

Worksheet 5: Brian's story

Brian was born in 1925 in a small village in the Hampshire countryside. He always spoke very fondly of his childhood, describing it as 'idyllic.' When he was 18, Brian was conscripted into the army and served as a radio operator in the Middle East for the last two years of WWII. He maintained a keen interest in amateur radio and science for the rest of his life.

Brian was a 'biker' and pursued this interest in motorcycles by securing a job in a motorcycle dealership in a large city in Hampshire, which he moved to when he was in his early 30s. At this dealership he met Bernadette and fell instantly in love with her. They married in 1959.

Brian and Bernadette had two children – a son and a daughter. They were a close family. Brian worked as a laboratory technician in a university for many years, retiring at the age of 65. He enjoyed his retirement, filling his days with gardening, tinkering with projects in his beloved shed, spending time with his family – often involving lots of tea and cake!

Brian had been very fit and well for most of his life but was diagnosed with prostate cancer when he was 84 for which he was successfully treated.

It was around this time that Brian's daughter noticed that Brian was doing 'odd' things. Brian had been an excellent driver for many years and although he had given up driving when he was 75, he still knew his way around a car. His daughter noticed though that Brian often could not work out how to open the door of her car when they went out together; he didn't seem to understand the difference between the door handle and door lock so often locked himself in the car. He changed the style of shoe he wore because he couldn't work out how to tie shoelaces. He seemed to have difficulty recognising edges... often walking into doors or furniture. He sustained several falls. His son noticed that Brian was spending less time in his shed but when he did go out, perhaps to look for something or mend something, he would be in his shed for hours and return having not achieved what he went into his shed to do.

Brian's relationship with Bernadette changed over the years and he started blaming her when he was not able to find something, suggesting that she had moved it on purpose. He blamed his son for 'borrowing' the tools which he could not find, being very surprised when his son found Brian's tools in their usual place in his garage. Again, Brian blamed his wife or son for moving them and trying to 'trick' him.

Brian's family spoke together about these changes but agreed that it was most likely Brian's age and the fact that he had always been a bit argumentative and 'crotchety' that were causing them. Brian was a very proud man and had always been 'the head of the house'; not a man to argue with or express concern about as he always responded angrily to any idea that there might be something 'wrong' with him. His family did not therefore feel able to talk to Brian about their concerns.

As time went on Brian spent more and more time indoors, spending hours at his desk copying text from some of his science books. Although he and Bernadette liked to go out shopping or for a coffee, this was becoming less and less frequent as Brian seemed to be losing his road sense – having walked out in front of cars several times. Bernadette was

also anxious when he went to public toilets because on several occasions he could not find her again afterwards. It seemed evident that Brian was worried about his continence – though he never explained it to his family, he started taking a spare pair of underpants and a lidded container with him whenever he left the house. Brian was also telling his family about all the animals that visited him in the house; the tiger and bear who lived in his bedroom, the seven cats he fed every morning. Brian's family suspected that he was hallucinating but as Brian did not seem at all distressed by the hallucinations they agreed to 'go along with it'.

Brian was also becoming very repetitive in his speech, much of which centred on reminiscing about his childhood, schooldays and life in 'the village'. Brian began to repeatedly sing lines from old songs and recite poetry – always the same lines. He seemed to really enjoy doing this. His daughter would join in with him and they would sometimes dance together. Bernadette never joined in as she found it very difficult to cope with Brian's constant repetition and her negative feelings towards him at this time.

As Brian approached his 87th birthday, he suggested to Bernadette that he should go and see their GP as 'something wasn't right'. Bernadette accompanied him and following a brief consultation, Brian was diagnosed with depression and prescribed anti-depressant medication. This did not seem to improve Brian's mood and his skills and abilities continued to change. Brian was also becoming more labile in mood. He and Bernadette returned to the GP who made a referral for Brian to be seen by their local Older People's Mental Health Team. A doctor from the team visited Brian and Bernadette at home, took a history of Brian's symptoms, asked Bernadette some questions and then administered a Mini Mental State Test with Brian. Brian scored 12 out of 30. The Doctor told Brian and Bernadette that she would share these results with their GP. Some days later, Bernadette received a phone call from their GP to say that Brian probably had Alzheimer's Disease. He said that he had prepared a prescription for Aricept – an 'anti-dementia drug'. At this point, Bernadette and the GP agreed not to tell Brian his diagnosis.

Brian and Bernadette were seen by a Community Psychiatric Nurse (CPN) every three months to 'check his medication was working'. Bernadette was referred to a 'Memory Matters Course', which was run by the NHS Memory Clinic, but as she did not drive and there was no bus to the venue, she was not able to attend. Bernadette and Brian were given information about day centres for Brian to which he replied, 'Over my dead body... Why would I want to spend my day with strangers playing stupid games?'

It was about two years later that everything came to a head when Brian had a fall in the local supermarket. Brian's gait had been getting worse and worse and he was shuffling his feet to such an extent that on this occasion he lost his balance and fell. He fractured his right arm and sustained cuts and bruises. He went by ambulance to A&E and was discharged home later that evening. He slept in his armchair as he was unable to get up the stairs due to his fractured arm and being unable to hold on to the banister. Bernadette slept downstairs with him.

Brian's daughter bought a single bed, commode and urine bottles, a wheeled walking frame and several other items which she hoped would help Brian at home. Although the home was open plan, Bernadette and Brian agreed that the dining area could be turned, temporarily, into a 'bedroom' for Brian. Brian's daughter made a request to her fathers' Local Authority for the provision of an additional stair rail. She was told that there was a two-year waiting list for this service.

A week later Brian was admitted into hospital via A&E having become delirious with a urine infection and infected wound on his elbow from his fall the week before.

Brian remained in hospital for several weeks due to his health needs and because Bernadette was also admitted into hospital for several weeks with acute pancreatitis. During his time in hospital Brian became doubly incontinent, was unable to weight bear and required assistance with all his daily living tasks. His verbal communication had also deteriorated, and he spent most of his time sleeping or sitting with his eyes closed. Sometimes he recognised his family when they visited, sometimes he did not.

Bernadette and her children were asked to consider whether they would be able to provide for Brian's needs at home and a social worker completed an assessment which showed that Brian would require a full Care Package of at least four visits a day, plus respite for Bernadette, adaptations to their home, including a hoist, and ongoing support from physiotherapy, CPN and a social worker. Unfortunately, the social worker at that time informed Brian's family that, due to budget cuts and poor staffing levels, the only Home Care Provider in their local area that was able to take on Brian's case could only provide one visit per day in the morning. The social worker also told them that it was unlikely that she would be able to find a respite bed for Brian and that there was an eight-month waiting list for community physiotherapy.

Brian's children, who both worked full time, and Bernadette, who was still recovering from surgery, therefore agreed that it would not be possible for them to meet Brian's needs safely at home. The family and the care team agreed that Brian's needs would be met within a nursing home.

Brian's daughter knew of a nursing home in the very village where Brian had lived as a child. The nursing home was rated 'Outstanding'. Of all the places Brian's family could cope with him being, this was the one.

After a further six weeks in hospital Brian was transferred to the nursing home. When the nursing home manager assessed Brian in hospital, she asked his daughter for a copy of the life history document she had completed for her father. When Brian and his daughter and son-in-law arrived at the nursing home and were taken to Brian's room, his daughter saw a picture of a motorcycle next to his door. Brian's daughter took this as a sign that her father would be well cared for... the staff had taken the trouble to get to know Brian before he had even arrived.

Brian lived well for a further seven weeks in the nursing home who treated him and his family with love, respect and sensitivity. Brian became more animated and showed such love for his family that it was overwhelming for them at times. Bernadette felt that Brian was responding to her as though they were 'courting' again. She went with it; putting her hair up as she used to when they met, stroking his hands and forehead and gazing deeply into his eyes.

Brian died, surrounded by his family, just two weeks short of his 90th birthday.