

# ACQUIRED BRAIN INJURY

'Unlocking minds and opening doors'

Open Door series by Neuro Key



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# Foreword

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Since inception Neuro Key, the working name of the Charity, Tees Valley, Durham and North Yorkshire Neurological Alliance (Registered Charity 1119043), has harnessed lived experience as an educational tool to improve service delivery and professional understanding of the hidden threads between neurological conditions. From enabling participants to take part in research, delivering lived experience seminars, making sure people can respond to surveys and strategic consultations or supporting people to lead the operational direction of the Charity, we are passionate about our social purpose.

We promote a culture of mutual exchange across all neurological conditions. More importantly, we do not define by the deficits a condition may impose on people's lives. We concentrate on the value of lived experience to professional knowledge and skill, the contribution to the evidence base and for people themselves to share and learn from each other. By supporting people to be more confident in knowledge sharing and cooperation across social divides, we sustain a well-informed neuro community to improve self-management skills, neuro-literacy and social capital.

We foster collaborative working partnerships to respond, support and sustain a high customer service focus to encourage creative problem-solving and efficiencies by reducing risk and crisis. We strive for excellence with agreed standards and outcomes.

Our Open Door series of booklets has been developed to acknowledge the challenges of living with a neurological condition that is misunderstood, subject to media-driven or political myths and is neither prevalent nor the focus of national publicity campaigns.

An acquired brain injury (ABI) is an injury caused to the brain since birth. There are many possible causes including a fall, a road accident, a brain tumour, stroke, brain haemorrhage, infection like meningitis, carbon monoxide poisoning or encephalitis.

For some people, there are complex long-term problems affecting their personality, their personal and working relationships that can compromise their ability to lead an independent life. Despite access to rehabilitation or peer support, people with ABI, their partners and families are likely to have challenges that increase the stress of their daily lives.

The following stories are all real life narratives written by people who have sustained an acquired brain injury. We have adopted fictional names to protect their identities.

## **NEURO KEY**

October 2017

# Christopher's story

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## The Journey

Christopher grew up in a close family in a rural town, with his Mum, Dad and sister. He held a keen interest in cars from being a child, through his Dad and grandfather, just sitting alongside them in the car and them taking him to watch events with cars and motorbikes. When other children were out playing football he was out on his bike, forming the beginning of his fascination with wheels, cars and engines. It felt like motorsports were in his blood. He became fanatical about rally driving and he gained a nickname, 'Rally Chris'; his dream was one day to become a rally driver himself, if he had the financial means. He loved outdoor activities such as sailing, which he did with his school in France and this led him and his friends to take up windsurfing as teenagers. He enjoyed mountain biking and was highly active and fit.

On leaving school he took a job as an apprentice draughtsman. The atmosphere was oppressive, working in a Nissen hut with lots of contract workers who were heavy smokers. He took the chance to gain some further qualifications and gained an HNC in mechanical engineering. He was enjoying life, what with his windsurfing and his first car, a VW Beetle. He dreamed of one day having the Beetle's 'older brother', the Porsche 911!

Off he went to Polytechnic to study for a degree in engineering. He loved living the student life. He took the opportunity to use one of his summer vacations working and seeing the sights in the USA and gained a really valuable experience travelling independently and meeting people along the way. His hopes and aspirations were to return to the USA in the future to work in the aerospace industry for NASA. He finished his degree and was offered jobs in the aerospace industry in the UK but he didn't want to pass up the challenge to study for a PhD, and this was the option he selected.

He collapsed on campus a week into his PhD. He was 24 years old. He returned home to try and find out what the cause of his eyesight problem was. The optician detected a problem, which set the ball rolling for a diagnosis of brain

tumour. This was a frightening time and knew it would involve surgery, but with his engineering background, he knew he could put his faith in medical technology and he would be fine. He had two neurological operations, one of which involved removal of the posterior fossa, which turned out to be malignant and would require radiotherapy. In his emotional state he pushed for hospital discharge earlier than advised. As the effects of surgery were wearing off he had the extremely frightening experience of visual fits; bizarre black waves washing over him, flames licking his face and a white building

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The long line of hands eventually stopped and he was 'out on the street' and had to find his own direction and learn things for himself

cleverly dissolving brick by brick in front of his eyes. Luckily, after the third one these ceased for good. He was home for two weeks then experienced a stroke.

The world had been his oyster and now, he thought, it was all gone. This was the start of being passed through many sets of hands in the healthcare services. Hospital experiences weren't good. Physiotherapy wasn't

great and occupational therapy seemed worse; so long as he was able to make a drink and snack it was considered he was deemed fit for the world. One strange experience he will always remember; he was asked to describe a photograph of a scene with a Range Rover and found himself unable to answer. The words were in his head but he felt locked in. The photograph was taken away and nothing said by either party. That was the first time he realised that his cognitive functioning was affected. The long line of hands eventually stopped and he was 'out on the street' and had to find his own direction and learn things for himself, something that he thought needed to be greatly improved.

Christopher's and his parent's plight led him to feel like he had fallen through a trapdoor and inside, it was a dark, dark

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place. He still felt like the same person but he didn't have the life he had before. It was hard for him but it was hard for his family too. They pulled together as a family, but Christopher was lost as to where he was heading. His future had gone out of the window and they had to stop dreaming of the old future and had to get to grips with looking forward. His parents were very good and kept saying that they loved him. His father decided to seize the moment, to stop Christopher's physical problems from getting any worse and they were aware that his walking was weak. He bought a book on recuperating from stroke and set up a self-physiotherapy programme for Christopher. They started doing exercises on the living room floor to improve his prospects. Through a work contact they had access to a running track that had periods when it wasn't being used and Christopher was allowed access to it to practice running, without an audience. He did his best with what he was presented with but realised he had a dead area of his brain and would remain a one-handed person and has no regrets about how hard he tried.

Christopher found himself in a place where no one had really gone before and he had to forge his own path. It was as though there was a lack of 'neuro-culture' to draw on and advise him or relate to. He found himself in a flat spin he couldn't get out of. It was like being on a roundabout spinning so fast he couldn't get off because he was frightened to. He saw his life in engineering terms of 'drifting and spinning', with no 'absolute zero' and he was 'dragging his anchor'.

He was assisted by services to get a flat on his own in a lovely old building, in the same town, but it was by no means suitable for someone with mobility problems, fresh out of hospital, being on the first floor. His love of driving was put in jeopardy, with his driving licence taken away for two years, which made him dependent on lifts. When it was returned he was restricted to a semi-automatic gearbox and utilised the Motability Scheme, which he found hugely beneficial.

He wanted to get back into a career but it wasn't easy. A trip to the Job Centre made him really angry. The manager looked at his notes and then the computer screen before declaring, "Well your degree hasn't done you much good has it!" The man

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It was as though there was a lack of 'neuro-culture' to draw on, advise him or relate to

had no comprehension of Christopher's situation. He began a course using past skills and it was only through the experience of trying this out that his eyes were opened to his own limitations. He began to realise that he wouldn't be able to pursue what he wanted to. His parietal lobe was affected by the brain injury; previously he'd derived a great deal of pleasure from this, in that it is the area of the brain used for mathematics. Job placements came and went, making him very disillusioned with the system; jobs were promised at the end of placements if he did extra work for no money, which came to nothing, in one case being passed over for a young apprentice. The employers took the money for placements and put him back on the street. He felt used, abused and like a commodity. He realised what the system was all about and did no more work placements.

Christopher realised that he needed to seek what he was; he needed to seek some kind of self-identity on which to hang his hat. He felt that so long as he didn't have that self-identity his memory wasn't working properly, as if the self-identity were the gears for the memory. The problem was that he didn't venture far at all as he still felt like he was on a roundabout spinning. It was as if he were living an inverse of the life he had previously led. There was nothing he could compare this to or relate to. It led to an immense feeling of loneliness. One day he was watching a film on television called, 'Awakenings' by Oliver Sacks. He was intrigued by what he was seeing. He obtained the book from the local library and in the process of reading the book, he found it was the first time he could identify with something; the character named Leonard. Leonard was also doing a PhD and had a brain injury. He made notes about what Leonard was saying and focused on two quotes in particular. One acknowledged the dark and lonely place that they were both in. The other was more optimistic, along the lines of, having been to that

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dark and lonely place, what else could there be to fear that's worse. This was a revelation to Christopher and contributed to him becoming closer to society and beginning to feel more normal.

Christopher felt that he wanted to close the trap door that he seemed to have fallen through, into an immensely dark place. He began a quest to try and do just that. He was aware others may follow him and fall through the trapdoor and he wanted to close it.

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He realised that he would have no more physical repair and he would have to treat himself like a new 'system'

His flat was representative of his head; he hoarded and it was in a bit of a mess! He described himself as a car jacked up on bricks, wheels spinning, not going anywhere or alternatively, on a roundabout going so fast he was afraid to step off. He still needed to seek what he was. It was at this point in his life (about seven years post-injury), that he allowed a friend to get close enough to him, in order to slow the roundabout down, to a point where he could consider stepping off it. He saw that he needed to experience things in life or he'd never know what he was capable of. He told himself that nobody with these types of problems would be better at dealing with them than himself; he had an engineering background, which gave him skills to tackle problems with a degree of strategy and problem solving. He liked researching things and solving puzzles. He had the family trait of diligence and doing one's best. He found he could conjure up techniques through what other people take for granted. His Dad encouraged him to get out and about before life had passed him by. He was an advocate of the phrase, "use it or lose it" and decided he needed to stay on top of his stroke. He researched Pilates and began a regime of Pilates exercises. He found that he could usually solve a problem by just approaching it differently and appreciating that it would take him longer. He began to be thankful for the little things in life, gaining joy and appreciation

from them, which saw him through the dark patches.

His knowledge of life pre-injury in engineering was a vital resource on which to draw; he was able to analyse his life, strip it down and re-build it, in the right order, using the right process. He knew that appearances could be deceptive. He learnt to play and adjust things to try and get what he wanted. He realised that he would have no more physical repair and he would have to treat himself like a new 'system'. This was a difficult realisation as he was still grieving for his past life at the time.

A charity was starting up in the town, to try and establish a disabled living centre, which he decided to become involved with. This gave him a social outlet once a week and he took on the unpaid role of running the website. He had hoped that they would offer him the contract to run the website on a more permanent basis and was disappointed when they chose not to do that; he didn't know if they lacked trust in him or were fearful about placing the responsibility in his hands. Having had that website, which he'd designed, taken away from him, he decided to establish his own.

He'd become interested in photography and the local national park had commissioned him to do some work for them. It was through this link that he began advising them on disabled access; for Christopher to go rambling he would need the use of an off-road wheelchair and the park authority was looking to buy some. This satisfied a need to still be involved in electro-mechanics, through the specialist vehicle, as well as contributing to making the national park accessible to people with mobility issues. It also meant that he was maintaining links for possible future commissioned work and so was very happy to be involved.

In social encounters Christopher felt the need to declare his disability, in terms of his head injury, which is not obvious through conversation. Another disabled person once criticised this, after introducing himself as a disabled person. The man said he wanted to know about Christopher and not his disability. This was the first time he was aware that he was in the habit of doing this. He became aware that he

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did this so as to take some of the pressure off a potentially awkward social situation, by explaining before a judgment is made about him because he doesn't meet someone's usual expectation in a social situation. He was aware that there was much ignorance in society about brain injury. Also, he found motorists had no consideration for disabled people when it came to parking in bays for disabled people. He felt quite happy to challenge people if they parked there without entitlement, feeling like an advocate for people with disabilities. In general he thought society needed to be more open minded to disability issues, of all sorts.

A significant factor in initiating Christopher to move forward in life has been finding a girlfriend, Amy. They share common interests and have similar taste. Amy gave Christopher something much more valuable than money, much more valuable

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In general, he thought society needed to be more open minded to disability issues

to him than anything else: time. Consequently he gives her time back and they operate like a team. She has a physical disability herself, which she's had from birth. He sees her experience as giving a different perspective on life, growing up having had to fight for things; whereas with an acquired disability like his own, he had to overcome everything being taken away, before finding his way again. But she helped him do this and has taught him a lot about life. He's not sure she fully grasps the extent of his brain limitations but she helps with these and is someone to turn to. All in all meeting Amy, and making the move to a bungalow in a village to be more independent, was the start of 'seeing light at the end of the tunnel' for Christopher. It had taken 17 years post-injury to think like this and reach this psychological milestone. He still needs periods of peace and quiet to cope with his brain injury. The quietness of the village gives him clarity of thought and he is able to better plan and think because of it. He's more reliant on his car now he lives in a village, for fetching



and carrying and accessing shops, as there are no services in the village.

Some years ago Christopher had tried to windsurf again, to no avail, as he couldn't get back on to the board if he fell off. He tried land yachting, but wasn't allowed to take it to a competitive level, as he required assistance to get going. He missed activities that gave him an adrenaline rush. Many of the sports he looked at didn't have the infrastructure to support competition for disabled people, until he looked at sailing and 'Sailability' for disabled people who wanted to compete. Amy was the catalyst to engage him in this and said, "Come on, let's go" and they liked what they saw, became involved and hope to take it to a national competitive level. Finances are limiting when income is restricted to benefits, so they aren't able to afford their own boat and ideally would like sponsorship and are considering ways this might be done in the future. The practicalities are complex; once finding out about the venue of competitions they have to source the boat hire and the accommodation with disabled access. Some of the people they meet in the competitions are quite inspirational, it's exciting to compete and something they really want to be part of. It's also a serious playing field for competition they can engage with, rather than a disability 'sideshow' in other sports.

Frustration in completing physical tasks has been an issue for Christopher over the years. An engineering trait is to be

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practical and the use of one hand limits Christopher this way, especially when trying repairs at home. He has been adapting a recumbent trike that he bought to use for cycling. He recently joined in a planned bike ride with a local cycling club. The club members are willing to accommodate him and it allows him to engage in the social aspect of cycling as well as the rehabilitative aspect of physical activity. He still does daily Pilates exercises recognising the link between physical activity, a healthy immune system and good mental health. The alternative way he participates with his recumbent trike gets him to consider the alternative dynamics, from the engineering point of view. The outdoor activities like the sailing, cycling and rambling give Christopher material to populate his website. This website is not just for people with brain injuries, but a resource for any disabled person. It is an opportunity for him to share the wealth of experience and knowledge he has accumulated in the 23 years since having his injury. It is for disabled people to share firsthand experience and knowledge to aid those new to disability or in similar situations; to stop them falling through the trapdoor. He began building websites with no experience of this and had to engage in a great deal of problem solving in order to be successful at it and learnt a lot along the way. Looking back, he wonders how he came across with the original website for the charity and why they chose not to give the contract to him. Of course hosting a website means that he needs material to update it, so the outdoor activities go some way in fulfilling this function. Publicity and promotion are areas that he needs to develop and has tried various methods to date, such as business cards and wearing T-shirts at the Motability show.

Christopher has continued with his charity involvement and took the responsibility as chair of one charity and committee member for a new branch of Headway. His preferred way of the charities operating is to be proactive rather than complacent and comfortable. Ways of increasing revenue is a current concern, as is publicity. The charity involvement has led to other activities too. He has done some auditing for the NHS and this led him to undertake a leadership course to assist with this. He found that the course allowed the

participants to blossom and made him realise his limitations in terms of public speaking about his personal situation; he needs to be aware of becoming emotionally overwhelmed.

The benefits system is a continued source of frustration for Christopher, especially recently with regard to cuts and the bedroom tax. He feels everyone wants to put a hand in the disabled person's pocket these days. It makes him feel like a conduit or being traded like cards, being given money at source and then someone further down the line taking it away again.

These days he is still prone to falling and is beginning to think it may be linked to his eyesight and co-ordination, as well as low blood sugar when tiring. He does not realise it is happening until he begins to fall and then feels like a passenger in the event, unable to stop. One particular time he fell crushing Amy's Christmas tree, which wasn't well received. He manages independently in his bungalow, apart from his laundry, with a few hours of care support each week.

The website has the potential to become part of the 'neuro-culture' that wasn't there for him when he had his injury and has gone partway to fulfilling his quest of closing the trapdoor. It is contrast to the public perception of disabled people being looked at as being 'useless' and allows him to be taken seriously again. He has learnt to be in control of his own destiny again, rather than someone else being in control. He has begun to feel some of the pride in life he'd lost and he has begun to move to a point of seeing his life as being more than looking for replacements for the old life he'd lost and this new life has value and he no longer feels inferior. Now he feels like a man of substance and even though he's as poor as a church mouse he feels rich in so many other ways. He views brain injury as a mammoth thing and views his experience as one of two lives, before and after brain injury. Looking back to his first life, he could have seen himself coming out of university, achieving and possibly becoming a capitalist and that doesn't interest him anymore.

Now he's more intent on becoming a catalyst.

# Angie's story

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## The Journey

Angie was born in the 1970s and grew up in a large urban town. Her family consisted of her mother, father and her older brother, Jack. The family was close and together they spent time supporting Jack, who had cerebral palsy, at events such as the Special Olympics, where he was a swimmer. Angie's mother had had her children relatively young and as Angie watched her mother mature into an adult she hoped that one day, she could be like her and do the things that she did. Her mother worked in a school for children with special needs and this, coupled with her experiencing life with a brother with similar needs, led Angie to make the choice of a future career that involved helping others. Her brother sometimes struggled with a number of issues and the frustration led to unexpected outbursts that the family had to deal with and Angie came to develop a strong dislike of conflict.

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On her eighteenth birthday she came round from the coma and Angie's life had changed forever

Angie decided to stay on at school to study for her A Levels and set her heart on becoming an occupational therapist. When she was in the upper sixth things didn't go to plan; her best friend became ill with leukaemia and she was also distracted from her studies with her first boyfriend. As soon as her exams were finished she and a friend headed off to Spain for their first independent holiday. The day after she arrived home she began to feel quite ill. Her parents took her to hospital and it was some time before the medics were able to confirm a diagnosis. Eventually it was decided that Angie had encephalitis and she slipped into a coma. On her eighteenth birthday she came round from the coma and Angie's life had changed forever.

Her parents were naturally anxious, thinking 'what would

Angie be like' when she regained consciousness, if she regained it at all. Angie was unable to speak but when she began to use sign language, (she had learnt this before her A Levels) her mother was relieved as it was an indication that she could make herself understood and that she would be alright. Gradually her speech returned but what was apparent was that Angie was struggling to remember anything of her former life and that she was struggling to recognise even familiar people. Once physically well enough she was discharged from hospital with no follow up care on offer.

Angie did not gain the A Level grades to get her onto her chosen occupational therapy programme, so returned to college to attempt study again. Her tutors were supportive and understanding of her need for extra time and helped her through to gain the required grades for university the next year. At home, life became quite difficult. Most of Angie's friends had left for university and her best friend had subsequently died. Still being unable to recognise people, Angie's remaining friends became distant; she tried to involve herself with social engagements but the memory issues meant that she didn't remember facts about her friends and social situations became awkward. The encephalitis had also resulted in a change to her sense of taste and she no longer liked the taste of most alcoholic drinks. Coupled with fatigue, this resulted in her not being able to take part in nights out that her friends typically engaged in as young adults. If a friend suggested going places it became awkward for Angie as she had no sense of direction and it would have meant having a lead in time to an impromptu event, as she needed to plan a route and make notes about how to get there and get home. She found it embarrassing going out in the town where she had grown up as she didn't recognise familiar faces from school and elsewhere. The difficulties led Angie to not really understanding what was happening to her and why she was no longer in control of her life. She began to become frustrated which led to emotional outbursts and clashes with her Mum and Dad, with whom she had been incredibly close. Afterwards she would feel guilty at her

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behaviour, as she had seen this happen with her brother and didn't want to do this to her parents. Her Mum began to tell her that she'd changed, which made her even more frustrated as she felt like the same person and couldn't understand why they were saying this to her. She'd always kept a diary and began to look in her diaries for clues as to the person she used to be but this gave her no answers. She began to ask herself, "Well if I'm not the person I was before the encephalitis then who am I?" She had always looked up to her mother and wanted to emulate her and this led to her feeling enormously disappointed in herself.

She entered a period of depression and panic attacks at home which led to her being referred to a neuropsychologist undertaking research. The psychologist administered various tests to precisely diagnose Angie's cognitive difficulties and devise some additional coping strategies. Angie was diagnosed with deficits in her memory, sequencing and a perceptual difficulty called prosopagnosia or face blindness. She was advised to try a number of strategies, such as repetition, making notes and inventing funny names in her head for people she met regularly. Some of the strategies worked but life was still difficult and often socially awkward; it seemed unnatural to make notes in social situations so she generally refrained from doing this.

She went off to university where the problems continued. Arrangements were made for her special educational needs and she began to experiment with coping strategies of her own. Academically the programme presented challenges but these were overcome. It was when she found herself in professional practice situations that she came up against barriers. She was struggling with recognising patients and asked if she could implement her strategies, such as making extra notes during patient interactions, but the educators seemed unsupportive and she was eventually asked to leave the programme. This was heartbreaking for Angie as her dream was to become an occupational therapist. The emotions at the time meant that she didn't have the strength to challenge the system

and she agreed to transfer to an academic programme of study that didn't involve placements with patients. The prosopagnosia continued to cause her problems and on one occasion compromised her safety; she was walking in the city centre and saw a man smile at her so, being a friendly person, she naturally returned the smile, assuming she knew him but didn't recognise him. He approached her and invited her to go along with him and she suddenly asked him, "Do I know you?" and he replied that she didn't. When she thought about the possible consequences of a young female going off with a male stranger she was quite shocked. Other issues emerged such as becoming anxious as to whether or not she had locked the door on leaving the house and she found that 'negative chatter' made her constantly put herself down.

Being unable to express exactly what she was experiencing was a familiar feeling for Angie. When she was in hospital a fellow patient had given Angie a poem she had written to express how she felt. Angie decided to try this as a technique and found that it allowed her to capture her frustrations more readily than natural spoken word. She wrote a poem about her time at university and this did indeed help her.

During her final year at university her parents decided to move some distance away to a small rural village where they had enjoyed family holidays over the years. Angie moved to be with them, as she was someone who had always helped her mother with her brother Jack. Jack was in supported employment and making progress. They found that some of his colleagues were given pay rises whilst he was overlooked and this sparked the family to develop advocacy skills to right this injustice. This led Angie, now unable to be an occupational therapist, to follow this route in her career. After volunteering and gaining experience, she took a job as an advocate, which she thoroughly enjoyed. The volunteering had been especially helpful to her as it allowed her to test out what she was still capable of in terms of work, rather than being unrealistic and she had lost much of her confidence due to recent experiences. The

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element of helping others was extremely important to her. At the same time she developed more and more strategies to try and help herself. She found that the diary writing had become essential, to allow her to have an idea of what she had taken part in in the recent past. But social situations continued to pose a problem. Now living in a new area she came across few people her own age and when she did she no longer wanted to do the things that they typically did, such as socialising that involved drinking alcohol (which had an unpleasant taste now).

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### The introduction of accessible satellite navigation was the best invention for Angie

She tried joining a local squash club but the members seemed reserved and competitive. She developed a friendship with a woman she met whilst volunteering who had cerebral palsy. She saw her as an inspiration as she was someone who overcame barriers put in front of her, which Angie could model. She enjoyed the friendship as it gave her the opportunity of going to the cinema or bowling. However she did live over an hours' drive away.

Driving was an essential part of Angie's life, especially



now that she lived in a rural area. The transport links were few and far between but when Angie tried to drive she had no sense of direction, both in finding locations and getting home. Any journey involved planning routes on the computer beforehand and a number of times she found herself lost and had to ring her Dad to come and find her or guide her back. The introduction of accessible satellite navigation was the best invention ever for Angie as it hugely contributed to her independence, even though she found herself lost with this sometimes.

One may have thought that Angie's difficulties of finding her way from place to place would have deterred her from fulfilling a long-held desire to travel independently but it didn't. Her German pen friend was spending time travelling and working in Australia and New Zealand and Angie decided to try this too. She made her way to Australia and met up with her friend for a short time before making her own way round for a number of months. She took agency work in care homes, which wasn't without its difficulties; she was left with more responsibility than perhaps temporary staff should have been and it led to her sometimes forgetting essential tasks. However, she always acted responsibly and contacted the home if she remembered later. The social awkwardness was less apparent staying in hostels as often people were transient and it meant she didn't have to remember their faces or facts about them. She did have some incidents that were due to this, such as agreeing to meet someone somewhere and not being able to find it, which led to her feeling guilty afterwards. Her employer, allowing a sabbatical after so many years' service made the trip abroad possible.

She was by now working in a social care setting with a very high caseload. She had tried general administration work but it didn't suit her as she always planned a career working with people, helping with their injustices, just as she had with her brother Jack over the years. When she had begun her employment with the organisation she had found her manager supportive and provision was made for her to have a period of induction and a weekly session of

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home working. The home working allowed Angie to spread all of her paperwork out on the floor and organise it in a structured manner, as a strategy to ensure that she didn't forget to do anything she was supposed to. However, as the department became under increasing pressure Angie didn't have the time to engage with her usual coping strategies and it caused her stress. The stress made her memory worse and her manager appeared to becoming quite critical. Coupled with the fact that Angie was managing an unreasonably large caseload of vulnerable people, she began looking for work elsewhere.

It made her question how much she would reveal her memory and prosopagnosia issues in future. When work becomes pressured she felt that it can be used as an excuse, rather than addressing the real issues in the workplace. She does have a toolkit of coping strategies, which she goes to extraordinary lengths to put in to practice. She took another job linked to social care and advocacy with a charitable trust, this time being careful who she let know about her invisible disability.

Angie's Mum encouraged her to make contact with The Encephalitis Society to see if they could be of any support to her as she was going through a period of feeling lonely. She followed this up only to find that most of the events were in the South of England, some distance away, but heard that there may be developments closer to home in the near future. She made herself known to them and was invited to come along to a weekend retreat. She was nervous about this, in light of the fact that social situations caused her anxiety, but with encouragement from her Mum she went along.

On the retreat, for the first time she met people with similar difficulties to herself. This was a huge relief to her because at last she had found people that understood exactly what she had been going through for so many years. She no longer felt alone; even though her parents had continued to be supportive and lived close by she couldn't help but feel that the relationship had changed with her illness

and that they didn't really understand what it was like to experience the things that she did. But here on the retreat she found many people that did just that! It was the first time she had felt normal in a social situation since her illness. She bonded immediately with a number of people. One friend taught her not to take herself too seriously; she had experienced a different type of encephalitis and now mobilised in a wheelchair. Angie was inspired to see her coping with far greater challenges than she was ever presented with. Another friend, Alison, had prosopagnosia similar to Angie and they were able to share how they managed. A difficulty was that they usually didn't recognise each other on meeting, so they devised a way of doing this; the symbol for the charity was a jigsaw piece so they made matching necklaces with a jigsaw piece that they wore to overcome this. Alison even introduced her to a male friend she had met whilst in hospital. He also had a brain injury and Alison was sure that they would be a good match, (which indeed Angie and he have become).

Angie looked back on the retreat as a real turning point in her life. At last she felt an answer to the "Who am I?" question that had been in her head for many years. She decided to take on the role of regional representative for the charity, which involved being a link person with people who contacted the charity in her local area and offering information and support. She also wrote a poem about the experience, which was published in the charity newsletter.

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At last, she felt an answer to the "Who am I?"

Angie now lives in a small rural village and is very much part of the local community but doesn't recognise her neighbours or other people who live in the village. Her fellow churchgoers are aware of this as her Mum is also friends with them and discloses this. She finds the community much more conducive to her daily life than the large urban

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town, where she worried about not recognising her peers from school when they stopped to talk to her. She finds the church friendly and welcoming and has taken on some roles of responsibility there. She takes part in activities in the village hall, such as keep fit and tap dancing and socialises with the women afterwards. Overall the difference between the large town and small village is that she feels a more equal member of the community here and less likely to be judged. It also means that she is close to her family and she can continue to help her brother. They have a routine of going to church together on Sundays then eating Sunday lunch together. Her boyfriend is currently considering moving to the area to be with her, but as he is unable to drive due to his acquired brain injury they will need to move from the village, as the local transport network is limited.

In her house she extensively utilises labeling as a tool to identify where familiar objects are, such as her clothes and kitchen items. Her bedside calendar is part of a regimen of turning it over last thing at night for purposes of orientation with date and time. She relies on a birthday book and large wall calendar to ensure that she can plan what is happening on what day. She has experimented with a 'sense-cam' given to her by the Encephalitis Society, which keeps a visual record of events that she can load to her laptop. This is partially successful in that she would benefit from being able to record audio information to remember what she had been doing at the time of the visual record as her verbal memory is better than her visual one. Video recording in her daily interactions is limited though, for example due to retaining peoples' privacy and she does not wish to highlight her usually invisible disability.

One strategy she employs is the choice she has made of partial disclosure of her disability in the workplace. Only some of her colleagues know of her disability. To ensure she has a method of avoiding social awkwardness she watches the television news on a daily basis, which arms her with ready conversation so she doesn't have to remember facts about work colleagues, to make conversation with

them. She engages with prolific indexing and diary writing, or she has no memory of what happens from day to day. One manager took away the opportunity for a weekly session of home working, which posed a problem to Angie, working in a busy open plan office and no longer having a weekly catch-up to spread out her notes and organise in a quiet environment. It means that she brings an amount of her work home with her to sort outside of office hours, especially now she has she gained a managerial role. The work role is not that of an occupational therapist as she had always hoped, but she has followed a similar career path and the work covers similar issues.

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### Only some of her colleagues know of her disability

Reading self-help literature about discarding 'negative chatter' has been very helpful to Angie over the years. She makes the link between the positive thinking in

the books to her understanding of religion and sees the connection between them as a way to interpret life. She is aware that through the restriction in opportunities to make social contacts over the years, her friends are either much older or have disabilities and whilst valuing these friends she is aware of an absence too. Reflecting back on what she has gained from her experiences she thinks that perhaps her life has made her stronger and more open to different experiences than she may otherwise have been had she not experienced acquired brain injury. The amount of time and effort required to implement her toolkit of coping strategies is considerable but she continues and is always open to learning new ones. She is still ambitious for the future.

# Doug's story

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## The Journey

Doug is in his seventies and lives with his wife in a small remote rural village. His wife, Rose, had a brain injury as a result of negligence in hospital. They moved to the area to access a good brain injury service to meet Rose's health and rehabilitation needs.

Doug was born and grew up in the Midlands. His working career began in the men's clothes retail business and he moved with his work to live in the South of England for some time. It was when he decided to move back to the Midlands that he first met his wife. This occurred as a coincidence in that they both travelled from London to his hometown on the same day, with Rose travelling to meet one of Doug's family. They identified with each other from the very beginning and became not only romantic partners but the best of friends too.

It was whilst seeking career advice that he was steered from visiting as a client to actually working in the Job Centre service. He took on an administrative role, which eventually proved very successful. He gained status through a number of promotions, working his way to regional responsibilities of leadership, finance and people management. His wife worked in the same service and they were notable in their relationship in that they spent lunchtimes together, holding hands, which displayed the strength of their marital relationship to their work colleagues.

Their leisure time was also predominantly spent together, which Doug saw as a defining factor of their friendship and closeness. In his early mid-life Doug began to focus on his health and fitness, having realised one day how unfit he was and involved Rose in this too. They became keen runners and took a developmental and leadership volunteer role in a local running club. Doug focused on competitive long distance running and encouraged Rose with this too. Other restorative activities involved camping and caravanning in the UK and Europe, where they enjoyed the variety of travel and local culture and established a social network

that they would meet regularly. As his career progressed circumstances led to Doug becoming self-employed and he took up courses in financial management and began helping small businesses manage their own finances.

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## One evening she had a cardiac arrest and acquired significant brain damage

The holiday trips abroad continued to be important in their leisure time and it was following one trip to Europe that Rose, who had been healthy and fit to this point, required emergency hospital admission due to becoming unwell.

It took some time to diagnose the cause of her illness and there were severe complications in stabilising her medically. This was questioned by Doug and other family members. Healthcare fell well below the expected standard and Doug spent most of his waking hours supporting Rose in a hospital which was short staffed and patients' basic needs often not attended to. Some years later this was acknowledged in a public enquiry into the standards of care in this particular healthcare Trust. Whilst Rose was in the hospital's high dependency unit one evening she had a cardiac arrest and subsequently acquired significant brain damage. To this day Doug carries guilt and regret at trusting that Rose was being supported by nursing staff, in the unit that night, whilst he went home to rest. The medical advice given was that Rose would not recover and it would be kinder to withdraw treatment interventions to allow a swifter death. Doug remained at her side, comforting her and it was him that detected some small signs of recovery. The medical staff dismissed this but he remained persistent and optimistic until they acknowledged this themselves and treatment was re-administered that led to Rose having a degree of recovery.

A rehabilitation programme was introduced as a result of Rose's signs of recovery, but again this fell below

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expected levels of healthcare and administration of basic needs. There were numerous incidences of neglect, such as being left requiring toileting assistance and food being left untouched, as Rose couldn't reach it or feed herself if he wasn't there to help. Physiotherapy intervention was productive and improvements were made cognitively and physically, though psychologically Rose deteriorated. Intervention involved purely medication to address the subsequent mental health issues, which they considered wholly inadequate.

Discharge home brought additional problems, as the house was not adapted to Rose's physical disability needs. The 24-hour care that she had been assessed as needing by the social worker did not materialise. Housing adaptations in their particular urban area seemed unobtainable, with what seemed an incredible notion of having to wait to be put on a waiting list! Doug relied on the assistance of friends, as statutory services were not forthcoming. Transport to hospital day services for rehabilitation was unsuitable and worsened Rose's health status too.

He found the reaction of friends and family to their situation difficult to understand; some became closer and provided invaluable support whilst some displayed a complete rejection. People they had previously classed as close friends made it clear they would not be

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People they had previously classed as close friends made it clear they would not be visiting

visiting in hospital and the friendship waned. Some close family members also refused to visit in hospital. This latter reaction took Doug by surprise, as he and Rose were still the same people that they had always been, just now in difficult circumstances and in need of help. During this very difficult time of coping they were made aware that some areas of the UK had much better brain injury services,

through a relative living about 250 miles away in a rural area. They made an immediate decision to move to the distant rural area, leaving behind long-established friends, but balanced by the intensity of the need for better support and rehabilitation for Rose.

This move proved hugely successful, as the multi-professional healthcare services were immediately responsive and individualised to Rose's needs and housing adaptations were prompt too in this remote rural location. Knowing that there was always someone from the brain injury service to help at the end of a telephone was reassuring. Occupational therapy to encourage independent living was well received by Doug and Rose and the contact with the hospital consultant excellent. Doug views this sporadic shortfall in services nationally as limiting progress and activity for many people with acquired brain injury. A financial compensation package for negligent medical care followed, allowing them to buy an adapted property and 24-hour support, but he acknowledges that many people with brain injury have to rely on statutory services, often lacking and leaving families unable to cope.

Doug and Rose have always coped with their situation by continuing as far as possible with normal activities. Rose remains Doug's best friend and closest companion. Following her biographical disruption she made cognitive and physical progress to walk with minimal support. Although they lost their leisure time pursuit of caravanning with friends they were able to re-establish going abroad, by finding a small, adapted hotel run by very accommodating English hoteliers. Their emotional closeness has been maintained throughout and for their 40th wedding anniversary they went on a cruise and Doug made his marital and emotional commitment clear by asking Rose to marry him again. They renewed their vows on board ship in what was a surprise service for Rose, Doug even going ashore alone to buy Rose a special outfit for the event.

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A setback emerged in Rose's health status on their return and even today, some year's later, her recovery is less marked than following her first episode of ill health and brain injury. There is unpredictability in Rose's health status that contributes to the challenges of living with an acquired brain injury, in terms of planning where to go, what to do and when people can visit. However, Rose does not identify herself as a disabled person, even though she has cognitive and physical disabilities. She prefers not to holiday in large hotels that specifically cater for people with disabilities as she finds this distressing, though is sympathetic. Instead she prefers venues that are accessible for all and visited by all, especially overseas.

Doug and Rose used some of the financial compensation from the medical negligence on buying an already adapted bungalow. They try to live as man and wife but Doug is responsible for managing a 24-hour a day, 7-days a week rehabilitation and support package for Rose. Doug has the skills for leadership, people and financial management from his previous career role which has helped tailor a very specific rehabilitation package for Rose's optimum recovery. This is underpinned by a belief that individuals can development grow under the right circumstances. However, a dilemma does arise. He finds himself in the situation of people management during the day, yet the same staff seeing him in his pyjamas at night and entering his shared bedroom to support Rose if she needs assistance during the night. Some of the staff are understanding but not all and it can undermine what he is trying to achieve in terms of a comprehensive, well run rehabilitation package for Rose. He feels the need to be responsive in a professional manner at all times, yet he feels intense pressure and stress in both roles. He and Rose have affection for a number of the staff who has been with them since arriving in the area and count them as friends, but personnel issues do arise. Currently Rose's niece assists with the managerial issues on a part-time basis and they have established a routine of enabling staff to take responsibility for key areas of Rose's needs to try

and manifest the smooth day to day running of issues. A limiting factor of the rural environment is the fact that support staff has to travel long distances to work and it restricts the flexibility of working hours.

Doug and Rose's relationship continues to reflect the friendship and emotional closeness of their long marriage. They continue to engage in activities together, such as shopping trips and visits out for lunch or coffee as well as holidays. Despite this, Doug sees himself as having lost much of the role as husband, possibly due to the intrusion on privacy that Rose's care package brings with it. So much of his time is absorbed in meeting Rose's health and wellbeing needs in managing her rehabilitation package well that much of the intimacy is lost, which he mourns and puts an increasing strain on him. Rose maintains her role as homemaker and sees cooking and cleaning as part of this. Doug has incorporated this into her rehabilitation programme, by encouraging her to wipe a few pots after the meal and make small contributions to home care, rather than the tasks being done by the care staff.

It has been made clear to Doug that in order to maintain his own health and wellbeing he needs to spend some time outside of the home with restorative activities. The constant pressure of emotional stress and managing Rose's care staff has an impact on both his psychological and physical health. He still identifies himself as fit individual but acknowledges the impact of his situation on his own health. However, it is not easy to spend time outside of the home to counteract this, as their social circle is limited and their location remote, in addition to Rose being his closest companion for many years. Their closeness brings a dilemma in that he wants to be there as emotional support and companionship for Rose, whilst at the same time it puts him under great strain. He doesn't feel able to make the case for his own health and well being with Rose in case it causes her anxiety and prompts more seizures. This extends to his reluctance to make a case for himself to sleep alone to get a restful sleep; he and Rose have always slept together, yet now she requires help from paid carers

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in the night and this wakes Doug and prevents him from resting. Also, he knows the nuances of optimum intervention through rehabilitation with Rose like no other and sees it as essential that this is promoted and sometimes individual staff members are not fully aware. He still recalls the night he left Rose's care in the hands of nursing staff and she experienced a cardiac arrest that led to the brain damage. The strong need to protect Rose is evident. All in all, this leads to him feeling trapped in the situation and seeing no resolution at times.

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He values shared decision-making with healthcare Staff and draws on their expertise to validate rehabilitation choices

Doug has always been protective of Rose since her brain injury, possibly spurred on by that occasion when he left her to the trust of healthcare professionals and the brain injury occurred, changing their lives. This has been exacerbated by a recent hospital admission when he had to intervene with a nurse administering incorrect medication through not reading Rose's case notes. The majority of the brain injury service in the rural area has been excellent, but he remains dismayed when senior healthcare Staff gives damning prognoses when he feels they should be motivating. He values shared decision-making with healthcare Staff and draws on their expertise to validate rehabilitation choices they make for Rose.

Over-archingly, Doug's approach is one of looking for growth and development with optimism for people with acquired brain injury, including Rose. He is quick to dismiss a vocabulary of 'care' around Rose, instead promoting 'rehabilitation'. They engage in normal activities and she is his life-long companion and best friend. They still look towards being able to travel abroad at some point in the

future, even though progress is needed in the rehabilitation in order to make this happen. He expresses his admiration for Rose and acknowledges her resilience in the face of continued ill health.

The property they live in is very remote, though suitably adapted. As they are a couple who have always enjoyed socialising and visiting places they now have to think carefully how far they go away from home as places may not have toileting facilities accessible for a wheelchair. They would prefer to move to a local town but suitably adapted properties are few and far between and they would be in competition with other buyers if something did come on to the housing market and have to sell their own property first. Established friends have been left behind in the Midlands and there seems to be few opportunities to make new ones. The local pub is one of the few community meeting places and Doug sees this as a valuable place to seek out male company, which he very much values due to so much time spent with female care workers. However, the type of previous friendships they had in couple relationships is not available here. It is more difficult to establish friendships where they are invited to visit people's homes and socialise, which is an activity they were familiar with before the biographical disruption. Doug feels the need to spend some time in male company away from the home, with the home being continually occupied with female support staff. However, there is a dilemma in that the pub is only busy in the evenings when he feels the need to be at home for Rose to settle her down to sleep, as they share a bedroom. Rose can become anxious if he isn't around, which can prompt seizures and subsequently they both become distressed.

He has an established group of friends in the pub with whom he has a share in a racehorse, which gives them a common interest and leisure activity of visiting the stables and hoping to visit the races as owners in the future. Horses are part of the culture in this rural location and something he has connected with since living there.

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Disappointment is expressed by Doug at the distancing of some family members, despite them living close by. Relatives that were once close and with whom they feel an emotional connection visit infrequently if at all and there is not an opportunity for Doug and Rose to visit due to houses lacking appropriate environmental design for

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### He and Rose enjoy visits to the stable to see and admire the horse as it develops in training

wheelchair access, even though many public spaces are accessible these days. They no longer receive invitations to people's houses, possibly due to it no longer being convenient. This adds to the disappointment at no longer having the wide social network they previously

enjoyed. This leaves a tinge of regret but he tries to put this issue aside and move forward.

They are fortunate in one respect that financial compensation followed the proven negligence in Rose's brain injury, allowing a full ongoing rehabilitation package with 24 hour assistance. But in no way does this compensate psychologically, emotionally and physically for Doug and Rose's situation.

Doug has not only drawn on his financial and management experience in organising Rose's rehabilitation package but also put these skills to good use in setting up a local branch of a brain injury charity in the nearby town. His approach has been to empower the members with brain injury to take on leadership roles for themselves and contribute to their self-development, which has brought him a sense of joy and satisfaction. This again reflects his approach of promoting growth and development of individuals with a brain injury and acknowledging both their needs and their potential contribution to society, just as he promotes this with Rose. He has been instrumental



in organising an annual weekend for people with brain injuries and their families in the North, for some years now at an outdoor activity centre. The weekend presents challenges to participants and promotes confidence and self-esteem, education around brain injury issues and fun. Often participants take part in activities they haven't attempted for years and express how much it improves their confidence.

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### He sees this as another opportunity for people with brain injury to develop and improve, with the appropriate kind of assistance and appears to hold an optimistic view of the future for the people with brain injury he comes into contact with

## Learning outcomes

	Be able to;	Relevant for
1	Identify the range of complex needs, physical and cognitive with sometimes hidden symptoms following an ABI	NHS personnel Primary care - GP's and staff
2	Understand the complexity of access to services for diagnosis and appropriate support. Ascertain the suitability of assessment criteria	NHS personnel Primary care - GP's and staff Social Workers
3	Identify the individual nature and complexity of symptoms, impacts and variations of ABI	NHS personnel Primary care - GP's and staff Social Workers
4	Recognise biographical disruption or how a person's intended life story is interrupted by an ABI and that of significant others	NHS personnel Primary care - GP's and staff Social Workers Mental Health teams
5	Note the non-biomedical needs and consider daily living with complex behaviour is life long	NHS personnel Primary care - GP's and staff Mental Health teams
6	Identify the support needs of caregivers and address the technical language communication difficulties	Family members, partners, siblings Primary care - GP's and staff Social Workers Care support assistants
7	Understand the challenges of daily living, potential self-coping and adapting strategies based on professional skills prior to the ABI	NHS personnel Primary care - GP's and staff Social Workers Care support assistants Mental Health teams
8	Establish routine ABI awareness training to distinguish the areas of potential stigma that can influence personal identity post-ABI	Primary care - GP's and staff Social Workers Care support assistants Primary, secondary and special educational needs schools
9	Have regard for people with ABI as people first, rather than solely as medical patients or place value judgements or a label by stigmatising their impairments	NHS Personnel Primary Care - GP's and Staff Social Workers HR personnel Care support assistants Mental Health teams

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What can we learn from these narratives?

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How can services respond more appropriately?

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Are the needs of significant others taken into account?

# Acknowledgements

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This booklet would not have been possible without the people with an acquired brain injury offering a willingness to engage. They never lose sight of something better for themselves and their families.

We are thankful for the opportunity to produce this resource in partnership with researchers Dr Claire Brewis, Independent Occupational Therapist, Professor Anna Van Versch, Teesside University and collaboration with Kerry Reynolds, the Headway Acute Trauma Support nurse from James Cook University Hospital who works tirelessly to provide information and support to individuals and family members in the acute stages following a traumatic brain injury.

We hope these narratives provide inspiration.



We are very grateful for the support from the Middlesbrough Philanthropic Foundation, Headway - the brain injury association and Headway Teesside



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