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Alzheimers disease and driving : review of the literature and consensus guideline from Belgian dementia experts and the Belgian road safety institute endorsed by the Belgian Medical Association

**Reference:**

Versijpt Jan, Tant Mark, Beyer Ingo, Bier Jean-Christophe, Cras Patrick, De Deyn Peter Paul, De Wit Patrick, Deryck Olivier, Hanseeuw Bernard, Lambert Margareta, ....- Alzheimers disease and driving : review of the literature and consensus guideline from Belgian dementia experts and the Belgian road safety institute endorsed by the Belgian Medical Association  
Acta neurologica Belgica / Société belge de neurologie. Groupement belge d'études oto-neuro-ophtalmologiques. Groupement belge de neuropathologie - ISSN 0300-9009 - 117:4(2017), p. 811-819  
Full text (Publisher's DOI): <https://doi.org/10.1007/S13760-017-0840-5>  
To cite this reference: <https://hdl.handle.net/10067/1471780151162165141>

**ALZHEIMER'S DISEASE AND DRIVING: REVIEW OF THE LITERATURE AND CONSENSUS  
GUIDELINE FROM BELGIAN DEMENTIA EXPERTS & THE BELGIAN ROAD SAFETY INSTITUTE  
ENDORSED BY THE BELGIAN MEDICAL ASSOCIATION**

Jan Versijpt<sup>1</sup>, Mark Tant<sup>2</sup>, Ingo Beyer<sup>3</sup>, Jean-Christophe Bier<sup>4</sup>, Patrick Cras<sup>5</sup>, Peter P De Deyn<sup>6</sup>,  
Patrick De Wit<sup>7</sup>, Olivier Deryck<sup>8</sup>, Bernard Hanseeuw<sup>9</sup>, Margareta Lambert<sup>10</sup>, Jean-Claude Lemper<sup>11</sup>,  
Eric Mormont<sup>12</sup>, Mirko Petrovic<sup>13</sup>, Gaetane Picard<sup>14</sup>, Eric Salmon<sup>15</sup>, Kurt Segers<sup>16</sup>, Anne Sieben<sup>17</sup>,  
Evert Thiery<sup>17</sup>, Jos Tournoy<sup>18</sup>, Maurits Vandewoude<sup>19</sup>, Manfredi Ventura<sup>20</sup>, Jurn Verschraegen<sup>21</sup>,  
Sebastiaan Engelborghs<sup>22</sup>, Tom Goffin<sup>23</sup>, Michel Deneyer<sup>24</sup> & Adrian Ivanoiu<sup>9</sup>

<sup>1</sup>Vrije Universiteit Brussel, Universitair Ziekenhuis Brussel, Department of Neurology, Brussels,  
Belgium

<sup>2</sup>CARA department, Centre for Fitness to Drive; Belgian Road Safety Institute, Belgium

<sup>3</sup>Geriatric Department, UZ Brussel, Vrije Universiteit Brussel (VUB), Brussels, Belgium

<sup>4</sup>Department of Neurology, Erasme Hospital, Université Libre de Bruxelles, Brussels, Belgium

<sup>5</sup>Born Bunge Institute and Antwerp University Hospital, University of Antwerp, Wilrijk, Belgium

<sup>6</sup>Laboratory of Neurochemistry and Behavior, Reference Center for Biological Markers of Dementia,  
Institute Born-Bunge, University of Antwerp, Belgium & Department of Neurology and Memory Clinic,  
Hospital Network Antwerp (ZNA) Middelheim and Hoge Beuken, Antwerp, Belgium

<sup>7</sup>Department of Neurology, AZ Sint Jozef, Malle, Belgium

<sup>8</sup>Department of Neurology, AZ St Jan, Brugge, Belgium

<sup>9</sup>Department of Neurology, Saint Luc University Clinic and Institute of Neuroscience, Université  
Catholique de Louvain, Brussels, Belgium

<sup>10</sup>Department of Geriatrics, AZ St Jan, Brugge, Belgium

<sup>11</sup>Afdeling Geriatrie, SILVA Medical, Scheutbos, Brussels, Belgium

<sup>12</sup>Université catholique de Louvain, CHU UCL Namur, Department of Neurology, Belgium & Institute of Neuroscience (IoNS), UCL, Brussels, Belgium

<sup>13</sup>Department of Internal Medicine (Geriatrics), Ghent University, Ghent, Belgium

<sup>14</sup>Department of Neurology and Memory Clinic, Clinique Saint-Pierre, Ottignies, Belgium

<sup>15</sup>Memory Clinic, Service of Neurology, CHU Liège, Belgium

<sup>16</sup>Memory Clinic, CHU Brugmann, Brussels, Belgium

<sup>17</sup>Neurology Department, Gent University Hospital, Gent, Belgium

<sup>18</sup>Geriatric Medicine and Memory Clinic, University Hospitals Leuven & Department of Clinical and Experimental Medicine, KU Leuven, Belgium

<sup>19</sup>Universitair Centrum Geriatrie & ZNA St Elisabeth, Universiteit Antwerpen, Antwerpen, Belgium

<sup>20</sup>Direction Médicale and services des Neurosciences, Grand Hôpital de Charleroi, Charleroi, Belgium

<sup>21</sup>Expertisecentrum Dementie Vlaanderen, Antwerp, Belgium

<sup>22</sup>Reference Center for Biological Markers of Dementia, Laboratory of Neurochemistry and Behavior, Institute Born-Bunge, University of Antwerp, Belgium & Department of Neurology and Memory Clinic, Hospital Network Antwerp (ZNA) Middelheim and Hoge Beuken, Antwerp, Belgium

<sup>23</sup>Legal Expert Ordre des Medicins/Orde der Artsen, Belgium

<sup>24</sup>Vrije Universiteit Brussel, Universitair Ziekenhuis Brussel, Department of Paediatrics, Brussels, Belgium & Vice President Ordre des Medicins/Orde der Artsen, Belgium

**Address for correspondence:** Jan Versijpt, MD PhD, Department of Neurology

Laarbeeklaan 101, 1090 Brussels

[jan.versijpt@uzbrussel.be](mailto:jan.versijpt@uzbrussel.be)

Tel +32 2 476 37 39

Fax +32 2 477 68 00

## ABSTRACT

Dementia Alzheimer's disease (AD) is a highly prevalent condition and its prevalence is expected to further increase due to the aging of the general population. It is obvious that the diagnosis of dementia AD has implications for driving. Finally, driving discussions are also emotionally charged because driving is associated with independence and personal identity. However, it is not clear how to implement this in clinical practice and the Belgian law on driving is rather vague in its referral to neurodegenerative brain diseases in general nor does it provide clear-cut instructions for dementia or Alzheimer's disease AD compared to for example driving for patients with epilepsy and as such does not prove to be very helpful.

The present article reviews what is known from both literature and existing guidelines and proposes a consensus recommendation tailored to the Belgian situation agreed by both dementia-AD experts and the Belgian Road Safety Institute endorsed by the Belgian Medical Association.

It is concluded that the decision about driving fitness should be considered as a dynamic process where the driving fitness is assessed and discussed early after diagnosis and closely monitored by the treating physician. The diagnosis of dementia AD on itself definitely does not imply the immediate and full revocation of a driving license nor does it implicate a necessary referral for a formal on-road driving assessment. There is no evidence to recommend a reduced exposure or a mandatory co-pilot. A MMSE-based framework to trichotomise AD patients as safe, indeterminate or unsafe is presented.

The final decision on driving fitness can only be made after careful history taking and clinical examination, neuropsychological, functional and behavioral evaluation and, only for selected cases, a formal assessment of driving performance.

**Key words:** driving – dementia – Alzheimer's disease - neurodegeneration

## INTRODUCTION

~~Dementia is a prevalent condition and its prevalence is only expected to increase due to the aging of the general population.~~ Alzheimer's disease (AD) is the most prevalent type of dementia, accounting for an estimated 60-80% of all dementia cases [1]. Since cognitive domains like attention, executive function, visuospatial ability and information processing speed are all essential to the driving task, it is clear that the diagnosis of ~~dementia-AD~~ has implications for driving, with the ensuing fear for an increased motor vehicle accident (MVA) rate ~~for drivers with dementia~~ [2]. ~~Dementia-AD~~ is of particular concern not only due to this effect of cognitive decline on driving safety, but also because ~~AD patients~~~~persons with dementia~~ often lack or have limited insight into their deficits. Consequently, they do not develop or consistently utilize strategies to increase or even maintain their driving safety. As such, as disease progresses, problems occur with navigation, lane-checking and changing skills, merging, turns, route following ability and signaling to park [3]. On the other hand, at least two longitudinal studies revealed that 88% of drivers with very mild dementia and 69% of drivers with mild dementia were still able to pass a formal road test [4,5].

~~It is not clear how to implement all this in clinical practice and the Belgian law does not provide clear cut instructions for driving cessation neither in neurodegenerative diseases in general nor in AD more specifically, compared to for example the formal rules that exist for driving in patients with epilepsy.~~

Driving is considered as an integral or essential part of life, particularly in developed countries, providing autonomy and other psychosocial benefits and preserving self-esteem. As such, the loss of driving ability has been shown to lead to a lower engagement in community activities, a decreased life satisfaction, an increased isolation and even depression or anxiety and a sharp decline in general physical health with an increased 3-year mortality [6-9]. Moreover, a recent study showed that the transition to non-driving was associated with a faster cognitive decline, where another study already showed that driving cessation increased the institutionalization risk [10,11]. On the other hand, drivers with a diagnosis of dementia as a group are at an increased risk when driving where often a 2-8 fold increase in MVA rate compared to age-matched controls is mentioned [12].

The issue of driving and ~~dementia-AD~~ is however not always problematic. Indeed, many ~~AD~~ patients ~~with dementia~~ surrender their license voluntarily. Also, the number of MVA caused by drivers with

dementia AD is lower than might be expected, maybe related to the natural avoidance behavior seen in dementia AD patients. As such, it was even suggested by at least two studies, including one of the largest studies published up till now with mild to moderate dementia patients with a mean MMSE of 15 (mean age 71 years), that there was no increased risk of MVA when looking at state recorded crash rates rather than those recalled by subjects, carers or relatives [13,14]. A recent study showed that, contrary to what could be expected, drivers with dementia have a lower number of MVA than patients with e.g. fainting/dizziness, diabetes or depression [15]. Finally,

Aa Cochrane review on dementia and driving using published literature until 2012 concluded that the available literature fails to demonstrate the benefit of driver assessment for either preserving transport mobility or reducing MVA [16]. The present article reviews concisely what is known from literature and existing guidelines and proposes a guideline tailored to the Belgian situation agreed by both dementia experts as well as the Belgian Road Safety Institute.

It is not clear how to implement all this in clinical practice and the Belgian law does not provide clear-cut instructions for driving (cessation) neither in neurodegenerative diseases in general nor in AD more specifically, compared to for example the formal rules that exist for driving in patients with epilepsy. The present article reviews concisely what is known from literature and existing guidelines and proposes a guideline tailored to the Belgian situation agreed by both dementia experts as well as the Belgian Road Safety Institute.

Since AD is the most prevalent cause of dementia and since driving assessment in other types of dementia is even more complex with few data available from literature, the current guideline strictly refers to AD. Some general aspects to be taken into account concerning other types of dementia are however mentioned as well.

## METHODS

The first author (JV) reviewed the literature and wrote the article. Pubmed was searched using the following terms: Alzheimer, dementia, neurodegeneration, cognition and driving. The last literature search was performed on June 8, 2017. The guideline was discussed at several meetings of the Belgian Dementia Council (BeDeCo). Also, a formal meeting was organized between representatives of the Belgian Road Safety Institute and BeDeCo to further finetune the consensus guideline. The MMSE cut-offs in the consensus scheme were obtained from literature data and by means of a survey amongst BeDeCo members. Finally, the article was reviewed by the Belgian Medical Association, especially from a legal point of view. All authors agreed on the final content of the manuscript.

## **PREDICTORS FOR DRIVING FITNESS IN PATIENTS WITH AD**

Studies evaluating driving skills in people with dementia are fraught with methodological difficulties and are largely focused on rare outcomes such as MVA and therefore rely on surrogate markers such as cognitive tests, driving simulators and road tests. The overwhelming majority of these tests has not been evaluated prospectively in people with dementia and so can only offer speculative data on MVA risk. Below an overview is given of the different methods and their potential role in the assessment of driving fitness.

### **HISTORY TAKING**

Because of a lack of insight into one's condition is a common consequence of AD, determining when to cease driving cannot be left up to the discretion of the individual. Caregiver opinion of driving fitness in demented older adults has been associated with road test performance [17]. It has been shown indeed that, when family members do raise concerns about driving safety, they are often accurate and their concerns should be strongly considered [18]. However, caregivers may be biased by a wish to avoid conflict or may overestimate or underestimate their loved ones' capacities as they may rely on them for transportation, or fear they will become responsible for chauffeuring them following license revocation [19,20]. The family member should preferably be interviewed alone, allowing for safe disclosure of any driving concerns. In order to assess patients for driving safety a non-validated but easy-to-ask question to carers could be 'would you let your spouse drive your grandchildren?'. Finally, a recent study suggested that adult children may be more accurate reporters of driving ability than spouses, possibly because of less personal bias [21].

### **COGNITION**

Existing driving fitness assessment procedures almost invariably emphasize cognitive measures. However, these may play a less determining role in driving performance in mild to moderate dementia than is commonly understood. What can be concluded from available studies is that tests correlate only grossly and without helpful cut-off points with road test performance and driving simulator

performance. Both general cognitive measures and selected neuropsychological tests are used to predict driving fitness, however most traffic safety experts conclude that psychometric tests may mainly serve to identify drivers at risk or to interpret driving performance observations but should not be the sole determinants in deciding to continue or revoke driving privileges.

### **General cognitive status**

Given that multiple cognitive functions are necessary for driving, it is unsurprising that composite cognitive test batteries have been found to predict driving performance with greater accuracy than tests covering only a single cognitive domain [22]. Global cognitive measures are however not strongly associated with the risk of involvement in MVA and a consensus has not been reached for formal cut-off scores to define an increased MVA risk. As such, a brief mental status screen should never be the sole determinant of driving recommendations.

### **Selected Neuropsychological tests**

The evidence base for a single or a combination of neuropsychological tests is lacking and the use of neuropsychological testing for this purpose remains a controversial area, with no consensus reached on what areas or tests are particularly useful. The most likely role of single tests is in screening those drivers at risk or those in need of a more detailed evaluation. If single tests are chosen, tests of visuospatial skills are the most relevant predictors of driving impairment, however, a recent review concluded that no single cognitive domain was found to be the most reliable when determining driver ability [23,22]. As for single tests, Hird et al concluded that the Trail Making Test and the Maze test emerged as the best single predictors of driving performance [16,24,25]

### **FORMAL TESTING FOR DRIVING PERFORMANCE**

Formal testing, by simulation or on-road is often considered as the gold standard for the assessment of driving fitness. However, one should be aware that, faced with the threat of a test, the older driver with dementia may withdraw from driving. It is interesting to note that a Danish population-based study who evaluated the safety effects of the introduction of a cognitive test as an age-based screening tool for older drivers seemed to produce a shift among older persons from driving towards

unprotected, significantly less safe modes of transportation. As a consequence, the number of fatalities in this group even increased [26].

Also, with the potential for fatal crashes at stake, the tenor of the vast majority of studies based on formal testing are directed towards driving cessation rather than preserving mobility since they tend to focus on negative outcomes, which, although serious, are rare and in doing so reinforce a negative stereotype on a large number of cognitively impaired drivers. Moreover, driving behavior has several hierarchies: *strategic behavior* involved in planning destinations and routes and avoiding hazardous weather or traffic conditions; *tactical behavior* which refers to anticipatory behavior such as speed adaptation and finally *operational behavior* which refers to the physical performance of the task itself. The latter is examined in most studies. These previously mentioned factors could explain partly the discrepancy between high failure rate on road tests and the low reported MVA rates [16].

### **Driving simulation**

With the increasing availability of technology, the utility of driving simulation shows promise as a relevant tool. They provide the opportunity to present challenging situations and events in a standardized setting, with a high reproducibility compared to on-road driving assessments where situations cannot be manipulated. However, driving simulators are not widely available and costly, a large number of packages are available and a common standard is lacking. Moreover, some authors believe that the performance in driving simulators is not strongly related to the on-road driving performance and they have not been shown to predict prospective crashes [27]. Finally, about 25% of the patients suffer from simulator sickness [16].

### **On-road driving capacity testing**

The on-road assessment is generally considered as the gold standard in most studies and has been shown to correlate well with the naturalistic driving performance [28]. However, it lacks an accepted standard and considerable variation exists in terms of vehicles, routes, tasks and scoring method. As such, the on-road assessment failure rate for very mild AD ranges in literature between 0 and 19% and between 22 and 41% for mild AD [24]. Moreover, few data show that road tests correlate with crash involvement and finally, there might be a risk to both the driver and examiner while performing the examination [29].

## BELGIAN LAW

Worldwide, all legislation has a propensity to recommend that a diagnosis of dementia alone is not sufficient to withdraw an individual's privilege to drive, but it offers no guidance on what constitutes fitness to drive, for those expected to make this recommendation.

In Belgium, like in France and Germany, the driver's license has an unlimited warranty, this in contrary to many other countries where, mostly only from a certain age - varying between 45 and 70 years old - the fitness to drive needs to be reassessed every 2 years (e.g. Spain, above age 70), 3 years (e.g. UK and Italy) or 5 years (e.g. the Netherlands). It is interesting to note however that a system with this built-in mandatory age-based driver testing has not been shown to decrease crash rates [30]. Accordingly, in Western and South Australia for example, mandatory driving tests for older drivers were recently abandoned [31]. Concerning these global differences in regulations on driving and aging, it is interesting to note that in China, people older than 70 are prohibited to drive and that in Japan, drivers over 75 years are required to display a mark on both the front and rear of the car indicating 'aged person at the wheel'. [For an overview of the different driving regulations on people with dementia for several countries we refer to an excellent overview by Kim et al \[32\]](#)

In Belgian law (RD 23/3/1998, annex 6) neither the word 'dementia' nor 'Alzheimer's disease' is mentioned. There is only a general referral to mental or neurological diseases where the decision about driving fitness has to be made by the neurologist. The latter is not in line with routine clinical practice where also geriatricians and psychiatrists are entitled to diagnose and manage AD patients with dementia. Moreover, the exact wording where a referral to dementia could be suspected is somewhat unclear. More specifically in the section on neurological diseases, the law refers to 'diseases with a reduced functional capacity' (*verminderde functionele vaardigheid / capacités fonctionnelles réduites*) in which case the patient should be referred to the *Centre for Fitness to Drive and Vehicle Adaptations* or CARA, a department of the Belgian Road Safety Institute for further assessment. Further in the text, referral is made to 'progressive disorders with consequences for functional capacity' (*evolutieve aandoening met invloed op functionele vaardigheid / affection évolutive influençant les capacités fonctionnelles*), where it is stated that a regular examination is necessary and the duration of the driver's license should not exceed three years above the age of 50. Finally, referral is also made to 'acquired disorders with deficits in behavior, judgmental, adaptive or perceptive

capacities or disturbing psychomotor reaction times' (*verworven stoornis met een belangrijke afwijking in gedrag, stoornis in oordeels-, aanpassings- of perceptievermogen of die de psychomotore reacties verstoort / affection acquise avec anomalies du comportement, troubles de jugement, d'adaptation et de perception ou qui perturbent les réactions psychomotrices*) where driving should be prohibited. All this renders the law not really useful as a guideline in clinical practice for advising patients with a cognitive impairment.

In Belgium, the treating physician does not have the obligation, unlike other countries e.g. UK, to report to authorities those patients likely to continue driving despite being advised not to when it is no longer deemed safe, unless the patient forms a threat to himself or to society [33]. It is interesting to note that a study in epilepsy was not supportive of this system of mandatory reporting [34]. Also, the treating physician cannot be held responsible if a patient keeps on driving despite being told otherwise and provokes an accident [33]. On the contrary, a treating physician could be held responsible if he does not inform the patient about a, post hoc, evident incapacity to drive. Since, as shown above, the Belgian law is somewhat unclear and moreover, every citizen is obliged to know the law even with a mild cognitive deterioration, the latter is probably only a theoretical consideration. Finally and more importantly, the greatest responsibility lies probably implicitly with the patient since most insurance contracts indicate that the driver has the obligation to report about any future change in the medical situation in order to maintain a legal insurance coverage. To what extent this can be expected from even a mild AD patient with on one hand a continuously advancing disease and on the other hand most likely a partly reduced decision making capacity or an impaired judgement or lack of insight is a matter of debate.

## **CONSENSUS GUIDELINE**

Tackling the issue of driving cessation should be a collaborative process between the physician, patients, their families and driving license authorities. A proposal for a guideline tailored to the Belgian situation is shown in Figure 1. It should be stressed that the proposed guideline does not have any legal value nor is it intended to have one. It merely aims to present a framework to the clinician faced with the problem of driving and **dementiaAD**.

The first assessment of fitness to drive should be made early after diagnosis by the treating physician (both specialist and general physician), anticipating that driving cessation will likely occur in the future. The advantage of doing this lies in the fact that in many cases, a positive message still can be given in an early stage where the independence of the patient and his maintained driving capacities based on partly preserved cognitive abilities are stressed. Also, it allows time for ventilation or dissipation of anger. At this point however, even if a positive message can be given, it should already be stressed that this is a temporary measure and careful monitoring is needed. Discussions should resolve around the inevitability of the eventual driving cessation and mobility counseling (transportation alternatives and/or barriers to driving cessation) should be repeated over time with both the individual and caregiver, to lay the groundwork for eventual driving cessation. It is recommended that a formal document (*Model VII / Modèle VII*) indicating the patient's fitness to drive is given to the patient and that a limited duration of this document is entered ranging from 6 months to one year. On this document, restrictions can be indicated concerning the perimeter where patients can drive, the type of roads one can drive (e.g. no highways) or the circumstances (e.g. only in daylight). Indeed, it has been shown that restricted licenses are associated with a reduced MVA risk [35]. Care should always be taken whether the patient can retain such restrictions. On the other hand, there is **little-not enough** data to suggest that clinicians should recommend reducing exposure in patients with dementia (e.g. limiting trips) or mandating a co-pilot to significantly reduce driving risk [12,36,37]. Finally, when a negative advice is given concerning driving and the patient is not willing to obey this recommendation, other practical solutions can be considered like not repairing or even sabotaging the car or removing the car (keys).

Since there is no commonly used method of assessing **dementia-AD** severity in relation to driving, the MMSE was chosen at the start of the decision process since it is widely used by both dementia

specialists, general neurologists, geriatricians as well as family physicians and is relatively simple to administer. We are fully aware of the many shortcomings of using the MMSE, next to depend heavily on the educational level, literacy and verbal ability of the subjects tested, as a basis for this guideline and this was also a strong matter of debate amongst the authors of the present guideline.

Nevertheless, it has on the other hand been shown that the MMSE correlates with the degree of driving impairment on road tests and with the history of crashes [22]. However, like many other tests, it does not appear to predict the future involvement in MVA and valid cutoff-scores have not been defined [38,39]. Part of this could be related to the fact that many dysfunctions likely to compromise safe driving, such as poor judgment or impulse control, are not adequately assessed by the MMSE. Therefore, the MMSE cut-offs presented in Figure 1 should only be seen as rough estimates upon which other variables mentioned in Figure 1 exert their influence. In general, this approach is in line with a general consensus that, rather than dichotomizing drivers as safe or unsafe, trichotomization should be employed, dividing drivers into three groups (safe, indeterminate and unsafe) [40]. The higher cut-off of 24 above which driving could be considered as safe is in agreement with other guidelines as well [among which the guideline of the American Academy of Neurology on 'evalutation and management of driving risk in dementia'](#) [41,17]. The lower cut-off of 19 is in line with a previous descriptive study by Logsdon et al [42].

Since mild cognitive impairment (MCI) is a very heterogeneous condition and too few literature data are available on driving in MCI [43,44], it seems prudent – in general – not to advocate the cessation of driving in MCI patients, certainly when there is doubt about the underlying pathology and unless other risk factors are present which preclude the driving fitness.

## **Role of CARA**

The CARA department of the Belgian Road Safety Institute is the only and officially appointed center for fitness to drive evaluations in Belgium. CARA is an evaluative center: it takes the fitness to drive decisions. The product of the fitness to drive evaluation is a ‘Model XII’, signed by the concluding physician of CARA. This ‘Model XII’ has the same status of the ‘Model VII’, previously mentioned. This medical attestation confirms the fitness or unfitness to drive, the duration of its eventual validity, and the eventual terms, conditions and restrictions. As with the ‘Model VII’, this document is delivered to

the 'candidate driver' (patient) who is expected to take this document to the local driving license authority. There, the original driver's license will be kept. If the document confirms 'fitness to drive' (of any sort or duration) the local authority will produce a new driver's license in accordance.

A referral to CARA is sometimes mandated. In case of visual disability resulting in unfitness to drive on ophthalmological grounds, only CARA can make an exception to the official minimal norms based on the practical driving evaluation (and a positive advice of the ophthalmologist). More relevant to this population, in the case of a limitation in driving by locomotor or reduced functional capacity, referral to CARA is also mandated. The latter, reduced functional capacity, is an interpretation left to the discretion of the referring physician. The basic philosophy of the fitness to drive legislation is that a mere diagnosis is not a sufficient reason for referral. The diagnosis should give rise to a significant limitation in driving. In addition, but also on practical grounds, the referral is only to be made when the fitness to drive decision cannot be taken (for whatever reason) by the referring physician. Hence, clear-cut cases (clearly fit or clearly unfit) should not be referred. The CARA referral should be limited to 'grey zone' patients.

The fitness to drive evaluation procedure at CARA starts when the 'candidate driver' returns the CARA medical questionnaire. On the basis of that it is decided which evaluations will be performed to take the final decision. This evaluation is free of any cost. In case of a candidate driver with dementiaAD, it is very likely that theis procedure will include an evaluation by the CARA physician, the (neuro)psychologist, and the expert in practical fitness to drive. This means that many aspects of driving will be evaluated and will be taken into account: general health, pure locomotor abilities, psycho-motor and cognitive functions, sickness insight, etc. Also, a practical on-road driving evaluation will be performed. The purpose of this practical evaluation is to observe whether the medical and psychological observations, data and results have an influence on the participation in traffic (while driving a car). If so, it is discussed on a multidisciplinary basis whether the eventual observed negative consequences are or can be compensated for. This compensation could be on 'mechanical' or on a 'personal' level. On a mechanical level, automatic transmission can be a solution to 'simplify' the driving task. By simplifying, more attention can be devoted to other important aspects of driving. However, *changing habits* is not always a good solution. On the other hand, the use of the driver's license could be limited. Examples of that are restricting the validity to a certain radius around the residence of the patient in order to restrict driving to a known environment, only day-time driving,

or not on highways. Of course, one could question whether the driver is likely to ‘obey’ to these restrictions. Therefore, it is clear that these delicate decisions are always and purely made on an individual and multidisciplinary basis.

## **OTHER TYPES OF DEMENTIA**

Few data are available in literature on driving fitness and other types of dementia [45]. Some general aspects are however mentioned below.

### **Frontotemporal dementia (FTD)**

Few studies are available on driving and FTD, indicating that patients with FTD are more likely to show dangerous driving behavior, even from an early disease stage [46-49]. Based on this and on common sense, it seems probably wise that patients with the behavioral variant of FTD are declared unfit to drive. As for patients with primary progressive aphasia variants, as long as mainly verbal language is affected, patients could be declared fit to drive.

### **Vascular dementia (VaD)**

VaD has rarely been formally tested and if tested, then mostly as a part of an unselected dementia population. One study concluded that driving performance errors were comparable between VaD and AD patients [50]. No formal guideline for this type of dementia can be given.

### **Diffuse Lewy Body Disease (DLBD)**

Although not specifically studied to the best of our knowledge, there is a reasonable suspicion of a higher risk for MVA given the deficits in visuoperceptual and attentional skills and impaired judgment and disinhibition in patients with DLBD. Moreover, the common occurrence of visual hallucinations and the fluctuating level of alertness, may raise significant concerns about driving safety for patients with DLBD [51].

## **CONCLUSIONS**

The decision about driving fitness should be seen as a dynamic process where the driving fitness is assessed early after diagnosis and closely monitored. A final decision can only be made after careful history taking, neuropsychological testing and, for selected cases, a formal assessment of driving performance. In general, both driving legislation and recommendations from medical practitioners require further research that addresses both preserving individual mobility and reducing MVA in order to provide the best outcome for both drivers with dementia and the general public. As for now, the application of a comprehensive, interdisciplinary approach to the driver with cognitive impairment will have the best opportunity to enhance our patients' independence, social connectedness and quality of life, while meeting their psychological and medical needs and maintaining personal and public safety.

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