

CFU Carers' Support Group



For carers and relatives of people with fronto-temporal dementia and semantic dementia

Newsletter

June 2008

www.cfucarers.org.uk

Welcome

Welcome to the June edition of the CFU Carers' Support Group newsletter! We hope you are all well.

Thanks to everyone who came to the meeting in May. At this meeting, we welcomed Barbara Hatton, an occupational therapist who works at the Wrightington Mobility centre in Wigan. She gave an excellent and informative talk about driving and dementia. As many of you will know, this can be quite a difficult and emotive subject, as driving can be very important, often playing a large part in our independence from others. Barbara gave plenty of

advice on how driving is assessed when people have been diagnosed with dementia, and also how to attempt to stop someone from driving if you feel they are unsafe on the roads. We've included an overview of her talk in this newsletter for those of you who were unable to attend. Don't forget you can also log onto our website at:

www.cfucarers.org.uk to read previous newsletters and summaries of invited talks.

We look forward to seeing you at our next meeting in July.

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Driving and Dementia

Barbara Hatton, Centre Manager, Wrightington Mobility Centre

What is the mobility centre?

Wrightington Mobility Centre is one of 17 independent centres covering England, Scotland, Wales and Northern Ireland, who offer professional, high quality information, advice and assessment to individuals who have a medical condition or are recovering from an accident or injury which may affect their ability to drive a motor vehicle.

Driving is becoming an increasingly salient issue for carers of people with dementia. At the Wrightington centre, people with dementia are now one of the largest groups of people that attend for assessment.

What kinds of licences are there?

There are two types of licence:

- Group 1: this is what most people have, covering cars and motorcycles
- Group 2: this also includes large lorries and buses

The medical standards for group 2 licences are much higher than those for group 1. This is because of the higher

risks involved in driving for longer periods of time in larger vehicles and vehicles with passengers (e.g. as a bus/lorry/taxi driver).

What are the typical licensing rules?

Group 1 licences are normally held until 70 unless restricted to a shorter duration due to medical reasons. If a medical condition is declared, it will be investigated by the DVLA.

After 70, licences must be renewed every 3 years.

What counts as a medical condition?

The DVLA state that you must inform them of any new medical conditions or pre-existing illnesses that have worsened since the licence was issued. However, they are not generally interested in physical conditions. So, for example, if you were to declare that you had developed arthritis, they would thank you for informing them, but would be unlikely to investigate it. However, if the illness is likely to affect cognition and in turn the driver's ability to make appropriate decisions with regard to safe

driving, the DVLA would be likely to investigate.

What happens if you have a medical condition that might affect your driving?

There are certain non-negotiable rules, for example, if a person has uncontrolled epilepsy and regular fits, they would not be allowed to drive. However if they had been fit-free for 1 year, they would be allowed to hold a group 1 licence, but not a group 2.

In the case of dementia, cases are taken individually. If the person has undergone a medical assessment and has been declared fit to drive, a group 1 licence may be held on a renewable basis. This is typically a 1 year licence. Group 2 licences are typically revoked in dementia cases.

Who notifies the DVLA?

It is the driver's responsibility to notify the DVLA of a medical condition. If the driver does so, the DVLA will write to the person's GP/consultant and they will give their medical opinion of whether the person is fit to drive.

What happens if they refuse to inform the DVLA?

Convincing your relative/friend to inform the DVLA can be very difficult if they do

not want their licence revoked. If you feel they are unsafe to drive and they will not inform the DVLA, the doctor is obliged to do so. However, you can actually do it yourself. In fact, anyone can inform the DVLA about someone they think is unsafe on the roads. If you are concerned about the repercussions of this, you can do it anonymously as a third party notification. You can be assured that the DVLA will respect your privacy in the matter.

What is the advantage of an independent assessment centre?

A person's fitness to drive is often a very emotive subject, especially as driving often constitutes a large part of someone's independence and character. It seems to be a particularly sensitive subject amongst men, many of whom have been driving almost all of their lives and have often acted as the main driver in the household. Therefore, convincing someone that they might no longer belong in the driving seat can be very difficult and can often cause large problems within families. It can also be a contentious issue with doctors, and it is common for people who still believe they should be driving to feel betrayed by the doctor who has, in effect 'stopped them from driving'. The option to use an independent assessment centre can

therefore be extremely helpful in convincing a person that they are no longer fit to drive. Since the centre has no prior relationship with the person, and the assessment can be seen as a more practical and formal way of viewing their driving skills, people with dementia might be more likely to accept the final decision and outcome.

What happens if they do not agree with the decision?

If your relative/friend is assessed and does not accept the outcome, they are able to appeal the DVLA's decision, but it is highly unlikely that it will be changed in dementia cases.

What do I do if they won't stop driving?

Reasoning with people with FTD and SD is obviously very difficult. Nonetheless, it is worth telling them the implications of their actions and emphasising how dangerous the situation is. If the DVLA is not informed of the condition, their licence is invalid. If the licence is invalid, then so is the insurance. If this is the case, then the person is breaking the law, and there is a chance of prosecution if they are stopped by the police. Furthermore, if they are involved in an accident and the insurance is invalid, the consequences could be extremely costly.

If all else fails, some people report that the only way they have managed to prevent their relative/friend from driving is to do something more practical, for example, hiding the car keys, or removing the spark plugs. It may sound drastic, but in a case where a person may be a danger to themselves and to others on the roads, it might just be necessary.

What does the driving assessment involve?

The assessment is just that: an 'assessment' rather than a 'test'. Unlike a traditional driving test, the examiners are not looking for procedure perfect 'test-standard' driving, and take into account the habits that people might have developed over the years, and also the medical condition that the person has been diagnosed with. The centre has a static rig that they use for assessing a person's capability for understanding basic instructions and for testing response times. However the majority of the assessment uses real (dual-controlled) cars on a set route around the local area. Before the start of the assessment, the person is taken to a quiet area and asked to do a few manoeuvres in order to settle them into the car and make them feel comfortable in the situation. Occasionally, the

assessment stops there if the examiner feels that the person is not safe to go out on the test route. However in most cases, the person is then taken on a 21 mile set route that incorporates lots of different driving situations. This lengthy route allows the examiner to assess:

- Spatial awareness: *road positioning and proximity to other vehicles*
- Decision making: *judgements, speed regulation, choice reaction*
- Forward planning: *approach to hazards, speed regulation*
- Observations: *visual attention*

Why is the route so long?

The fact that the route is long allows assessment of fatigue. If the person becomes tired, then they are allowed to take a break, and their own recognition of this is a good indicator of their self-judgement of their suitability to be on the road.

The examiner is not concerned with 'one-off' mistakes that might occur in the person's driving; rather they are looking for negative trends. Some people with dementia only drive under certain circumstances, for example, the same familiar route, with someone else in the car, at the same time of day. However as your driving licence legally allows you to drive anywhere, at any time, there is

the issue regarding what the person with dementia is legally allowed to do, regardless of whether they actually do it or not. Furthermore, there are instances where we cannot just follow the same route – if there are roadworks and we need to take a diversion, as drivers, this should not be a problem. However in the case of someone with dementia who is not confident in such a situation, there is potential for hazard.

How much does it cost?

The assessment costs £50. Most centres accept self-referrals and you can also be medically referred by a GP or hospital consultant.

What should I look for if I am wondering about my relative/friend's safety on the road?

Scrapes and bumps can indicate poor judgement and awareness. Ask other members of your family, or others who know the person for their opinions. If you are a passenger in the car with them, look out for other drivers using avoidance techniques, e.g. changing lanes, keeping their distance. Changes in medication might also affect driving ability.

Common problems reported in frontotemporal and semantic dementia

- Using inappropriate speed
- Impulsivity
- Slower reactions to hazards
- Confusion between pedals in stressful situations
- Simply stopping in traffic when complex or fast cognitive processing is required
- Failing to give way appropriately
- Poor understanding of road signs and hazards in semantic dementia

How do I plan for the future?

As dementia is a progressive condition characterised by a progressive lack of insight, it is important to tackle the issue as early as possible. Talk about the prospect of giving up driving as soon as you can as it is almost certain that their licence will be revoked in the future.

Changing to automatic transmission may help initially, but the longer a person remains dependent on driving as their main mode of transport, the more difficult it may be to stop driving in the future.

One way of approaching the issue is to limit driving to shorter routes and to seek out and use alternative transport strategies, such as buses, trains and trams. This has some significant

advantages. First, it is very good in situations where you might be travelling to unfamiliar places. Since bus passes can now be used anywhere (they are no longer region specific) they provide a great way of travelling around places that you are unsure of. Secondly, there are huge benefits in terms of cost. Petrol price rises, parking fees, and the introduction of congestion charges in some areas now makes travelling by car very expensive, particularly in comparison to bus and train services, which provide an inexpensive way of getting around.

In cases where the only issue is direction, satellite navigation systems can be quite useful. However in frontotemporal and semantic dementia, this does not tend to be the primary problem, so is unlikely to be a good solution.

Links

The Wrightington mobility centre can be contacted on:

01257 256409

mobility.centre@alwpct.nhs.uk

The Forum of Mobility Centres can also provide information and advice about driving:

0800 559 3636

<http://www.mobility-centres.org.uk>

