**Carer Stories**
**All names have been changed.**

**Marie**
*Carer for husband Paul, who is living with dementia.*

Paul slept pretty well apart from waking to go to the loo / wet bed. Although I slept, it was the sleep when you're on the alert to wake at any noise, rather like being alert to listening for a baby to cry for a feed. He also slept a lot during the day but thankfully this didn't mean he slept less at night.

**Greg**
*Grandparent with dementia.*

My grandmother acquired early onset dementia in her 40s. My grandfather had to keep watch on her, especially at night, to ensure she was safe and secure. He decided the best way was to sleep in a chair by her bed to keep vigil. He did this for many many years until her passing. He was then unable to sleep in a bed even after her passing, again for years. This was due to the mental and physical changes that had taken place in him that prevented him from ever being able to sleep properly again.

**Sandy**
*Former carer for her husband, who had vascular dementia*
We were fortunate to have always had a wonderful sleep routine. Most nights, by 10pm we would be ready to settle down and we regularly got the recommended 8 hours sleep.

In 2016, my husband was diagnosed with vascular dementia. For the first 12-18 months nothing really changed. Soon after this our sleep disturbances began. First, he would wake in the early hours and wander around the house. I placed motion sensor lights around to help with his safety, and also I knew which room he was in by which light was lit. Then the wandering increased and I would have to follow him as he would turn the TV or fire on, or try to open windows or doors. This meant my sleep was disrupted as I would constantly have to be alert to him rising. Whilst he could sleep during the day, I could only catnap ready for when he woke.

Next came the twitching and moving. I made the decision to get single beds. We had these pushed together but at least we each had our own mattress and bedding. His mobility also began to decrease and he would often fall, so I had to be alert to all his movements. He would sleep less and less at night and then go to bed about 5 in the morning.

I didn't realise how exhausted I was until he moved into a nursing home. I had to rediscover my sleep schedule, but for almost a year I was still waking regularly and tuned into every noise. The first time I slept through the night I
awoke in a panic envisioning a missed fall or escape.

It is now 18 months since I lost him and I'm just beginning to get back to a regular routine again. However the sleep deprivation has had a marked effect on my health. Hopefully I will

continue to make progress with my new routine and start to improve my mental health and sleep quality.

I didn't know the full extent of what caring and tiredness can have on a person until 6 months after my caring role ended. Having missed several health reviews my body eventually decided enough was enough and I collapsed and knocked myself out. A scan revealed a small bleed on my brain and I spent 9 days in hospital. During that time I had counselling which continued for 12 months after my discharge. No significant cause could be found apart from stress and exhaustion.

I'm now working with a new counsellor to rediscover me as a person.

**Diane**
*Current carer for husband living with dementia*

This is very difficult to write and something I have never been able to talk about with anyone

As a carer for my husband who has had dementia since 2008, I was able to manage the earlier stages well. Since 2016, when his dementia dramatically worsened, I felt exhausted physically and mentally from caring for him without support, and I also began to suffer from severe sleep deprivation. He began to sleep more during the day, something I had no control over. However, every night he was repeatedly awake up to around 4am banging around and demanding to eat or go for a walk etc. I got to the point where I was unable to sleep as I had to be alert to his risk of falls. I can't stress enough that, although his GP and Social Services knew about this, they did nothing to help me. I only ever slept when utter exhaustion took over. This led to my mental health deteriorating to the point where I was suicidal. Additionally, my physical health deteriorated to the point where I developed Atrial Fibrillation and ended up in hospital. Things worsened during COVID-19, where I experienced additional isolation on top of his deteriorating condition, where he would often injure me during his falls. My immune system was compromised due to utter exhaustion and sleep deprivation and meant that, when I caught COVID-19, I was rushed into intensive care and nearly lost my life. When I eventually was discharged, it was back into a full-time caring role. I couldn't even look after myself and never really recovered. Exhaustion continued, and eventually the council put in care for 1 hour each morning. He was at high risk of falling at night, so I was sitting up with him. Months later, I caught a variant of COVID-19 and rapidly became critically ill. The level of sleep deprivation I experienced and the effect of utter unbelievable exhaustion was compounded by the lack of support from those who were able to help but failed to hear my cries for it put my life on the line three times. It took my consultant to call "ENOUGH", forcing the care services to find a space in a care home for my husband, COVID-19 or not, in order to save my life.

Lack of sleep and utter exhaustion has caused me physical injury, and mentally still creates problems with my sleep patterns. I sleep in my chair downstairs as I cannot sleep in my bedroom. I spend my night still on alert to every sound. NO ONE HEARD... NO ONE LISTENED…NO ONE CARED WHAT WAS HAPPENING EVEN THOUGH THEY COULD SEE IT.

**Kate**
*Carer for husband David who is living with Alzheimer's Disease*

Sleep, by John Fletcher (1579 - 1625)
Come, sleep, and with thy sweet deceiving, lock me in delight awhile. Let some pleasing dreams beguile all my fancies. That from thence I may feel an influence. All my powers of care bereaving….

This verse came to mind when I started to write this paragraph, it was an English Lieder song that I used to sing…

When David was diagnosed with Alzheimer's in 2013, I started to worry about all the 'what ifs'. One of them was, 'what if he can't sleep and starts to get up during the night etc. Fortunately, I can truly say that night disturbances did not happen with David. He had always been a good sleeper, unlike me, who would wake up anxious and be very disturbed. David had a knack of holding me tight until I settled - and it worked. This he continued to do well into the progression of his illness, and I found it very comforting. I felt that David was blessed by being able to lock himself into the delights of good dreams and put to one side the strains and stresses of trying to make sense of his world during the day. This also gave me much needed rest for the day ahead….

When David left home to be in care, he continued to sleep well. There were times when I would lie next to him in his room - I bought a bigger bed for him there, so that I could do this. I am sure he found comfort in this physical contact. Later on in his illness, I was told that he did wake during the night and would walk to the lounge and was often given tea and toast or biscuits and a chat before he went back to bed. Towards the end, David slept more and more…he had always used sleep as a healer when he felt unwell… it was his way of escaping to feel better. I have always felt very grateful that David's ability to fall asleep when his head hit the pillow, stayed the course with him.