SHORT REPORTS

Care Partner Perspectives on Driving Cessation in Dementia in the Province of Saskatchewan, Canada

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ABSTRACT

Driving cessation is an expected eventuality in dementia care that has significant consequences for people with dementia (PWD) and care partners (CPs) alike. In collaboration with the Alzheimer Society of Saskatchewan, we explored CPs' experiences of the driving cessation process. Using an online survey including closed- and open-ended questions, we collected data from 44 CPs of current drivers and from 207 CPs of former drivers. Our quantitative and qualitative analyses identified three key findings. First, although CPs want and expect regulatory bodies and medical practitioners to be involved in the driving cessation process, their involvement is often less than anticipated. Second, driving cessation poses unique challenges to CPs in rural areas given the centrality of driving in smaller communities and limited transportation options to access services. Finally, CPs of former drivers found several positive benefits from the driving cessation process that were unanticipated. In conclusion, these three areas represent opportunities for education, support, and resources for PWD, CPs, and professionals through the driving cessation process.

Key words: dementia, driving cessation, care partners, medical practitioners, regulatory bodies, rural, positive benefits

INTRODUCTION

The process of driving cessation is recognized as a significant challenge for people living with dementia (PWD), their care partners (CPs) and health-care providers.(1) In this process, CPs assume a myriad of roles including decision-making about driving, navigating the licencing regulatory system, providing alternative transportation, and managing the emotional impact of driving cessation for the PWD.(2–4) Although the significant care responsibilities, and emotional and psychological consequences of driving cessation on CPs are well-documented,(3–11) further understanding of their support needs, particularly for people living in rural areas, is needed.(5,6) In collaboration with the Alzheimer Society of Saskatchewan (ASOS), we aimed to explore CPs' experiences throughout the driving cessation process in a mixed rural and urban population. In Saskatchewan, licence renewals are required every five years, and changes in medical conditions, such as dementia, must be reported at the time of renewal. Physicians and other health-care professionals are required to report to the provincial driving authority any drivers who have medical conditions that may affect their driving. We also planned to assess gender differences in our findings, based on previous research.(12)

METHODS

Study Design and Participants

In December 2020, the ASOS distributed online surveys to two groups: CPs of PWD who were currently driving, and CPs of PWD who were no longer driving. The two surveys included the same questions with minor wording changes for applicability to each group. Ethics approval was obtained from the Baycrest Academy for Research and Education (REB#21-31).

Data Collection

The surveys (see Appendices A and B) were hosted on SurveyMonkey® and distributed via a weblink to 1,258 CPs in the ASOS client database and via an open call invitation on the ASOS Facebook page. Participation was voluntary. Due to survey distribution methods, the number of recipients is unknown and the survey response rate could not be calculated.

Baseline characteristics, open- and closed-ended responses, and multiple select questions explored four areas related to driving cessation: 1) challenges and concerns, 2) supports received, 3) needs/gaps, and 4) life impact.

Analysis

Baseline characteristics and closed-ended responses were analyzed using descriptive statistics. Differences between groups and gender differences were analyzed with Chi Square and Fisher's exact tests using SAS software, V9.4 (SAS Institute Inc., Cary, NC). Free-text survey responses were independently coded by two investigators (DS, ES) using NVIVO software, V12 (QSR International (Americas) Inc., Burlington, MA). Thematic analysis was performed using an inductive approach as described by Braun and Clarke.(13) Coding was compared between researchers and iteratively refined until consensus was reached.

RESULTS

Demographics

A total of 251 completed surveys were received, including 44 from CPs of current drivers with dementia, and 207 CPs of former drivers with dementia. Most CPs of current and former drivers with dementia were women, aged 60 years or older, and just over half identified as the spouse of the PWD. More CPs of PWD who continued to drive lived in smaller communities (< 20,000 residents) than CPs of former drivers (52.3 vs. 31.5%, *p*=.01) (Table 1). An equal number of participants reported that the PWD had stopped driving one to three years ago (41.09%) and greater than three years ago (41.09%). Driving cessation had stopped for 16.83% of PWD less than a year ago, and 0.99% indicated they were unsure as to when the PWD stopped driving. Most PWD no longer driving (67.01%) stopped driving either because a physician told them to, they failed a road test, or were required to by the driving regulator.

Quantitative Results

Analysis of the closed-ended questions revealed two key differences in survey groups regarding decision-making responsibility and positive outcomes from driving cessation (Table 2). CPs of current drivers with dementia largely expected family doctors (70.5%) to be involved in decision-making, followed by regulatory bodies (52.3%), and medical specialists (34.1%). The actual involvement of others in the driving cessation process was less frequent among CPs of former drivers than was anticipated by CPs of current drivers: family doctors (34.0% vs. 70.5%; *p*<.0001) and regulatory bodies (30.5% vs. 52.3%; *p*=.0083). When asked if anything postive had come from or was anticipated to come from driving cessation, CPs of former drivers were more likely to identify something positive (56.9%) than CPs of current drivers (36.1%, *p*=.0171). Analysis by gender did not reveal any significant effects.

Qualitative Results

Through our analysis of the open-ended questions, we identified the following three key themes, which reflected the responses above (see Table 3 for exemplar quotes).

Significance of Medical and Regulatory Involvement

CPs of current drivers with dementia provided few comments about medical and regulatory involvement in the driving cessation process, in contrast with CPs of former drivers, who emphasized their importance. Having a physician make the recommendation to stop driving and/or connect the PWD to the driving authority for a driving assessment

TABLE 1.
Survey demographics

		Person with Dementia Driving (N= 44)	*Person with Dementia Not Driving (N=203)*	*Statistic P value*
Care Partner Gender *n (%)*	M	8 (18.2)	50 (24.6)	Fisher's Exact Test *p*=.54
	W	36 (81.8)	152 (74.9)	
	Other	0 (0)	<5 (<1)	
Care Partner Age *n (%)*	<60	14 (31.8%)	51 (25.1)	χ^2 (1)= 0.836 *p*=.36
	60+	30 (68.2)	152 (74.9)	
Relationship to PWD *n (%)*	Spouse/Partner	23 (52.3)	115 (56.7)	Fisher's Exact Test *p*=.65
	Child	14 (31.8)	65 (32.0)	
	Other Relative	5 (11.4)	13 (6.4)	
	Other Non-Relative	2 (4.6)	10 (4.9)	
Residence of PWD *n (%)*	Own home	39 (88.6)	118 (58.1)	χ^2 (1) = 14.53 *p*<.0001
	Other (Assisted living, personal care home, LTC)	5 (11.4)	85 (41.9)	
Size of Care Partner's Community *n (%)*	Larger community (20,000 or over)	21 (47.7)	139 (68.5)	χ^2 (1) = 6.82 *p*=.009
	smaller community (under 20,000)/ other	23 (52.3)	64 (31.5)	

was immensely helpful in addressing driving cessation. It meant averting "chaos" and lessening potential blame on the CP. Other CPs of former drivers reported that support from the medical/regulatory community was lacking, indicating, for example, that physicians were "hesitant" to contact the licensing organization, who were also deemed "unhelpful". Overall, involving both physicians and the driving authority was frequently mentioned as a recommendation to ease the decision-making and transition to non-driving for CPs and drivers with dementia.

Unexpected Positive Outcomes From Driving Cessation

CPs of current drivers expected that they would feel a sense of relief after driving cessation in knowing that the PWD was safe. While feelings of relief were echoed by CPs of former drivers, they also described other, unexpected positives, such as savings on gas and car insurance, and a strengthened relationship through increased quality time spent with the PWD. Several CPs talked about driving cessation as a moment to recognize that the PWD needed more help, facilitating access to care and support. Some felt they gained control over a previously out-of-control situation, and experienced an improved quality of life post-driving.

Centrality of Driving in Rural Communities

Driving was noted to be particularly integral to life in rural areas as a means of accessing the community and maintaining independence. Both groups of CPs frequently mentioned rural driving cessation challenges, which included the lack of alternative transportation options. CPs of former drivers described the stress of being the sole driver over long distances, with some relocating to the city to access services. However, CPs of current drivers also described feeling comfortable with the PWD driving in their small community, despite declining abilities.

DISCUSSION

Among the multifaceted implications of driving cessation, we highlight three notable areas in the CP experience. First, although medical and regulatory authorities are expected by CPs to play an important role in the decision-making process regarding driving cessation, our findings suggest that in practice their involvement is relatively low. Quantitative results indicate a marked difference between CPs of current drivers' anticipation of family doctors' involvement and their actual involvement as reported by CPs of former drivers. Qualitative results reveal a wide range of engagement with family doctors, health specialists and driving authorities, from no contact at all to support that significantly eased the decision-making and transition process. This inconsistency in family doctors' responses and lack of driving safety conversations has been documented elsewhere(14,15) and points to their discomfort and subsequent avoidance of driving cessation. Contributing factors include a lack of familiarity with driving assessments, legislative requirements and processes, and how to offer support, as well as fears of impacting the doctor–patient relationship.(16,17)

The immense relief and helpfulness reported by CPs when health-care providers and regulators were involved in the driving cessation process is consistent with previous research documenting CPs' awareness of changes in driving skills, but inability to address these changes personally.(10,18) The advice of these professionals not only carries more weight, but may also help CPs preserve their relationship with the PWD by shifting anger and blame away from CPs.(7) The frustration documented by CPs who did not receive support highlights the importance of system-level engagement in driving cessation decision-making, and the need to educate primary care providers about this issue.(16) In addition, CPs' references to requiring more support and involvement from

TABLE 2.
Selected survey questions

		Person with Dementia Driving	*Person with Dementia Not Driving*	*Statistic, P value*
Who do you think will be involved or who was involved in decision making regarding driving cessation? n (%)		*N= 44*	*N = 203*	
	Driving Regulatory Bodies	23 (52.3)	62 (30.5)	χ^2 (1) = 7.57, *p*=.0083.
	Family MD	31 (70.5)	69 (34.0)	χ^2 (1) = 19.96, *p*<.0001.
	Specialist	15 (34.1)	57 (28.1)	χ^2 (1) = 0.63, *p*=.43
Do you think there will be anything positive for you that might come out of your FM not being able to drive some day? /Has there been anything positive for you that has come out of your FM no longer driving? *n (%)*		*N= 39*	*N = 188*	
	Yes	13 (36.11)	107 (56.91)	Fisher's Exact Test, *p*=.0171
	No	8 (22.22)	44 (23.40)	
	Uncertain	15 (41.67)	37 (19.68)	

TABLE 3.
Example quotations

Theme	*Example Quotations*
Medical and Regulatory Involvement	“Doctor was a great help with first putting a restriction on the hours she could drive and then recommending to stop.” (Care Partner (CP) of Person with Dementia (PWD) No Longer Driving (NLD) “I called (driving regulatory organization)… (who) followed up with family member. Had I approached him, it would have resulted in chaos.” (CP PWD NLD) “I am actually glad the neurologist took the stance he did with (PWD) re. driving as it meant more than me asking him not to drive and hiding keys.” (CP PWD NLD) “When there is clear evidence that they should no longer be driving there should be less hoops and hurdles to go through to have license taken. Dr should be notified and that’s it! Not all this proof and back and forth liaison. Stop dad pretending not to have received notifications! Bull crap. Denying fact isn’t an option. Save a life or more.” (CP of PWD NLD) “The doctor was hesitant to send a letter to (Driving Regulatory Organization) and only did it when I had concerns about him hurting someone if in an accident again.” (CP of PWD NLD) “Don’t be afraid to let (Driving Regulatory Organization)/the doctors take the blame. Yes, we as family members are probably the catalyst for this change, but its an expert decision, not a cruel whim.” (CP of PWD NLD) “Talk to your family physician to start the evaluation process. My family physician was a God-send.” (CP of PWD NLD) “Perhaps (Driving Regulatory Organization) should be including some kind of relevant info to all drivers throughout their driving years.” (CP of PWD NLD)
Positive Outcomes	“It isn’t just about your loved ones, it is also about the others that are on the road that may be involved or around your family member that may be injured if something were to happen.” (CP of PWD Still Driving) “I no longer have to worry about her constantly- where she has been and what she is doing. I know she is safe in her assisted living retirement community. My mom no longer driving has been a big support to me.” (CP of PWD NLD) “We have bonded more. I don’t golf but enjoy taking her. She says she’s the only one in town with a caddy.” (CP of PWD NLD) “We have special moments that are very sweet and also sad. It has brought us very close.” (CP of PWD NLD) “Recognizing the significant impact dementia was having and getting him into care that was appropriate” (CP of PWD NLD) “Less financial dealings etc. with (Driving Regulatory Organization), payments, etc. Less cost to family member due to not owning a vehicle.” (CP of PWD NLD) “I’m more comfortable with me driving as I have more self-confidence.” (CP of PWD NLD)
Rurality	“Arranging for transportation to appointments and other social opportunities will be difficult in a rural community - and difficult for me to schedule with my own full time job.” (CP of PWD SD) “What does a person do who lives in a small rural community or on a farm where there is no easy access to transportation or where the family member lives a distance away? We need to remind ourselves that we are helping to keep people safe.” (CP of PWD NLD) “I am now the only driver for medical trips for my husband… 600 to 800 km from my community.” (CP of PWD NLD) “Move into town or neighbouring city if his dementia declines slowly. We will be ready to move to senior living where we would not be responsible for maintenance and maybe even meals, where there are handivans or taxis.” (CP of PWD NLD) “Living on a farm means driving is the only way to physically access the community. Also, no longer driving on a farm is very difficult for her as driving is integral to most of our work activities.” (CP of PWD NLD) “Driving is so integral to our independence on the prairies.” (CP of PWD NLD) “When the time comes, my husband will stop driving. At present he only drives 5 blocks one way to two locations in our small town of 1500 people.” (CP of PWD SD) “So far she also has been able to drive when she wishes. Smaller community. Most driving is done during week in off peak traffic times.” (CP of PWD SD)

driving regulators (e.g., clarity about driving assessments and reporting processes), highlight the need to broaden the role of driving regulatory bodies.(14,16)

Given the largely negative view that the loss of driving privileges holds for PWD and CPs,(14,18) our second notable finding was the unexpected positive outcomes of driving cessation reported by CPs of former drivers. Similarly, a recent study also found that PWD who had stopped driving reported more positive impacts from driving cessation than PWD who were still driving.(18) In addition to reductions in stress and anxiety, participants in the current study described financial and relationship benefits, as well as decreased caregiving burden. Highlighting these positive benefits to affected individuals and the general public may help minimize negative associations and normalize driving cessation.(14)

Finally, the challenges of driving cessation in rural areas were notable in our data, as a large proportion of participants resided in rural communities. The lack of available alternative transportation was reported to be a major burden, marking the unique significance driving holds in rural communities,(19) where public transportation options are limited or non-existent.(3,5) These challenges may contribute to some rural primary care providers' reluctance to discuss driving cessation or refer drivers for evaluation.(20) For PWD living in rural communities, the potential need to relocate should be considered early in planning for driving cessation.

Study limitations include the smaller number of respondents supporting PWD still driving compared to CPs of former drivers, and the small number of men, which may have limited our power to identify significant gender differences. The results are exploratory and based on a convenience sample, with no sample size calculation, power analysis or correction for multiple comparisons.

CONCLUSIONS

The driving cessation process involves significant challenges for PWD and CPs. However, increased involvement from medical providers, clear information from regulators, a focus on the potential positives from driving cessation, and increased support for people in rural communities, present opportunities for improvements in the process, as well as for further study.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood the *Canadian Geriatrics Journal*'s policy on conflicts of interest disclosure and declare that the authors have no conflicts of interest.

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APPENDIX A. Survey A: Care Partner of Person with Dementia Still Driving

I. Respondent Information

1. Do you currently support a family member (FM) with dementia who is still driving? *(Yes, No)*
2. What is your gender? *(Male, Female, Other)*
3. What is your age? *(Under 20 years, 20 to 39 years, 40 to 59 years, 60 to 79 years, over 80 years)*
4. What is your relationship to the FM with dementia that you are supporting? *(Spouse or partner of FM, Child of FM, Relative of FM, Other)*
5. Do you reside with the FM with dementia that you are supporting? *(Yes, No, Other)*
6. Where does your FM currently live? *(In their own home, In an assisted living facility, In a personal care home/private care home, In a long term facility, Other)*
7. What is the size of the community you live in? *(Large urban city – 80,000 to 250,000, Small city – 20,000 to 79,999), Small community (1,000 to 19,999), Rural community – under 1,000), Other)*

II. Driving History of Family Member with Dementia

8. How long has your FM been driving? *(Less than 20 years, 20 to 39 years, 40 to 59 years, greater than 60 years, Unsure)*
9. How often does your FM drive? *(Everyday, 1-2 times per week, Other)*
10. When your FM stops driving, what forms of transportation will they likely utilize? *(Walking, Public bus, Community transportation service, Rides from spouse or partner, Rides from adult children, Rides from extended family and friends, Community transportation services, Other)*

III. Decision Making and Planning

11. How will you know when it is time for your FM to stop driving? *(FM is told by their family physician and/or medical specialist to stop driving, FM is required to give up their driver's license by the driving regulator and/or fails their driving assessment test, FM indicates that they no longer want to drive or are unable to drive, FM demonstrates declining ability to drive, FM is involved in one or more motor vehicle accidents, FM receives tickets for traffic violations more frequently, Other)*
12. Have you and your FM made any plans and/or decisions about how and when they might stop driving some day? *(Yes, No, Uncertain)*
13. If you and your FM have made plans and/or decisions about stopping driving, what are they? (open-ended response)

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    ____

    ____

14. If you and your FM have not made any plans and/or decisions about how and when they might stop driving, what supports would help you to do so? *(Information about the impact of dementia on driving and why my FM may have to stop driving, Information about how to have discussions with my FM about stopping driving, Open conversations with my FM's doctor(s) about stopping driving, Talking with a staff member from the Alzheimer Society about dementia and driving, Talking with others who have been through the same experience with their FM, Other)*
15. When your FM needs to stop driving, who do you think will be involved in the decision-making process? (*Driving Regulator and/or Driving Assessment Centre, Family physician, Medical specialist, Other health care professional, Spouse or partner, Children of FM, Other)*

IV. Key Challenges and Supports

16. What concerns and/or challenges do you face around your FM's driving? *(Uncertainty about what I should do about my FM continuing to drive, I don't know where to get information about driving and dementia or who to contact, Concerns about the safety of my FM when driving, Concerns about others who might be hurt if my FM was involved in a motor vehicle accident, Concerns about my FM getting lost while driving, Resistance from my FM to give up driving, Disagreements with other family member about the ability of my FM to drive, I do not have any concerns or challenges about my FM's driving, Other)*

17. What do you think will be the most difficult challenges for you when your FM stops driving? (*Having to be the primary provider of transportation for my FM, Having to get alternative transportation in place for my FM, Dealing with the emotional impact of not being able to drive on my FM, Dealing with the social impact of not being able to drive on my FM, Having no one to talk to about how I could best support my FM during this time, I don't anticipate having any significant challenges when my FM stops driving, Other)*
18. What supports have you received to help you when your FM stops driving? *(Information about how to emotionally support my FM, Information about how to keep my FM socially connected within their community, Information about how to have discussions with my FM about their transportation needs and options, talking with my FM's doctors about how I could help my FM cope when they stop driving, Talking with a staff member from the Alzheimer Society about how to support my FM, Talking with others who have been through the same experience with their FM, I have not received any supports to date, Other)*
19. What might make supporting your FM easier for you when they stop driving? (open-ended response)

V. Personal Impact

20. How has your life changed since your FM stops driving? (open-ended response)

21. Do you think there will be anything positive for you that might come out of your FM not being able to drive some day? (Yes, No, Uncertain).
22. If you answered 'yes' to question 21, what positive things may result for you when your FM is no longer driving? (open-ended response)

23. What advice or encouragement would you give others about supporting a FM with dementia who is still driving? (open-ended response)

APPENDIX B. Survey B: Care Partner of Person with Dementia No Longer Driving

I. Respondent Information

1. Do you currently support a family member (FM) with dementia who is no longer driving? *(Yes, No)*
2. What is your gender? *(Male, Female, Other)*
3. What is your age? *(Under 20 years, 20 to 39 years, 40 to 59 years, 60 to 79 years, over 80 years)*
4. What is your relationship to the FM with dementia that you are supporting? *(Spouse or partner of FM, Child of FM, Relative of FM, Other)*
5. Do you reside with the FM with dementia that you are supporting? *(Yes, No, Other)*
6. Where does your FM currently live? *(In their own home, In an assisted living facility, In a personal care home/private care home, In a long term facility, Other)*
7. What is the size of the community you live in? *(Large urban city – 80,000 to 250,000, Small city – 20,000 to 79,999), Small community (1,000 to 19,999), Rural community – under 1,000), Other)*

II. Driving History of Family Member with Dementia

8. How long has it been since your FM stopped driving? *(Less than 1 year, 1 to 3 years, Greater than 3 years, Unsure)*
9. How long did your FM drive prior to stopping? *(Less than 20 years, 20 t0 39 years, 40 to 59 years, Greater than 60 years, Unsure)*
10. What forms of transportation does your FM currently utilize? *Rides from spouse or partner, Rides from adult children, Rides from extended family and friends, Community transportation services, Other)*

III. Decision Making and Planning

11. How did you know that it was time for your FM to stop driving? *(FM was told by their family physician and/or medical specialist to stop driving, FM was required to give up their driver's license by Driving Regulator and/or failed their driving assessment test, FM indicated that they no longer wanted to drive or were unable to drive, FM demonstrated declining ability to drive, FM was involved in one or more motor vehicle accidents, FM received tickets for traffic violations more frequently, Other)*
12. Did you and your FM make any plans and/or decisions about how and when they might stop driving some day? (Yes, No, Uncertain)
13. If you and your FM made plans and/or decisions about stopping driving, what were they? (open-ended response)

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14. If you and your FM did not make any plans and/or decisions about how and when they might stop driving, what supports would have helped you to do so? *(Information about the impact of dementia on driving and why my FM may have to stop driving, Information about how to have discussions with my FM about stopping driving, Open conversations with my FM's doctor(s) about stopping driving, Talking with a staff member from the Alzheimer Society about dementia and driving, Talking with others who have been through the same experience with their FM, Other)*
15. When your FM stopped driving, who was involved in the decision-making process? (*Driving Regulator and/or Driving Assessment Centre, Family physician, Medical specialist, Other health care professional, Spouse or partner, Children of FM, Other)*

IV. Key Challenges and Supports

16. What concerns and/or challenges did you face when your FM stopped driving? *(Uncertainty about what I should do about my FM continuing to drive, Didn't know where to get information about driving and dementia or who to contact, Concerns about the safety of my FM when driving, Concerns about others who might be hurt if my FM was involved in a motor vehicle accident, Concerns about my FM getting lost while driving, Resistance from my FM to give up driving, Disagreements with other family member about the ability of my FM to drive, I didn't have any concerns or challenges when my FM was still driving, Other)*

17. What were the most difficult challenges for you when your FM stopped driving? (*Having to be the primary provider of transportation for my FM, Having to get alternative transportation in place for my FM, Dealing with the emotional impact of not being able to drive on my FM, Dealing with the social impact of not being able to drive on my FM, Having no one to talk to about how I could best support my FM during this time, I didn't have any significant challenges when my FM stopped driving, Other)*

18. What supports did you receive that helped you when your FM stopped driving? *(Information about how to emotionally support my FM, Information about how to keep my FM socially connected within their community, Information about how to have discussions with my FM about their transportation needs and options, talking with my FM's doctors about how I could help my FM cope when they stop driving, Talking with a staff member from the Alzheimer Society about how to support my FM, Talking with others who have been through the same experience with their FM, I didn't receive any information, resources and/or assistance when my FM stopped driving)*

19. What might have made supporting your FM easier for you when they stopped driving? (open-ended response)

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V. Personal Impact

20. How has your life changed as a result of your FM not driving? (open-ended response)

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21. Has there been anything positive for you that has come out of your FM no longer driving? *(Yes, No, Uncertain)*

22. If you answered 'yes' to question 21, what positive things for you have come out of your FM no longer driving? (open-ended response)

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23. What advice or encouragement would you give others about supporting a FM with dementia who is no longer driving? (open-ended response)

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