

Dementia and the impact of not driving

Kate Swaffer, who lives with younger onset dementia, explains why, despite her sense of loss and grief at losing her licence, she believes people with dementia should not be allowed to drive



*Kate Swaffer worked as a nurse in aged and dementia care and in operating theatres for 20 years. She was then diagnosed with dementia, and subsequently forced to retire in 2009 after losing her driver's licence. Her blog, *Creating Life with Words*, can be found at kateswaffer.com*

Driving is a powerful symbol of competence and independence and a routine part of adult life. As a person living with a diagnosis of dementia, I have a first-hand experience regarding driving and dementia. In Australia, a diagnosis of dementia is not considered to be sufficient reason to revoke a person's driver's licence and cognitive and physical abilities are not used as the only markers of safe driving.

I would argue that this is insufficient and suggest a diagnosis of dementia automatically impacts safe driving, because our ability to accurately (or honestly) self-monitor, our beliefs about our driving capacity and at least two of the following important markers – cognition, concentration or judgement – have been clinically identified as being diminished. They have to be, for us to have a confirmed diagnosis of dementia.

My experience

Aged 50 and living with a diagnosis of younger onset frontotemporal dementia, I had my driver's licence revoked after failing a practical driving assessment. My neurologist thought I would pass. I thought I would probably pass. I failed, with a very low score of 35 per cent – a shock to us both. The loss of my licence has affected my independence and self-esteem and of course, my ability to get around. It has been one of the most emotionally debilitating aspects of my dementia. The emotional and financial impact of surrendering your driver's licence or having it revoked is significant, and many of the issues are not obvious, especially to others. The personal toll of having my driver's licence revoked includes:

- loss and grief: it feels like a death
- loss of independence
- loss of control
- loss of independent mobility
- loss of privacy
- lower self-esteem and self-worth (feelings of incompetence)

- social inequality
- increased stigma
- increased isolation
- loneliness
- guilt – feeling like a burden – leads to sadness
- unable to be self-sufficient
- tension and anxiety relying on others
- reduced family income; loss of work hours for partner to provide transport
- buses and taxis can be too difficult for me to negotiate
- sense of well-being significantly impaired.

Since I started relying on others for transport, I have come to realise many people still licensed to drive are less able to drive than I was. My father-in-law, who had Lewy Body dementia, was unsafe on the road. Dad was driving around roundabouts the wrong way, stopping suddenly on a highway or in other very unsafe places, driving on the wrong side of the road (yes, sometimes with the grandchildren in the car) and having numerous small accidents, but no amount of suggesting that his licence be taken away or that he be re-assessed made any difference to his GP. It took us 18 months to get his doctor to take the situation seriously and required us threatening to advise the insurance company that if Dad had an accident, the doctor should be held accountable. The doctor was protective of him: he said many times that he did not want to take away his independence. Dad always told the doctor he felt safe driving. Germaine Odenheimer, an American researcher, wrote that in regards to dementia and driving: "...because of the emotional nature of the topic of driving, many physicians are reluctant to broach the issue with their patients" (2006).

Assessment and risk

Driving is a risky business. It demands focused concentration, quick reaction

times, good judgement and efficient problem solving skills. You must have great alertness and good perception. At the core of this discussion is the safety of the driver and the safety of others: drivers, passengers and pedestrians. The majority of people start driving when they turn 16. It is not until we achieve older age that we are ever re-assessed for safety or fitness to drive, barring assessments required due to a known health issue. We do not have to undertake a single written test, or practical skills test, or a defensive driving course at any time after our licence is granted.

Whilst driving a motor vehicle is not as complex as flying a plane, this does seem unsafe. With a pilot's licence, the pilot has to have a bi-annual flight review / test and full medical examinations, which escalate after the age of 40. It includes eyesight, hearing, urine checks for diabetes and ECG; these tests must also be done if the person has not flown in the previous three months and pilots must do at least three take-offs, circuits and landings before they are allowed to take any passengers up. On the other hand, we are legally able to get a driver's licence in our teens, which we renew with money and a new photo. We are then considered safe to drive until our health assessments start at 70 years of age.

Austroroads and the National Transport Commission revised the *Assessing fitness to drive* guidelines in 2012 and they contain nationally agreed medical standards for the purposes of driver licensing, but is it enough? There are limited resources for testing drivers for safety and there are many variances in laws and the ways in which people with dementia are tested for safety between states and territories. The cost of assessing fitness to drive is high and borne entirely by the person with dementia; the required numbers of appropriately trained assessors are not yet available. The variation between states makes it unsafe, as drivers are not limited by borders.



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The Survey of Disability, Ageing and Carers (SDAC) reported that 84 per cent of people with dementia had a profound level of limitation in core activities, while an additional 9 per cent had a severe level of limitation (ABS 2010). As a person with a diagnosis of dementia, this seems at odds with those who advocate for our rights to continue to drive, even with a conditional licence. An investigation into changes in driving ability, led by Christina Fritelli and Davide Borghetti, found that: "Mild Alzheimer's disease significantly impaired simulated driving fitness, while mild cognitive impairment limitedly affected driving performance. Unsafe driving behaviour in Alzheimer's disease patients was not predicted by Mini-Mental State Examination scores" (Fritelli *et al* 2009). This is only one set of results adding to the growing body of evidence that driving performance decreases even with mild cognitive impairment or Alzheimer's disease.

Insufficient testing

I have anecdotal evidence of overly simplistic driving assessments being given to people with younger onset dementia. Because they look young, fit and healthy, the instructor gives them a simple drive around the block which they are usually able to pass, rather than the full assessment. I also have listened to drivers who tell me they know they are unsafe, but rely on looking healthy and on saying the right thing to their doctor. I know of older couples who support each other through unsafe driving: for example, one partner manages the gearstick because the driver cannot remember how to. They both report to their doctor that the driver is safe.

We all know that driving under the influence of alcohol or drugs is illegal. During my 'good' moments, I am probably safe to drive, but the issue is, I cannot predict when this will change or when the symptoms of dementia are worsening. In

this way, it is similar to being under the influence of alcohol, but with no warning. One of the followers of my blog, who is living with dementia, said: "Due to our brains ceasing to function as they did, I gave up my licence immediately after my diagnosis. I knew I was a risk and could cause harm to others. With my losing focus and having mental lapses ... that's a sure sign that the brain isn't doing its job?... I strongly speak out to others with dementia about what they are doing and they may cause serious injury to others, apart from the possibility of invalid insurance."

I personally feel like a burden on others now that I have to rely on help for transport. My initial guilt has turned to sadness at not being able to transport children, elderly parents, or meet up with friends. I do very much miss the spontaneity of being in control of my own transport, but I would still argue, based on evidence and anecdote, that people with dementia are simply not safe to drive a vehicle. People with dementia do still have a responsibility to regard the safety of others and if we lose the insight for this, then others should and must step in to help us regain perspective and support us emotionally through this difficult loss. ■

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