"I WANT MY DRIVER'S LICENCE BACK!" DISCLOSING DRIVING CESSATION IN THE CONTEXT OF DEMENTIA

PRINT THIS ARTICLE

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Case: Mr. R.

Mr. R., 80 years old and your long-time patient, comes into your office, very angry, saying, "I want my driver's licence back!" He was recently hospitalized for congestive heart failure at a tertiary hospital. A diagnosis of cognitive decline was made, and following his hospital stay he received a letter from the Ministry of Transportation stating a doctor notified them he was not safe to drive. What do you do?

Driving in the North American society, although a privilege and not a right, is often necessary for transportation, social contact, and independence. With the greying of the population, as patients accrue medical conditions that can impact fitness to drive, primary care providers (PCPs) are increasingly faced with the dilemma, "Is my patient safe to drive?" In seven of 10 Canadian provinces, there is mandatory reporting of unfitness to drive, and it is the physician's responsibility to determine the risk and address this issue. Often because of a lack of tools, time, and possibly expertise, driving safety is not addressed or communicated effectively. In most provinces, seniors must undergo some form of age-determined evaluation at the local vehicle licensing body. In Ontario, for example, starting at age 80 years, seniors must undergo a three-part test, consisting of a vision test, a multiple-choice test, and a group session. A few may be chosen for an on-road evaluation, but typically most do not undergo a road test. In the Canadian Medical Association (CMA) guide on determining fitness to drive (7th edition),[1] physicians are given information on a multitude of health conditions that can affect the aging driver. Some of these conditions are very well defined (i.e., vision loss, sleep apnea, syncope, or cardiac conditions). Other conditions are left to the judgment of the practitioner (i.e., dementia or other neurological conditions). The 8th edition of the CMA guide on determining fitness to drive was in draft at the time of this writing.

The dementia diagnosis does not automatically imply that the person cannot drive, as some persons with dementia (PWDs) may be safe to drive in the early stages of dementia.[2] It does, however, mean that the PCP must inquire if the person drives and must monitor the person as the illness progresses.

Older persons with medical conditions, including physical impairments (e.g., a loss of vision or arthritis), often voluntarily give up driving or self-restrict.[3] In contrast, PWDs may lack insight into their compromised skills and are thus at increased crash and fatality risk.[4] Cognitive deficits affecting driving include memory impairment, poor sequencing skills, impaired insight and judgment, apraxia, slowed processing time, and visuo-perceptual impairment. PWDs may be at risk of getting lost on the road, fail to pay attention to pedestrians, or have difficulty negotiating busy intersections.

To date, driving research has often studied older drivers without distinguishing between men and women. However, older women are the fastest-growing group of drivers on the road and could exceed older men in the future.[5] Attention to gender differences may be required in future research, for appropriate driving assessment and management.

Assessment tools are addressed in a separate article in this issue of the journal,[6] and the reader is also referred to the Dementia Toolkit for Health Professionals, for more information on the evaluation of fitness to drive.[7] The challenge for the treating physician is to explain the conditions that may reduce driving safety to the PWD (and caregivers), who may at times have difficulty believing that he or she is no longer safe to drive, especially if an accident has not yet occurred.

The conversation has to be tailored to the person's level of understanding and emotional state. It is important to involve caregivers in the process, educate them about the PWD's risks, and mobilize their support for the recommendation to cease driving. The legal responsibility of the physician may need to be explained, as well as the need to protect the PWD and others on the road. In unfortunate cases, there may be no time to adequately prepare the PWD/caregiver for this discussion, and the recommendation to stop driving may have to be "imposed" if it is deemed there is considerable driving risk for the PWD. Reinforcement with caregivers and finding

solutions to prevent the PWD from having access to a car may be necessary. The PCP needs to facilitate access to alternative transportation by mobilizing resources such as volunteer drivers or a form of accessible paratransit system (if available) for persons with disabilities (in Ottawa, it is called Para Transpo).

Ideally, the process should be handled in a sensitive, effective, and timely fashion in order to avoid negative outcomes. Ultimately, the manner in which the bad news is disclosed and support is given will shape the reactions of the PWD/caregiver, as well as the clinical outcomes. The physician should empathize with the PWD/caregiver, and acknowledge that the news will result in a significant impact on the PWD's life. When the disclosure is conducted in an effective manner, it can lessen the negative impact on the PWD's well-being, reduce the caregiver's stress, and maintain the integrity of the patient-physician relationship. It is recognized that this can be a time-consuming discussion and that a physician's office is often very busy. Time may need to be booked for a separate visit. In some provinces, such as Ontario, a billing code is available that can be used for assessment and counselling around driving. In addition, there is a fee code for filling in the appropriate form to inform the ministry of potentially unsafe drivers.

Our research has shown that in the domain of dementia, PWDs are often left with strong emotional reactions when they lose the driving privilege.[8] Some patients feel this is as bad as or worse than receiving a diagnosis of cancer. Normal grief reactions such as shock, disbelief, and anger are common. Driving cessation can also result in feelings of helplessness and depression.[9] Finally, there is evidence that driving cessation is an independent risk factor with a negative impact on the PWD's ability to live independently, at times precipitating entry into a long-term care facility.[10] Based on interviews with PWDs and caregivers in our qualitative study,[8] investing time in preparing for the possibility of driving cessation, especially for progressive conditions such as dementia, is needed both for the PWD/caregiver and the physician.

Driving cessation may have serious consequences for the person's daily life routine and various domains of their quality of life. These may be unavoidable and imminent in acute conditions such as a stroke. Generally, preparation for the eventuality should be considered for all those who are aging. Physicians should receive training and practise effective disclosure skills to ensure competency in approaching this issue in a sensitive manner. It is a conversation that may require time, resources, and, as mentioned, several visits to debrief. Thus, it is not surprising that many physicians find these discussions uncomfortable or tend to avoid them.[11] We hope that the following outline may assist PCPs with this challenging aspect of dementia care.

How to Prepare for the Discussion

Several steps can be taken to prepare for the discussion with the PWD and caregiver:

1. Ensure that the diagnosis of cognitive decline (mild cognitive impairment, dementia, and sub-type of dementia) is accurate and communicated to the patient (and caregivers) in a clear, understandable, and compassionate manner.[12]
2. Counsel those who have suspected early cognitive loss (e.g., mild cognitive impairment) that driving cessation may occur in the future. Explain that they have a progressive condition that will likely result in future driving cessation in order give them as much time as possible to explore an alternative transportation plan and to gradually adjust to the transition.
3. Document the results of evaluations of cognitive decline and how they may impact on driving safety (i.e., divided attention, reaction time, etc.).
4. Possibly discuss the recommendation to cease driving first with the caregivers, in order to explore the potential impact of this recommendation on the PWD and to develop strategies to best approach this discussion with the individual. Many PWDs lack insight and awareness of how the condition can affect their personal safety and public safety. Caregivers may be able to offer advice and support to help the PWD accept this difficult recommendation.
5. Be aware of your own discomfort in having to discuss this issue with PWD. Anticipate strong reactions and emotions. Be prepared to elaborate on the results of the testing and the diagnosis and how they impact driving safety.

Back to Mr. R.

In Mr. R.'s case, unfortunately there was little time to prepare, given that he had already received his letter from the Ministry of Transportation by mail, which likely accentuated his emotional response to the sudden loss of his driving privilege. Likely Mr. R. had early cognitive loss that was undetected prior to the hospitalization, and a thorough evaluation and assessment of any remediable factors (e.g., medications affecting cognitive function, metabolic derangements such as hypothyroidism, or medical conditions such as sleep apnea) should have been completed. Ideally, if there were any concerns raised prior to his hospital stay about his cognition, driving safety should have been assessed (refer to Driving and Dementia Toolkit for Health Professionals,[7] available at www.rgpeo.com). At that time, if deemed safe, the health practitioner conducting the assessment should have prepared Mr. R. and his family for the possibility of him not driving in the future and developed an alternative transportation plan for the eventual progression of his condition. If he was deemed not safe to drive, then a sensitive disclosure discussion should have taken place as outlined below.

Disclosure of Cessation Meeting

The PCP should be mindful of the following when meeting with the PWD and caregiver to discuss driving cessation (Figure 1) (adapted from Byszewski et al.[8]):

1. If possible, schedule a separate appointment for the discussion of driving safety.
2. Empathize with the PWD (and caregiver) and convey that you understand this is a very difficult recommendation with potentially great impact on the quality of life, but that it is your clinical, moral, and legal responsibility to address the risk. Emphasize that this is a recommendation made based on a detailed and comprehensive evaluation and, if necessary, reiterate

Figure 1. When meeting with a person with dementia to discuss driving cessation, empathize with the patient and convey that you understand this is a very difficult recommendation with potentially great impact on the quality of life, but that it is your clinical, moral, and legal responsibility to address the risk.

the basis on which the recommendation is made.

3. Expect normal grief reactions, which may include anger, bargaining, depression, and a sense of demoralization. Show empathy and be prepared to deal with emotions that arise.
4. Note that it may be easier for the PWD to accept recommendations that are based on physical impairments, such as vision loss or medication use (or adverse effects of medications).
5. Be prepared to offer transportation alternatives; discuss a subsidized transportation system for persons with disabilities, volunteer drivers, taxis.
6. Be firm yet empathic, and avoid getting into argumentative discussions. Emphasize your ethical and legal responsibilities, and the fact that dementia is a progressive and irreversible condition.
7. If necessary, explore with caregivers ways to deter the PWD from

driving. This may include removing the keys or disabling or physically removing the car.

8. To help preserve the patient-caregiver-physician relationship, refer to another physician, such as a neurologist or geriatrician, for a second opinion, if needed.

In Mr. R.'s Case

If Mr. R. has now progressed to dementia, it is possible that he has difficulty understanding and accepting the diagnosis. An example of how the discussion can proceed is as follows:

You, the physician: *Mr. R. you are a responsible person, and I suspect you were an excellent driver. I am sorry, but now, you have a new condition, dementia (e.g., Alzheimer's disease or mixed dementia), that unfortunately affects how quickly you can react in a sudden situation or how you can shift your attention. These are very important skills for safe driving in today's busy traffic. It is my medical and legal obligation to ensure you don't drive, so that you or others on the road don't get hurt.*
Mr. R.: *But I only drive to the grocery store two blocks away and to the church close by.*
You: *Yes, it is good that you have limited your driving. Unfortunately, most accidents occur close to home on busy intersections. Hopefully, you and your caregivers can look at alternatives to get you around, and make sure you can get out and do the things that are meaningful in your life. Here is some information for you and your family about the services available to you to help you develop an alternative transportation plan. I'll see you in 2 weeks to make sure your needs are met and you are adjusting well.*

You might also offer to refer Mr. R. to the local Alzheimer Society office to support him during the transition, and may provide materials for Mr. R and his caregivers: The Driving and Dementia Toolkit for Patients and Caregivers (paper copy or online at www. rgpeo.com).

Key Points

- *Driving fitness must be evaluated in older individuals with cognitive loss as intact cognition is essential for safety in operating a motor vehicle. Those who experience mild cognitive impairment or early dementia (if still deemed safe to drive) must be prepared for the possibility of eventual driving cessation. A plan for alternative transportation should be put in place as soon as possible in the eventuality of progression.*
- *The discussion must be held with PWDs and their caregivers in an efficient and empathic manner. If necessary, the physician should employ the support of caregivers in ensuring the recommendations are acted on. Communication should be clear and in both verbal (and ideally) written forms. Documentation by the PCP is important, given legal liability.*
- *Follow-up is essential to ensure that a PWD is adjusting and utilizing resources that are provided, and to monitor for emerging depression.*

Follow-Up

Several steps should be taken by the PCP subsequent to the disclosure meeting:

1. Provide a letter to the PWD explaining the reasons for driving cessation. This can also help the caregivers refer to a written account of what was discussed, should the PWD forget.
2. Clearly document the date and the content of the discussion regarding driving cessation, as well as the names of the caregivers present. This is strongly recommended, given the negative reactions of some patients (e.g., anger toward the physician, the threat of legal action) and the fact that some PWDs continue to drive despite a recommendation to stop.
3. Establish that an alternative transportation plan has been instituted and provide a list of alternative transportation resources.
4. Follow up on the PWD's reaction; monitor for depression and adjustment. Refer the PWD to community organizations, such as the Alzheimer Society, for education and support to help with this challenging transition.

Follow-Up Visit for Mr. R.

Mr. R. comes back to see you in 2 weeks. He is still very upset and keeps asking his caregivers for the keys to the car. You empathize with Mr. R., acknowledge his loss, explore the impact that driving cessation may have had on him and his caregivers. You reiterate the rationale for the decision. In rare cases, a disgruntled PWD may need to be referred for a specialized on-road driving test by an occupational therapist to settle this matter. Monitor for the signs of depression and, as necessary, refer Mr. R. to appropriate community support services. The caregivers have used the notification letter from the physician to remind Mr. R. why he can no longer drive. They have set up a list of volunteer drivers, and they have also developed a roster of drivers to be available to ensure Mr. R.'s daily needs are met and that he remains socially active.

Conclusion

The above recommendations serve as a general framework for the discussion about driving cessation. Obviously, they need to be tailored to the specific situation of each PWD. A key message of this article is that the implications for the PWDs and their caregivers can be enormous. These include a need for relocation from a rural to an urban setting, the use of support services to deliver food and medications, and arrangements for alternative transportation means for medical appointments and social events. Thus, as mentioned earlier, the recommendation should be taken very seriously and must be based on a thorough medical evaluation. It is important to remember that age alone is not a valid indicator of driving competence and safety. Driving cessation must be based on sound evidence and communicated in a compassionate and effective manner.

Research has shown that physicians lack confidence in performing driving assessments and discussing the recommendations, and are concerned that this can impact the patient-physician relationship.[13] With practice, PCPs can develop this competency in dementia care and can ensure that, as an increasing number of their patients develop

dementia, they are well prepared in addressing this important area of dementia care. There is emerging evidence that educational strategies to increase physicians' skills (i.e., vis-à-vis assessment and disclosure of a dementia diagnosis) can have a positive effect on physicians' perspectives and practices.[14]

With the increasing number of older drivers on the road, preparing seniors for the possibility of future driving cessation and holding the "driving retirement" discussion is a skill PCPs must receive training and practice in, so that they can broach the subject in a sensitive and competent manner.

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