, etc. Sam and I practised these again and again and in most cases, even with constant repetition, Sam would end up having to spell out the word rather than recognize it as a unit from sight. Only very gradually and with continual

exposure to the words did he increase his ability to recognize words at sight. He worked long hours at practising this skill.

Yet he had been working out much more complicated, completely unrelated word lists quite successfully even in the early days towards the end of his stay in hospital and on his return home, as described above.

Probable reason for the inefficacy of the phoneme/grapheme method

Sam's teacher/cousin, Derek, I myself and our ST just could not understand why Sam did not respond to this method. To all of us it was so logical and with young children in primary school the method was producing great results. Children are learning to read fluently within a year or two of starting school, thanks to this new method. So what was the problem with Sam?

We have come to the conclusion that people suffering from *pure alexia*, when reading, find they have to fixate on only one letter at a time. So, presented with a word like "*cheer*" they are unable to see the "*ch*" as a *phoneme/grapheme* representing a particular sound, but have to tackle the word, letter by letter, and then, most likely spell it out aloud, so that they then can work out the meaning of the group of letters that make up a meaningful word. This is a very laborious task and inevitably makes reading initially a very slow process. Only by constant practice and intense concentration can progress be made and it is no wonder that very many post-stroke patients probably give up trying to read at all. There was a strong temptation and a lobby of well meaning friends and relatives who suggested to Sam he should just enjoy TV, the radio and audio books for his mental stimulation. But he persevered and gradually when encountering more frequently used words he was able to recognize them at sight. However this took a very long time to accomplish! He has made outstanding progress through sheer will power, determination and very hard work!

A real breakthrough

The one big breakthrough that helped greatly was the suggestion in the paper on *hemianopic alexia*, given to us by our OT that when confronting a long word the problem would be helped by looking firstly at the ending of the word, and then one should work backwards until the word as a whole would be comprehended.

Accordingly I made long lists of words which had the same ending in common and Sam worked hard at these, finding that this strategy was amazingly helpful (I understand that sufferers from dyslexia find this technique also very beneficial).

The English language has a multitude of words with interesting endings. Consider for example "*-ation*". I would give him a list like: *nation, ration, probation, association, location, castration etc. etc.* Also *-ible* : *edible, visible, fallible, eligible, possible etc.etc.* And using this strategy he found his reading skills were markedly improving.

A résumé of the main problems encountered by Sam regarding his word recognition

Small words and big words

It is significant that the word lists given him early on in his recovery by the hospital speech therapist all contained *longer words* – mostly compound nouns, made up

of 2 distinct entities. Getting one half of the word helped him to work out the other half, as described above. We should also note that when Sam read the various leaflets or headlines from magazine articles (that I had brought him into hospital) it was always the longer, more complicated words that he found easier to work out.

Little words like *it, his, my, and, to, so, he, the*, etc were the words with which he had the greatest difficulty. I wondered if this is a common phenomenon with “stroke” patients as these lists of words given by the therapist came from “ECL publications”, a company that publishes work for patients suffering from *dysphasic* problems.

Difficulties with particular letters of the alphabet

Once we had started on the Read-Right therapy Sam was confident in recognizing all the letters of the alphabet although some letters did continue causing him problems for some time, particularly *j*, and *p*: *m* and *n* and *r* were sometimes easily confused but with time this confusion gradually decreased and rarely now causes him any difficulty.

Words with *double consonants* he found particularly problematic, e.g. *occupation, occurred, appeared, apparently, accountable*, etc. and even 17 months post-stroke (in April 2013) these combinations of letters occasionally present difficulty. (See Figure 6)

Small words, with no semantic connection with other words, as mentioned above, caused much dismay in the early days, e.g. *over, after, out, many, more, much, each, every, sure, so, for, from* etc.

And then there are many words which look very similar, only differ from each other by 1 letter and yet mean very different things e.g. *though, through, thought, thorough: started, startled, stared: for, from* etc.

Much more helpful than making out these “*grapheme/phoneme*” lists was the fact that when I sat beside him and listened to him reading aloud as he did his *Read-Right* therapy, I then wrote down the words he stumbled over or needed a prompt for. *Studying these lists that had some contextual relevance was much more productive*, and the old habit of *spelling them out loud* was practised a lot.

In the early stages, when Sam needed a prompt as he read I would utter a *full syllable, or even maybe two syllables*, and then he would get the word. But as time went on, he only needed me to prompt him by uttering the beginning consonant or phoneme of a word, e.g. *p, b, s, st, sl, ch* etc. and he then had it. (But he himself for a long time frequently had difficulty in articulating the beginning consonant/phoneme of a relatively unfamiliar word).

Another difficulty was not recognizing a word he normally knew very well at sight, e.g. *sure*, if it began a sentence with a “S”, a *capital letter, Sure*. This difference in a word’s configuration threw him on a number of occasions.

I have already mentioned the helpful strategy of tackling longer words by starting at the ending and then working backwards to the beginning. This strategy Sam found enormously helpful, in contrast to the *negative results* we had had from the “*grapheme/phoneme*” scheme.

Comprehension did not always lead to articulation

On not a few occasions, while reading, Sam saw a word, especially if he was reading on his own silently, that he fully comprehended but which he had not been able to articulate. A classic example was the word “*crocodile*”. Meeting this word he could visualise the creature lying on the bank of the Mary River in the Northern Territory of Australia, he could see its teeth and remember the quick abrupt movement of the beast as

apparent	alexia
apparently	atheist
agree	apolitical
agreed	apartment
agreement	apartheid
appear	apathy
disappear	amnesia
apparatus	
appal	
appalling	
apparition	
appeal	
appease	
appendicitis	
appetite	appropriate
apple	appreciate
appoint	
apprentice	
approach	

Fig 6. A list of difficult "app-"words

it suddenly returned to the water, but he could not say the word “*crocodile*” until I helped him.

Comprehension did not always lead to articulation

Other times he could see a word in the text which he would spell out to himself and understand its meaning but was unable to utter it, e.g. *achieved*, *confident*, etc. *Only after he had asked for help could he articulate it himself.* “Oh, is that how you say it?”

Not surprisingly many words that follow no patterns or rules presented huge difficulties, e.g. *owe*. “What kind of word is this?” he would ask. “*O - we?*” Then when he was told it he might remember it for next time. Another seemingly nonsensical word was “*combed*” “What on earth does “*com – bed*” mean, June?” He asked me. Well, how do you explain that is the word used to describe how you tidy your hair??!!

Occasionally when Sam understood perfectly the sense of what he was reading and *anticipated*, for example, *a word beginning with “c”* he would say “*cabinet*” *instead of “cupboard”*, the word that was actually in the printed text. Another similar instance was when he said “*hastily*” instead of the printed word “*hurriedly*”.

Difficulty with breaking up long words into syllables

Struggling with a long word is not easy especially if you have difficulty in breaking it up into the correct syllables, e.g. *facetiously*. If you think this is *face – tious – ly* you really have a problem! *Audacious* is really pronounced very differently from an attempt such as *aud – ack – ius* Or take *deceived*. Attempting to break it up into *deck – eived* is very deceiving!

And there were many other words which presented similar difficulties.

The benefit of spelling a word aloud

We have referred several times to the fact that Sam often spelt words out loud when he encountered a difficulty. This usually resulted in him comprehending what the difficult word was.

Mentioning this to those who were interested in his problems he was told that this was another route to the word banks formed in his brain over the 75+ years of his life. The *sound* of the letters sent a correct message to that area of his brain in which his word banks were stored.

Without realising this, that was exactly what had been happening at the very beginning of his recovery when he stated that he would recite the alphabet out aloud to himself until he came to the letter he was fixating on, and then he would recognize it!

However, even though he then *understood* the word, he was still *not able to articulate* it (as described above, especially with reference to the word “*crocodile*”).

Continual effort and practice have produced results

By April 2013 Sam is reading again with confidence and enjoyment. His reading speed has increased, although measured against the speed of a more fluent reader, it is still slow. The important thing is he fully comprehends what he has been reading and I

feel I don't need to read the books he has been reading as he has related to me so much from them!

In the past year he has read three long books, two of them novels, and one on the recent research on pandemic viruses such as AIDS. Not light reading by anyone's standards!

For months Sam was unable to read magazine articles or newspapers of any description. But by Easter (March 2013, 16 months post-stroke), he has been enjoying reading articles in the *National Geographic*. Newspaper reports he finds easier to read on the iPad as he can enlarge there the size of print – small print still presents a degree of difficulty.

As a stroke survivor, with physical disabilities, has to continually practise exercises recommended by a physiotherapist and requires individual attention in doing so in order to progress on the road to recovery, so, too, does a survivor with visual and language problems have to constantly and determinedly work at reading words, phrases, sentences and ultimately books if he/she is to have his/her reading skills restored to as near normality as possible.

Perhaps the most encouraging thing Sam has noticed is the fact that he now only “stumbles” or has real difficulty with words he believes he has not encountered since having had his stroke. These are, so to speak, *new words* to him. With these, even 17 months post-stroke, he has to resort to spelling out loud, considering the context in which they are placed, and then he usually fully comprehends their meaning. But still, he has often to seek my help in articulating these “*new*” words. If only he had a device that would help him to make this leap independently!

The need for one-to- one tuition/guidance/help

As we have worked through this therapy in our efforts to restore the skill of reading to Sam, a stroke survivor, we have been continually aware of the need for the survivor to have constant help and guidance from a reasonably intelligent, fluent reader.

It so happened that I, his spouse, was continually at hand and having been a teacher of modern languages I had the skill and interest in helping him along.

But for a person living on his/her own, who may be visited once every two or three weeks for at the most an hour by a NHS speech therapist, the kind of amazing progress Sam has made would be impossible.

There is a real need out there for more help.

As stated above, people with language problems such as those encountered by Sam need individual, one-to-one guidance and help in their recovery. Perhaps some help could be offered by young, intelligent, literate volunteers, who for some reason are willing to do some kind of social service (e.g. young people involved in attaining the Duke of Edinburgh Award, or Guides or Scouts or whoever, even perhaps some volunteers with a community interest in offering a useful service to those in need). We found that our nine year old granddaughter was able to help her grandfather enormously with words at the beginning stage of his recovery!

This kind of additional help should be organised through the professional speech therapists whose work load as we all appreciate is currently extremely demanding. Perhaps, too, volunteers could give additional help, for example, in helping patients to operate computers and guide them in the use of these newly available online therapies.

Of course, the bottom line is that the stroke survivor him/herself has to be determined to regain the skill of reading and it does entail a huge amount of time, determination, courage and appreciation of all help offered.

June Martin
April, 2013

Chapter 4.

Ideas for the Future

I suppose the reason for starting to write this article was initially a purely personal one, to help me get my problems of the last two years out of my system and to type up in a respectful way the huge mass of paper and records that June had generated during the early stages of my recovery. However as we wrote it became clear that there may in fact be something useful to other stroke survivors and their carers.

As you have seen, we only learnt slowly about the full nature of my problems, - that I had two problems rather than one, namely *hemianopic alexia* and *pure alexia* and that each needed a different type of therapy. Perhaps most important of all was the need for direct contact and help, especially when dealing with *pure alexia*, and this was offered to me by June's daily personal attention as she helped me with word recognition. It is of course impossible to expect private or NHS therapists to provide this level of attention. Although Dr Alex Leff's on-line Read-Right Therapy provides an excellent direct help for those suffering from *hemianopic alexia*, there are as yet no dedicated computer-assisted systems for dealing with *pure alexia*, i.e. word recognition problems.

Although I have resisted the temptation of accepting gifts of 'Talking Books' I do see the advantage of having a computer programme or an 'app' that can speak to me, (and other people with similar problems to my own) and tell me what a word like 'notable' sounds like; is it as I puzzled over it, 'no-table' or 'not-able' or whatever?

I suggest that what is needed, at an individual level, to help sufferers of *pure alexia* is a programme on a computer or on an iPad that can speak to the person affected. The programme would have a dictionary of common words and letters (A, a, B, b, C, c, D, d, etc). Each letter or word can be called up in two ways, firstly as '*Speak-it*' does, where the person types in the problem word and waits for the computer device to "speak it", and secondly, where the computer programme shows random letters or words and then "speaks them" when prompted by the reader. This latter system would have been extremely helpful to me during the early days immediately following my stroke, when I realised I could not read the letters of the alphabet, let alone small words like "in" or "it" or "is", "if", "no", "on" or "he". I envisage a system that would have a number of sections, each dealing with simple words increasing in length as illustrated below.

- 1: for the alphabet.
- 2: two letter words.
- 3: three letter words.
- 4: four letter words.
- 5: five letter words.
- 6 - 10: six to ten letter words.
- 11 - 14: long words beginning with "app", "ass", "occ", etc
- 15 - 19: long words with common endings, e.g. "...ity", "...able", "...ible",
....."....ious" "....ation" etc.
- 20: Random series of short sentences or lists of random words.

Sections 11-19 are included as June had noticed that during the early days of my 'lessons' that I had great difficulty with words beginning with app-, occ- etc and also

long words with common endings. She wrote out long lists of these various groups of words and I had to learn them off.

As I have stated above, access to such a system stated above would have been extremely beneficial to me as soon as I became aware that I had a word recognition problem. An additional feature of 'time keeping' would be beneficial, as it is a great encouragement when you can see positive improvement. Also it may be possible to link a system similar to the above into the Read-Right therapy programme. An additional speech-recognition facility would be of great help if patients/readers could call up the sound of a difficult word.

As I progressed with reading I found the *Speak-it* app very useful, but it was rather laborious as I had to type in each word I did not know. While reading on an iPad I realised that if I could just touch with one finger a word and the iPad would speak it, life would have become much easier! However, I hope that that is something that I now will never have to use. But perhaps some computer programming expert will think this to be an interesting and useful project even if not as financially rewarding as a game.

On the other hand, it can be much more fun, spelling out to my dear wife, June, while reading in bed, "June, how do you say N-O-T-A-B-L-E? Neither, "no table" nor "not able" fits this sentence." Without a moment's hesitation, June replies, "The word is NOTABLE, dear." And then we both burst out laughing.

Take care, and Good Luck,

Sam & June.

Appendices

Appendix 1.

Predicting Language Outcome and Recovery after Stroke

PLORAS Newsletter

During my visit to Dr Leff in the Institute of Neurology at UCL in March 2012, I was introduced to Louise Lim of the PLORAS team and the aims of their research programme were described to me. It was stressed to me that joining the programme would not benefit me personally but would help their research into how stroke survivors can recover from strokes hence in the longer term help develop new strategies in treatment for future generations of stroke patients.

As my son whom I visit several times a year, lives near to London, I was able to arrange visits to UCL at mutually convenient times and so I decided to sign up as a participant. My three visits over the last eighteen months have been very interesting and challenging and a considerable boost to my confidence. I highly recommend becoming a participant in a research programme such as this, since the more results the researchers can obtain the more the quality of their research will be improved.

During my last visit I was given a prolonged functional MRI scan and the PLORAS team has kindly given me a picture of my brain when it was active while I was speaking and reading.

The following Research Update is taken from the current PLORAS NEWSLETTER which can be seen on

<https://www.ucl.ac.uk/ploras>

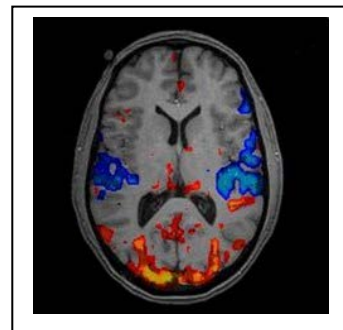
(Extract from PLORAS NEWSLETTER ISSUE 2 September 2013)

Research update

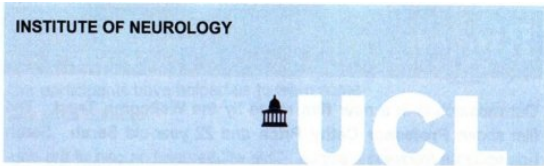
Functional MRI scanning (fMRI)

We have started the new **fMRI** part of our project with **stroke survivors** who have **aphasia**.

In fMRI, patients do **tasks** (such as **naming pictures** and **repeating words**) **in the scanner**. We can see which **parts of the brain** are used for **different tasks**, by measuring blood flow to the brain (**more blood flow = more brain activity**).



We look for two things in the brains of **stroke survivors** who have made a **good recovery of language**: 1) Do they use **other (nonlanguage) areas of the brain**? 2) Do they use the **remaining language areas but with more effort** (is there more blood flow?)



PLORAS Newsletter

Predicting Language Outcome & Recovery After Stroke
Issue 1; February 2013

Welcome!

This is the **first issue** of the **PLORAS Newsletter**. The newsletter is to **update** you on the **research**, and any other **related news**.

In this issue

- Coffee morning
- 'Big Picture' video
- UK Stroke Forum 2012
- Meet the team
- Research update

World Stroke Day coffee morning

In **October** we held a **coffee morning** for **World Stroke Day**. We met with **participants** and **new stroke survivors**. We shared our **research** and listened to people's **experiences** of stroke. We also enjoyed the fresh **coffee** and **Danish pastries!** **Professor Cathy Price** (Lead Researcher) said, "We are delighted that so many remarkable people were able to mark this important day".



BigPicture

Our research is in a **new film** made by the **Wellcome Trust**. The film shows **Professor Cathy Price** and 22 year-old **Sarah**. Sarah has **aphasia** following a stroke. This will be used as part of the educational series, '**Big Picture**'. You can **view** the video here: <http://tinyurl.com/bigpicture-ploras>.

UK Stroke Forum 2012



We had an exhibition stand at the **UK Stroke Forum** in **Harrogate**. We are soon setting up a **focus group** with **stroke professionals** we met. This will help us find out how our research can be used in **clinics** by **doctors** and **speech and language therapists**.

Meet the team!

Each newsletter we will feature a member of the team so you can find out who does what.

Louise Lim

Louise is a **Patient Manager**, **Research Associate** and **Speech and Language Therapist**.



Her role includes:

- Recruiting participants.
- Language testing.
- Building links with the Stroke Research Network around the UK.

She is also embarking on a PhD in aphasia.

Research update

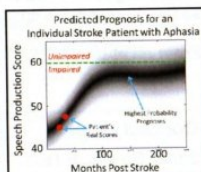


Our participants have helped us to learn some **key links** between:

- the **damage** that **stroke** can cause in the brain
- the likely **language problems** that people might suffer
- how much** people may **recover** over time

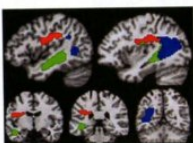
We can now start to **predict** how individual patients' speaking skills **might improve** in the years after their stroke.

Our **first research area** looks at how we can **predict language outcomes** for **new patients**. We do this based on what we know from the **participants we have tested**. This includes **scores on language tests** (speaking, understanding, reading and writing) and the **brain scan**. We have **built a system** that can **make those predictions**. It can also **learn** from patient data directly to keep improving the predictions it makes.



Our **second research area** tries to explain:

- why some patients **respond better to treatment** than others
- why some patients **recover more quickly** than others



We have found some '**critical lesion sites**' (**key areas**) for **speech problems**. Damage to these areas causes aphasia that can last for some time. Patients without damage to these areas may recover within a few years.

Mailing list

You have **received** this newsletter because you have **taken part** in our research, or **shown interest**. We hope you have enjoyed reading it. If you **do not wish to receive** future copies, please **contact** the team (details below).

If you have an **e-mail address** we can send the newsletter to in future, please **let us know**.

If you know **anyone who may be interested in participating or receiving this newsletter**, please **pass on our contact details**.

Finally!

A **very big thank you** to **everyone** who has **contributed** to the study so far. Your input is critical to its success.

From all at the **PLORAS Stroke Research Team**

Contact details

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🌐 **Website:** www.fil.ion.ucl.ac.uk/Price/Language_Group



Add us as a friend on **Facebook:** [Stroke Study](#)
'Like' our **Facebook page:** [Aphasia Research at Wellcome Trust Centre for Neuro-imaging, UCL](#)



Video: <http://tinyurl.com/talkingheads-ploras>

Appendix 2 Stroke Association

The Stroke Association supports the care of stroke survivors and research such as the development of the Read-Right therapy by Dr Alex Leff which is available on

<https://www.readright.ucl.ac.uk>

In a recent article in the Stroke Association's Newsletter (Autumn 2013) which is copied on the next page, the value of the free online therapies such as Read-Right and Eye-Search for stroke survivors is described. But to maintain the web site costs, currently carried by the Stroke Association, further funding is urgently required. Further information can be found on

<http://www.stroke.org.uk>

But please don't forget and make a donation via the following link:

<https://www.justgiving.com/Sam-June-Martin1>

'With your help, stroke survivors can get free access to vital online vision therapy tools.'



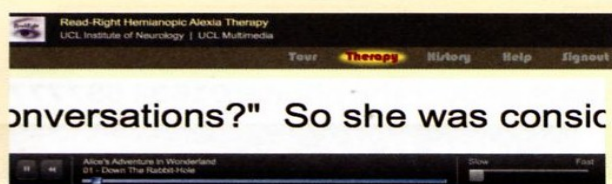
For stroke survivors struggling with vision loss, state-of-the-art rehabilitation websites hold the key. Their creator, Dr Alex Leff of University College London, explains why your support is essential to keep these 'open access' online tools available to all.

'One of the devastating effects of stroke can be the sudden loss of vision on one side. This condition, called hemianopia, affects one in five stroke survivors. It leaves people unable to carry out a whole host of everyday tasks such as driving, reading and shopping.

'Thanks to funding from supporters like you, I have developed two vision therapy tools that are available online and can benefit anyone with vision problems. These therapies train the user to compensate for their reduced vision by making deliberate movements of the eyes as they read scrolling text or track an object around a screen.

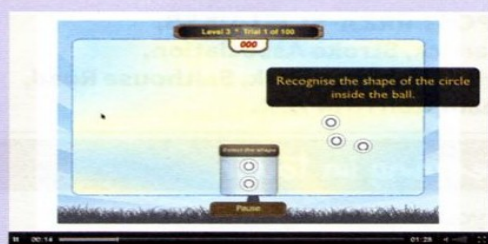
'I've been very encouraged by the progress people make when they use these tools. By using Read-Right for just 15 hours, for example, stroke survivors can experience a 40% increase in their reading speed. People can take control of their own recovery – they don't need to wait for hospital appointments or rely on visits from therapists.

'My hope is that these online therapy tools will be effective for vision problems, and eventually for other areas of stroke recovery such as aphasia and even loss of mobility. **We just need the funds to keep these dedicated websites available to everyone who wants to use them.'**



Read-Right

'Users read a scrolling line of text, adjusting the speed as necessary and track their progress as they improve. This technique was first proven effective back in 1993 – in fact, in its early days I used to send it to people on video cassette! I am delighted that the Internet is now making it available to everyone who can benefit from it.'



Eye-Search

'While Read-Right focuses on text, this site is intended to help people relearn other visual skills that are often severely affected by stroke. These include tracking moving objects, picking out individual items against a cluttered background, and seeing objects in their peripheral vision – essential for everyday living!'

You can help to fund the websites that make these invaluable online therapies available to every stroke survivor with vision problems. Please help raise the £10,500 needed to ensure everyone can benefit from this amazing technology.



Appendix 3

About the Authors

Sam and June Martin celebrated their 50th wedding anniversary in July 2012 with their three children and four grandchildren and a host of family and friends in a beautiful restaurant in North West Donegal. They met in the late 1950s while students at Queen's University, Belfast. June was an Arts student studying for a double honours degree in French and German, while Sam was a Scientist studying Chemistry, Biology and Biochemistry.

After completing his PhD, Sam and June moved to Surrey where Sam took up a post at the Animal Virus Research Institute at Pirbright. Here they also started their young family. In 1967 they returned to QUB where Sam was appointed to a lectureship in the Department of Biochemistry. During the next 30 years he built up a strong team of researchers in the molecular virology of enteroviruses and measles virus. In the early 1980s Sam was awarded a personal Chair in Gene Biochemistry and became the founding director of the newly formed School of Biology and Biochemistry at Queen's.

On graduating in 1960 June went straight into teaching but after 4 years when she and Sam moved to England in 1964 she devoted the next nine years to being a full time housewife and mother only to resume her teaching career in 1973. By this time she and Sam had returned to Belfast and being offered a position at Princess Gardens School in a part time capacity she was able to ease her way back gradually into the profession and by 1976 was well prepared to accept a full time post at the school. In 1987 when Princess Gardens was amalgamated with Ashleigh House School June was appointed Co-ordinator of Languages in the new school, Hunterhouse College. Her main interest was in the teaching of German and during the years 1976 – 1997, when she retired, she had arranged many contacts and visits to both Germany and France for her pupils and established a partnership with German schools, firstly in Hilchenbach, near Cologne, and finally in Berlin.

Partly due to June's strong interest in German and Germany the family were fortunate to have the opportunity in 1975 to spend a year in Würzburg, where, having been awarded an Alexander von Humboldt Fellowship, Sam worked at the Institut für Virologie with Professor Volker ter Meulen on the persistence of measles-like viruses in brain tissue. During this year abroad, their three children attended a German school which widened their horizons and self-confidence enormously, and undoubtedly contributed to the fact that in their adult lives they all have made very positive contacts, both professionally and socially, on a global scale.

Sam & June both retired in the late 1990s and have enjoyed the rapidly passing years, living in Belfast or Donegal according to the weather and the season, spending time, walking, gardening, writing and reading and travelling widely to many parts of the world.

