

# Driving and Dementia - My Experiences

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I am a person who lives with dementia and I want to share my experience of giving up driving because I think it will help other people with dementia who have to do the same.



Once you have passed your driving test, the law assumes you are able to drive unless you are disqualified for some traffic offences, or are judged no longer able to drive safely, due to certain illnesses, dementia being one. (Note that 'driving' includes the use of motorbikes and scooters.)

## Difficulties with my driving

My dementia did cause me to have driving problems, among other difficulties, such as attempting to drive down the wrong side of a dual carriageway several times. I was positioned to turn right, indicating, ready to proceed, and it was only due to oncoming drivers flashing their headlights at me, that I was prevented from making that potentially fatal manoeuvre. Had they not come along at that time, I would have been off down the wrong side. I couldn't understand where I had gone wrong.



When the average person hits problems, they devise ways to get round them. I was no different. I was also having trouble at roundabouts. When I approached and read the directions, I would forget in an instant where I had to go. I used to circle several times, feeling more and more dizzy and still take the wrong exit in panic. I began to take the first left and, if it was not the correct road, I would do a U turn and return to the roundabout, then take the next left and repeat the process until I reached the exit I wanted. It was a laborious, but safe, way of getting through roundabouts. This worked well until one day I turned left, and came to another roundabout. After that, I steered clear of strange roundabouts, and stuck to local routes.

I also started stalling the car, a thing I had never done since my early "L" plate days. My clutch control was haywire. I blamed the clutch and had it replaced. But I still stalled the car and grumbled that the garage had done a poor job. I hit kerbs (curbs) when turning corners, and I just couldn't fathom out what on earth was going on. Having been a keen cyclist, I knew how to turn a corner and I never hit a corner when I held a provisional licence. I did report my driving problems to my doctor, who advised me, to stick to roads I knew very well.

## Passengers

My wife, Maureen, refused to sit in the car with me if I was driving. Whereas before she had felt perfectly secure about my driving abilities, as I was a safe driver and had never been involved in an accident, she was now uneasy and concerned. She stopped me taking my young son out with me in the car, as she was frightened for him. She remarked that when going along a motorway I kept weaving from one side of the lane to the other side then back again. I couldn't seem to hold a straight line. This, of course, I strenuously denied. I was a perfect driver. Looking back it is clear I had a condition called anosognosia<sup>1</sup>, which is the denial or unawareness of an impairment/disability.

## Dementia diagnosis

It all became clear when I was diagnosed with dementia. You have a duty to report a medical condition, which might affect your driving ability to the **DVLA** (the regulating body in the UK for drivers), otherwise you are in breach of the conditions of your licence.

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1 <https://en.wikipedia.org/wiki/Anosognosia>



### What to do

**Write to:** The Driver's Medical Group, DVLA, Swansea,  
SA99 1DL

**Phone:** 0870 600 0301

**Internet:** <https://www.gov.uk/contact-the-dvla>

### Helpful resources

There is a helpful booklet called the **Customer Service Guide for Drivers with a Medical Condition**. It can be found here, or by phoning the DVLA:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/503525/INF94\\_150216.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/503525/INF94_150216.pdf)

## **Insurance**

You should also let your insurance company know because if you are in an accident, even though you are blameless, they could deny responsibility and you are left uninsured, facing legal and repair costs on your own. It is not worth the risk of taking a chance and keeping silent. A judge can apply to see your medical records. I thought my medical records were private; obviously not. My psychiatrist advised me to stop driving.

## **Feeling better after medication**

After coming to terms with my illness and receiving medication, I felt capable of driving, now that I knew what was wrong. I felt ever so much better and more aware of my surroundings, so I persisted with applying to continue to drive.

I sat a test arranged by the DVLA and passed it. I was given a licence to drive and continued to drive cars and vans. I had no further problems and felt I was driving safely in my comfort zone. I no longer undertook long journeys, as I felt it was not in my, or other road users', interests to get overtired. I, like many people with dementia, lose concentration when weary, or as the day goes on.



## Licence renewal

When my licence expired, and I was accident free, I applied to renew my licence, fully expecting (and rightly so) to sit another test. I heard nothing for six months, and on a Christmas Eve I received a letter from the DVLA saying they were withdrawing my licence. Why couldn't they have waited another day, especially after keeping me hanging on for six months? What a Christmas spoiler! They did tell me I could appeal to the Court (within twenty one days in Scotland and within six months in England) but warned me it could be costly and likely to be unsuccessful.

By this time, my wife was in charge of the finances and refused to give me money for an appeal. She was terrified I would get back on the road. I felt this was against my human rights and I should have been given another test. If I failed, then so be it; I would no longer be capable of driving safely and would have accepted it, albeit reluctantly. But I felt aggrieved that I was denied a chance to prove myself. I later found out that my GP had provided the report which barred me. Yet, the ironic thing is that after diagnosis by a Consultant, my GP had never mentioned the word 'dementia' to me. I only went to my GP when something was hurting me physically. She had no idea that I had been driving safely, and was unaware of my capabilities.



She was not the best person to have advised the DVLA. Dementia and driving were never discussed again. I feel very strongly that the medical person who comments on a person's ability to drive should be the person who sees and treats the person with dementia, for the dementia. If someone is having driving problems and has not been diagnosed with dementia, remember other illnesses can mimic dementia. Get a proper assessment as soon as possible.

If someone responds to treatment and medication, they should be allowed to sit a further driving test, and the result should be abided by.

I also strongly feel that in appropriate cases there should be a restricted licence available. For example, you could be restricted to, say, daylight only; A or B roads, not motorways; your local town; X miles from your home; or so many hours a day. If you live in a rural area or on an island, where the traffic is light, and there are no confusing roundabouts and the bus service is poor or non-existent, and you are tested and pass, you should be able to be allowed that restricted licence. You should of course be able to pass further tests. But you must abide by the restrictions and not be tempted to drive say, into a large city or on a motorway.



## No longer allowed to drive

It is a bitter blow losing your licence and you have no idea just how crippling it is, until it happens to you. Your mobility is turned upside down. Your freedom to get up and go at a moment's notice is gone. You lose your independence. You may have to rely on others to get about. You feel a nuisance if you ask and are reluctant to bother busy people. You may feel infantilised, taken about like a toddler. Some places are off bus routes and the beaten track and you can no longer travel there, unless someone has the time to take you. It can be humiliating and demoralizing. If lucky, you go in their chosen time, which may not coincide with your chosen time. For example, I might want to go and take a dawn photograph but the driver is only free in the evening. You are at their mercy.



After all these years it still rankles to be a passenger. I still feel I can drive (apart from big roundabouts) and when I sit in a car, I still “drive”. I watch the road, looking out for potholes, cars entering the main road, scanning for pedestrians, especially children and animals. I am always saying (to other’s annoyance) there is someone in the mirror. I am a terrible front seat passenger and get tired on a journey, as I watch the road like a hawk. My feet get sore with driving. Why both feet? The imaginary clutch and brake! I can anticipate other driver’s manoeuvres and know when they are going to turn, when not indicating. I feel I can still drive, just give me a chance.

### **Putting up a fight**

If you are the partner or son or daughter of someone with dementia who has to stop driving, do not expect them to surrender their car keys without a fierce fight. If they do hand them over, feel lucky. They may be aghast at any suggestion to stop driving. It can be like a death knell. There may be bitter recriminations, making you feel guilty about what you are doing to them. They sacrificed to bring you up! They were doting parents! They have been a lifetime, loving partner! They always put you first! How could you be so cruel and unfeeling?



But remember, you have a duty of care towards them. Sometimes, it is heart breaking making the right decision. You are tearing out their heart and demoralizing them, but you will have them for longer, without the added worry of what grief/havoc they could cause in someone else's life. Plenty of TLC comes in handy. Understand their anguish and possible anger towards you. You are surgically removing a great part of their life. It will be a knock to their self-esteem, giving them a sense of failure. Yet they did nothing wrong. There can be an overwhelming sense of loss. They may say "what have I done to deserve this?!"

It is better to persuade them to cease driving out of love and concern for them and others, rather than have some official body wrenching your licence from you. After twelve years, I am still resentful!

### **Alternatives to driving**

I would love to drive again even if it was on a race track while not in use, field, forest road or a (deserted) sand/shingle beach. You could use a beach buggy or a quad bike (helmeted of course). I have actually done this on a beach and on a supervised quad bike course. I have never tried a jet ski on snow or water and wonder if this would satisfy my yearning to control an engine again and feel the thrust at my fingertips.



One thing I will try some day is the dodgems at a fairground. But where are fairgrounds these days? I have never seen a simulator, but I wonder if using one and getting the feeling of being on the road again and manipulating the controls, would give me release from my torment of not driving.

Research what is available, to get you/them out of the house, to carry on life as before. Family, neighbours, friends and members of clubs may be able to offer lifts. Is there any other alternative to driving? I must admit, I do not sit back and watch the scenery. I watch the road like a hawk and test my wife's patience when I say things like "you went too slow there", "you could have passed" or "brake!" I am forever threatened with having to walk home if I don't stay quiet.

There may be free or cheap fares on public transport. Taxis in some areas offer discounted travel to people with disabilities. It could be healthy and stimulating to walk to the local shops for light shopping e.g. a newspaper.

### **Temptation**

After twelve years off the road, I have never lost my desire to drive again and when out in the car with my wife, I always moan that I should be driving again.



My wife was at my son's wedding in Australia (which I was too ill to attend) and left the car keys. I sat behind the wheel to start the engine and charge the battery, as she was away for three weeks. I felt so at home, I was severely tempted to go for a drive. Memories came flooding back. I felt like a young man again. I argued with myself and eventually turned off the ignition, and went indoors. But it was a near thing. She will have to hide the car keys from me, lest I give way.

Ten years to the month I last drove, I was on holiday in a wee bothy by the sea. It was right on the water and reached by a private road. My wife let me behind the wheel and I took off, no stalling and changed gear smoothly. It was fantastic and I had no trouble at all. I drove a few hundred yards in a straight line and got to second gear. My driving abilities were not tested in this short journey. Next day I took quite ill and was unable to drive any more, ending up in hospital.



## **Driving again after twelve and a half years**

I have never lost my desire to drive again. I once mentioned this in passing to a member of staff at the organisation “**Dementia Adventure**”<sup>2</sup> who take people, who may never been out of the house or a care home for years, on an adventure; an adventure they have longed for, for years.

Unbeknown to me, they made plans to make my dream come true. They told me they had arranged for me to go driving for two hours on an old airfield. They got in touch with a driving school, Tony's in Elgin, Morayshire, and a driving instructor who would take me driving in a dual control car. How Tony's agreed to that I will never know. I am seventy four years old, have dementia and had not driven for twelve and a half years.

## **I was in control again**

I wanted it to be like a driving test, so that I could handle the car like I used to do. I settled in and took off, no stalling or juddering. The instructor told me when to change to second gear and never advised me again. I went through the gears until I was doing sixty m.p.h. I could still hear the engine and knew when to change gear.

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2 <http://www.dementiaadventure.co.uk/> - 01245 237 548



There was a right angled corner on a curve and I slowed down by easing off the accelerator and changing down then, when straight, speeding up again.

I did three point turns, reversing round a corner, reversing between two cones from both directions, and changing up and down the gears. I watched my mirrors and indicated when coming to a stop or when turning. I WAS IN CONTROL AGAIN! The instructor did not need to intervene or change his career after the event. Elgin people could breathe again. I was disappointed I could not do a hill start (because I was on an airfield), but felt I could have managed one.

The airfield was owned by Bill, of Skid Car Scotland<sup>3</sup>, who also had an area for training lorry drivers and a skid pan. He took a keen interest in what was happening, came over and generously said I could have a try on the skid pan. He also said I was welcome back at any time, even on his day off. Thanks so much Bill, you are a gentleman. However, after two hours concentration, I felt mentally unable to handle any more and, as I knew I would never be on a public highway again, I politely refused. One good thing about dementia is that you get to meet a lot of lovely people who go out of their way to help you. Bless them all!

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3 <http://www.skidcarscotland.co.uk/>



## Beyond my wildest dreams

It took days for me to calm down after the event, I was on a high. I would never in my wildest dreams have imagined I would ever be behind the wheel of a car again. Afterwards, my wife and some of our friends from Dementia Adventure went for a cappuccino to relax and chat.

Thank you so much to all the staff at Dementia Adventure, including the behind the scenes backroom men and women, who made this dream come true. And thank you to the driving school.

When I got home, I found I could walk faster, as for some time I had been walking slowly, head bent. I found that I was able to recall facts from fifty years ago, things I had completely forgotten about. I was able to help more about the house, taking a little of the burden from my wife.

I was able to write this article by myself. My short term memory, notoriously bad, improved slightly. My sense of wellbeing was high.

I had such a great time I can't get a tune from 'Dirty Dancing' (a favourite film) out of my head. It kept coursing through my veins: "(I've had) The Time of My Life" by Bill Medley and Jennifer Warnes. I really did!



My wife will no longer be tormented by me saying “I could drive again”, when out driving with her on trips. She gained some respite from my experience, although that was not the intention. My troubled soul is fulfilled now. I will be less of an albatross round her neck. Unfortunately, dementia can dull your feelings and this had happened to me. I found that after the driving adventure I became more affectionate towards my wife, giving her the odd cuddle and being more considerate.

People with dementia need a good sense of humour to survive. Six days after driving, I went with my wife to a social evening with her church group. I was able to contribute to the gaiety with jokes that raised a laugh. I was part of the gathering.

## Making the 'impossible' possible

Now, what will the medical profession make of this? Am I unique, a one off? I certainly think not. Dementia Adventure took people who have previously sailed out on a boat, going against those who said it was no longer possible. Within a day, they were competent enough to take charge while the crew had a cup of tea.

I can see research coming out of these two events, a new life for people with dementia until the illness takes over, as it wins in the end. But you don't have to live a life of misery until that happens. You can live life again! Going out **enjoying** yourself! Why was I able to drive again? Is it a skill you never really lose, like riding a bike? Why are people able to do things that professionals have declared impossible?

There are too many people (whoever they are) stopping you from enjoying your hobbies with a trained supporter. Naturally there are some things, such as flying a passenger plane, which may not be possible, but **always consider alternatives**. Someone could take the pilot up in a glider with an instructor in the seat behind, who would keep them safe. If they have the funds they could sit in a flight simulator and enjoy "flying" again. With the right mindset you can make things happen. I would like others to emulate me and have that feeling of satisfaction when they succeed.



## Afterwards

I am under no illusions that I could ever drive on the public highway again. I can handle the mechanics of a car, as I have proved, but as I can only cope with one or two items at a time, I could not handle the complexities of driving while having to cope with bad drivers, pedestrians, cyclists, other road users and confusing town signs. I simply can't take it all in.

When sitting in a car with my wife driving, I get anxious at roundabouts. If we go through too many, I scream "get me out of here!" I get really agitated. In bed last night, I came up with the idea I should close my eyes and block out the roads. When people with dementia get overloaded they shut down. I cannot drive safely on the road, ever. Period!

I would not want others who I hope will share my experience, to think they are fit to be on the road. Be content, as I am, to have the satisfaction of knowing "I can do it". Will I drive again? I think not. I do not feel I need to drive again. I have proved I can still control a car in safe conditions. My beliefs have been vindicated and I can rest contented. I was out today for a run with my wife. I never once complained that I should be driving again. Oh blessed peace for her!



## Problems that people with dementia may face when driving

As well as my own experience, I am aware through conversations with others of a number of signs that there might be a problem with your driving:

- Hitting the gate post when entering a drive.
- Hitting the kerb when parking or turning corners.
- Being involved in “near misses”.
- Getting tickets for traffic offences e.g. bad parking: parking on double yellow lines, on corners, at fire hydrants, speeding, in safety zones, such as outside schools/hospitals and jumping red lights etc.
- Other drivers blasting their horns at you for some traffic violation, or gesticulating at you.
- Getting lost while driving, and having to stop to work out where you are, and whether you are coming or going.
- Having problems when turning at junctions across the stream of the traffic coming towards you (right in countries where you drive on the left and left in the countries where you drive on the right). This is where junctions may or may not, have traffic lights and filter lights.



- Misjudging the speed of other traffic when joining major roads from side roads, and when changing lanes, on dual carriageways and motorways.
- Weaving within your own lane. Ignoring your mirrors.
- Taking longer on routine, regular, journeys. Where did the time go?
- Going at an inappropriate speed e.g. too slow for the type of road you are on, or going above the speed limit for that road.
- Forgetting where you parked the car, or going home by some other means, such as bus/train/taxi or lift from a friend you met, forgetting that you came by car.
- Not slowing for pedestrians, who have the right of way and who may have to jump for their lives.
- Problems with driving in the dark, exacerbated when it is raining/snowing. (Note, a sight test may show the eyes are in order, or ok with glasses, but there may be a problem between what the eyes see and what the brain processes. There can be a communication blindness.)
- Passengers squirming, sweating, dismayed, telling you to be more careful as you have just done something dangerous and were lucky to avoid a collision with someone or something. Passengers expressing disquiet at your driving, etc. People refusing to sit with you, when you are driving.



- Driving home and forgetting to pick up your spouse/partner or the kids from school.
- A normally placid person experiencing road rage and swearing at other drivers.
- Muttering about how bad other drivers seem to be these days. Getting angry, confused and bewildered.
- There may be a connection to tachypsychia<sup>4</sup>. When a situation arises, the person may freeze in fear or fright. Time passes in slow motion as they frantically try to get out of it. There may be dilated pupils leading to loss of peripheral vision.
- Inside the car, forgetting to look in the mirror, signal, dip headlights, monitor the fuel gauge and watch the speed, according to the local regulations. Forgetting to wear their seat belt or ensure passengers use theirs.
- Outside the car - forgetting to check the engine oil, tyre pressures, washer bottle, weekly check on car lights and fuel gauge. Running out of fuel at times or putting in diesel instead of petrol and vice versa? Properly aligning the mirrors.
- Alexia/dyslexia, which is a problem with reading and explains why I had major trouble reading destinations at roundabouts.

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4 See [https://www.youtube.com/watch?v=NRf\\_lpGpvhs](https://www.youtube.com/watch?v=NRf_lpGpvhs)





## Getting in touch

If you have any queries or wish to share your views and ideas, you can contact us in a number of ways:

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