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### Driving and Patients With Dementia

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## Driving and Patients With Dementia

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# Driving and Patients With Dementia

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## Abstract

Driving is a symbol of autonomy and independence, eagerly awaited during adolescence, cherished during adulthood and reluctantly rescinded during old age. It is nevertheless an individual's privilege, not right, especially as driving may affect other drivers and pedestrians on the road. It is therefore not only the individual patient who is at stake but essentially the entire community. In this case scenario, we describe the situation that arose when a patient with multi-infarct dementia wanted to go for a drive and his son and grandson tried to convince him that he could no longer drive. What went wrong in the caregivers/patient interaction is presented. The futility of arguing with patients who have dementia is highlighted as well as the suspiciousness it may generate. Alternate actions that can be useful to avoid/avert the situation from escalating and having a catastrophic ending are discussed. Testing/evaluating patients with dementia for fitness to drive is also reviewed and a list of select resources is included.

## Keywords

Alzheimer's/dementia, anxiety, cognition, confusional states, caregiving and management

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## Objectives

At the end of this case study readers will be able to

1. Recognize why many patients with dementia can no longer drive safely.
2. Appreciate that withdrawing driving privileges has significant repercussions on the patient's autonomy, social life, ability to access daily necessities, health care, and to survive independently in the community, especially if the patient's spouse is unable to drive or the patient lives on alone.
3. Recognize that driving is an individual's privilege, not right.
4. Know how to avoid/avert potentially catastrophic situations when the patient should no longer drive and insists on driving.
5. Appreciate the difficulties involved in evaluating fitness to drive and recognize select tools for such an evaluation.

well controlled: sitting BP 132/78, no orthostatic drop, and HbA1C: 6.7%.

- Paul, Louis's son. They have been living together since Paul's wife died about 5 months ago.
- Peter, Louis's grandson, junior at college, visiting his dad and granddad.

## Scenario

It is Sunday afternoon. Louis, Paul, and Peter are watching a football game on TV. The game is slow, almost predictable. Louis is nodding off.

Peter says he is going for a drive. His father asks him where he is going. Peter replies that he is just going for a drive with his girlfriend. Paul starts cautioning his son about safe driving. Louis wakes up and says he wants to go for a drive, too.

Peter and Paul look at one another. They are worried. Paul says, "Dad, you can't drive." Louis responds, "Can't drive? Why not? There's nothing wrong with me and I don't need any one's permission to drive." Paul

## Case Presentation

### Characters

- Louis is a 67-year-old man, diagnosed with vascular dementia about 6 months ago, shortly after his wife's death. He has a long history of diabetes mellitus and hypertension. At present, both are

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counters, "Dad, your doctor said you couldn't drive." Louis cuts him off: "I don't remember seeing any doctor and what do doctors know about driving anyway. Just let them take care of patients and stop meddling."

Paul replies that Louis saw his family doctor who was concerned about his driving. He also patiently explains that recently Louis had been involved in several minor accidents: the garage door was clipped, a rose bush was run over, and about a week ago Louis received a warning ticket from a policeman because he ran a red light. Louis states categorically that all these accidents are other people's fault. He is a safe driver; in fact, he taught Paul how to drive.

The argument escalates. Paul states firmly, "Dad. You cannot drive. It is not safe. We will not let you drive the car." Angrily Louis says, "Son! This is my car. No one tells me when I can or cannot drive! I'll drive whenever and wherever I want to!"

Very upset Louis goes to the side of the door where the car keys are hanging and takes them. Paul grabs Louis' wrist. They both struggle for the keys. Louis defiantly slaps Paul on the face. Without thinking Paul retaliates by punching him. Louis falls backward, unconscious, blood oozing from his nose and mouth. A catastrophic ending.

## Case Analysis

### *Turning Points/Triggers That Led to This Aberrant Behavior Include*

*Peter stating he is going for a drive and the subsequent conversation with his father.* The statement Peter innocently made and the subsequent conversation with his father woke up Louis and triggered the entire episode. The family knew from a recent visit to his doctor that Louis should no longer drive.

*Could it have been avoided?* Rather than announce his intention of going for a drive, Peter could have gestured or just murmured to his Dad that he was going for a drive. He could have left while Louis was still sleeping and the entire episode could have been avoided. If his father wanted to caution Peter, he could have signaled to go next door and further discuss the issue without running the risk of waking up Louis.

*The car keys and car were clearly visible.* The car keys were kept in plain sight beside the door and the car was visible on the driveway beside the house. These visual signals reminded Louis of driving. Had these visual triggers not been so obvious, it is possible Louis would not have thought of driving especially if Paul and Peter did not discuss the issue of driving when he was nearby, even if he appeared to be sleeping.

*Could it have been avoided?* Given that Louis is not allowed to drive, these triggers should have been

minimized or hidden so as not to arouse his wanting to go for a drive. The car keys could have been kept out of sight and the car parked where it could not be seen from the house.

If the patient cannot drive safely and no one else will drive that car on a regular basis, it could be removed from the property, disabled, or hidden. If the car has to be left in plain view, fake keys could be left by the door or a nearby drawer so that if the patient used that key he will not be able to get access to the car.

*Paul confronted his father directly with the prohibition about driving.* Telling patients with dementia that they cannot engage in some activity may trigger restiveness and suspicion and is likely to elicit negative, sometimes violent reactions. The patient often feels victimized and accuses others of plotting against him. Every effort must be made to avoid even the appearance of "ordering" or "telling" patients what to do or what not to do.

*Could it have been avoided?* Confrontations often trigger paranoid delusions: the patient feels victimized and accuses others of plotting against him. Rather than telling Louis that he cannot drive because of doctor's orders, Paul could have found some other credible excuse for not letting Louis drive, such as, the car is disabled and needs to be towed to a mechanic, or that there is not enough gas in the car or some other excuse to justify that the car should not be driven by anybody, not only by Louis. The restriction therefore applies to everyone and is less likely to have a negative impact: Louis is no longer the only victim.

*An argument developed on whether Louis should/could drive.* Paul and Peter found themselves sucked into an argument with Louis on whether or not he should/could continue to drive.

*Could it have been avoided?* Arguments with a patient who has dementia should be avoided, as there is no way of rationally convincing a patient with dementia and winning the argument. Patients with dementia are not able to retain new information in their working memory and use their fund of knowledge to come up with a valid counterargument. Besides any point made is quickly forgotten, so arguments end up being circular.

Once the caregiver realizes that an argument is about to develop or is developing the patient should be distracted as soon as possible by bringing up a totally unrelated issue such as how comfortable his shoes appear to be, or how unusual is the pattern of the shirt he is wearing or that his hair looks good or needs trimming or that his eye glasses are dirty and offering to clean them, or showing him some old photographs that have "just" been found.

Equally important, before the patient has time to respond to the distractor, an alternate activity should be suggested to distract him. For instance, he could be

invited to go for a walk, or watch an old movie, have something to eat or drink or get involved in some other activity. In this manner, the patient's energy is redirected and focused on something different than driving.

Asking the patient for his advice about an issue such as a drawer not closing, a light that cannot be switched on or some other minor problem has the added advantage of making the patient feel needed, relevant and important. Chances are high that once distracted he'll forget that he wanted to go for a drive.

*The argument gradually escalated and ended up with a physical confrontation.* It is easy for tempers to flare up as an emotionally loaded argument unfolds. Louis felt very strongly that there is no valid reason for him to stop driving and refused to accept all the evidence his son and grandson produced and the recommendations made by his physician. There is no way this argument could be won by either side. To prove his point Louis grabs the car keys and is about to get to the car. At this stage, Paul has no other option but to physically interfere and try to forcibly extract the car key from his Dad's hand. Very upset, Louis slaps his son who involuntarily retaliates by punching his Dad who loses consciousness and starts bleeding.

*Could it have been avoided?* Once an argument starts developing caregivers should try to change the conversation. The purpose is to distract the patient from the wanted activity: to drive his car. To be effective this has to be done as soon as possible after the argument starts to develop. The longer this is delayed the more difficult it will be. Given that patients with dementia are easily distracted and have an impaired memory especially for recent events, these symptoms of the underlying disease can be exploited to avoid or defuse a potentially catastrophic situation. The family could try to distract Louis from his wish to drive the car. They may have, for instance, suggested they go for a walk, or get involved in some activity Louis enjoys or have a drink or something to eat. It is always useful to have a list of chores the patient enjoys doing and from which he derives a sense of relevance and importance. These chores will depend on the patient's background, hobbies, and skills. But even someone with minimal skills could get involved in a number of activities such as organizing a drawer, sorting out magazines, cutting out coupons, or folding laundry.

These activities could be used as distractors. Given the short attention span associated with dementia it is likely that once distracted from the initial desire to drive, Louis would have forgotten he wanted to go for a drive.

If the patient refuses the bait of distraction and still insists on driving the car, another ploy caregivers can use is to postpone the wanted activity: driving the car. They may for instance ask Louis to first help them with some chore that has to be done that day and cannot be postponed any further.

## Case Discussion

### 1. Scope of the problem

Road traffic accidents are the leading cause of injury-related deaths in adults aged between 65 and 74 years and the second commonest cause of death (after falls) in those 85 years old and older (American Geriatrics Society & Pomidor, 2016). It is estimated that the risk of being involved in a road traffic accident increases by twofold to eightfold in patients with dementia when compared to age-matched controls (Dubinsky, Stein, & Lyons, 2000). However, many patients with dementia are able to drive safely, some for prolonged periods, especially in a well-known familiar territory (Bennett, Chekaluk, & Batchelor, 2016; Ott et al., 2008).

One must nevertheless emphasize that even when driving in a very familiar, well-known territory, the traffic conditions may suddenly change: a child may run in front of the car, there may be a commotion on the side of the road, the road may be closed and a detour enforced, another car may suddenly overtake and cut in front of the car driven by the patient, a motorcyclist or cyclist may suddenly appear, a pedestrian may jaywalk, and several other unexpected factors may distract the patient, who, given the often slow reaction time associated with aging and aggravated by dementia, may not be able to respond satisfactorily in a timely manner.

Being able to drive often is an essential necessity for maintaining independence in the community. Withdrawing a patient's driving privileges, therefore, has significant psycho-socio-economic repercussions. Driving privileges, therefore, should not be automatically withdrawn once a diagnosis of dementia is made (Man-Son-Hing, Marshall, Molnar, & Wilson, 2007). However, the patient's need for independence must be weighed against the risk of getting involved in a road traffic accident. There is, therefore, a need to assess the patient's safety while driving. A number of assessment tools are available, some are listed below.

Most patients with dementia will eventually have to stop driving because they become hazards to other drivers, pedestrians, and also themselves. In the meantime many patients with dementia are oblivious of their impaired skills and even of the several accidents they may have caused while driving. They often refuse to accept their limitations and insist on continuing to drive.

Driving is often a sensitive issue that patient, caregiver(s), and often health care professionals avoid discussing. A conspiracy of silence often develops and persists even when it is blatantly obvious that the patient should not continue to drive. First, the patient often refuses to admit that his driving skills have deteriorated and usually blames other drivers or road conditions for the accidents sustained.

Second, the patient's close family may avoid bringing up the issue of driving because they fully realize that if the patient stops driving, the close family will become

the “taxi service” for patient and spouse. In most instances, given their other responsibilities, commitments, and tight schedule, most people are very reluctant to accept this added responsibility. So, even if the issue of safe driving is brought up, the patient’s family may gloss over it and minimize the potential hazards.

Third, clinicians and health care providers are often reluctant to bring up driving issues, not only because they may not have received formal training in this area, but especially because unlike most other medical ailments which may be managed by some medication; clinicians have no medication to offer patients whose driving has deteriorated to the extent of being a hazard to the patient and community. The only available remedy is for the patient to stop driving. But as already mentioned, this is a decision that has many widespread ramifications for the patient, caregivers, and loved ones. So the discussion about the patient’s safe driving and decision to withdraw driving privileges is often postponed sine die.

## 2. Skills involved in “safe” car driving

Driving is a highly coordinated and sophisticated activity demanding constant and full vigilance and awareness of the ever changing immediate and remote environment. The safe driver anticipates and takes appropriate action to adjust to changes in the flow of traffic caused by other drivers, the conditions of the road and even the weather as may happen when there is a sudden outpour of rain or when a storm suddenly erupts.

Safe driving demands intact cognitive functions, focused attention, and sharp reflexes. This is particularly the case given the number of cars on the road, potential speed of cars, long-distance driving, and advertisements by the road side. Furthermore, there are multiple potential distractors inside the vehicle such as information conveyed by various instruments including speed and gas efficiency, inside and outside temperatures, gas and oil level, engine temperature, as well as other controls for the car entertainment system. Using cell phones and texting by the driver and other drivers also increase the likelihood of distraction and, therefore, may interfere with “safe” driving.

Patients with dementia have to overcome several handicaps to drive safely including agnosia, apraxia, easy distractibility, short attention span, impaired judgment, and lack of insight. These have been discussed in previous cases and are further discussed below.

Independently of dementia, however, other concurrent diseases also may affect safe driving, such as heart failure, chronic obstructive airways disease (COPD), various types of arthritis, anemia, polymyalgia rheumatica, easy fatigue and narcolepsy. Furthermore, the aging process, per se, adds a number of other handicaps to safe driving including impaired vision, impaired hearing, and slower reaction time.

The main obstacles to safe driving in patients with dementia include (American Medical Association [AMA], 2010; Bedard & Dickerson, 2014; Budson & Solomon, 2016; Dorgan, Hutson, Duvall, Kinser, & Hall, 2014; Tappen, Ramos, Newman, & Newman, 2017; Gergerich, 2016; Jahn, 2013; Piersma, de Waard, et al., 2016; Piersma, Fuermaier, et al., 2016; Sadowsky & Galvin, 2012; Molnar, Patel, Marshall, Man-Son-Hing, & Wilson, 2006; Rabins, Lyketsos, & Steele, 2016; Silverstein et al., 2016):

- a. **Agnosia:** the failure to recognize and appreciate in a timely manner the significance of various signs such as a red light, a stop, or a detour sign. Agnosia is one of the main features of Alzheimer’s disease and may prevent patients with dementia from accurately assessing the distance between their car and other cars on the road as well as their speed and hence when it is safe to overtake a car or change lanes.

Getting lost in familiar territory is one of the very first warning signs that the patient’s driving may be impaired. Because of the agnosia, the patient is unable to integrate in a timely manner various visual stimuli received, correctly determine where the car is, and, bearing in mind the ultimate destination, determine whether for instance to continue on that road or turn at the next intercession.

This process of integrating various stimuli has to be constantly revised, updated, and adjusted for the driver to safely reach the final destination. This process is much more difficult if there are unexpected changes on the road such as a side road being temporarily closed to the traffic and the driver having to find an alternate route to the destination. Similarly a road sign that has been removed or is less conspicuous for instance because of the foliage of a tree that is now blooming may confuse the patient who is now missing important reference points on his way to the destination.

- b. **Apraxia:** failure to take appropriate action such as slowing down or stopping at a crosswalk or at a red light. Apraxia also may interfere with the driver’s ability to respond in a timely manner to acute changes such as a person jaywalking, a dog running across the road, or even a policeman redirecting the traffic.
- c. **Easy distractibility:** the patient with dementia may be easily distracted by a pedestrian, a sign on the road or even an unusual license tag or display on the car ahead and may not have time to respond to a change such as the traffic light turning red.
- d. **Inability to process several rapidly changing stimuli simultaneously and effectively for instance:** looking at the road ahead, responding to what is in the rear view mirror, side mirrors, and adapting to the speed gauge and other information displayed on dash board. The patient may become

engrossed by any of these various stimuli and overlook that the traffic lights have changed.

- e. **Lack of insight and impaired judgment:** Because of impaired judgment the patient may change lanes, overtake, or perform other hazardous maneuvers on the road that are not safe given the surrounding circumstances. This is particularly likely to happen in patients with frontotemporal dementia. The patient may not notice he is driving in the wrong direction in a one-way street because he has not seen or has incorrectly interpreted the “No Entry” or “No right turn” sign.

### 3. Unpredictable factors affecting driver safety

Several factors, apart from those directly attributable to the underlying dementing illness, arise when evaluating safety to drive. Fluctuations in level of cognition and alertness, although cardinal features of Dementia with Lewy bodies, are also often seen in other types of dementia and may affect detrimentally the patient’s driving performance.

Other factors that may affect safe driving include the intake of medications, whether prescribed or purchased over-the-counter, food and fluid intake as well as a host of other factors such as the patient being upset, not having had a good night’s sleep the previous night, experiencing pain, discomfort, or just having a full bladder. Any of these factors may affect safe driving. Being unpredictable, these factors are difficult to incorporate in any test evaluating “Fitness to Drive.”

### 4. Pointers to “unsafe driving”

Minor accidents, frequently getting lost in familiar places, difficulties parking, hitting curbs, incorrect signaling, repeated moving violations or citations, driving too slowly, confusing gas and brake pedals, running out of gas, or not having enough money to pay for gas are indications that the person may not be a safe driver. This is especially the case if the person cannot give a rational explanation as to how these accidents occurred. A traffic ticket, even a warning ticket, is often the first sign that the patient’s driving may not be safe.

### 5. Increasing the safety of cars

The car industry has taken several steps to increase the safety of driving. Side cameras on both sides of the car ensure safe changing lanes, especially if the visual stimuli of traffic on either side of the care are accompanied by flashing lights and/or by auditory stimuli notifying the patient whether it is safe to change lanes. The safety of driving can be further enhanced if the car will not change lane—provided it is safe to remain in the original lane—unless the driver actually overrides the system. Similarly self-parking cars and front collision prevention systems

further enhance the safety of driving. Voice activated GPS systems are very useful to prevent getting lost while driving.

Probably the ultimate safety will be provided by driverless cars which hopefully will become available in the near future, thus affording independence and ensuring safe mobility.

### 6. Evaluating “Fitness to drive”

A number of “Fitness to Drive” tests are available. An important issue to consider, however, is that although a patient with dementia may be deemed to be a “safe driver” on the day the driving assessment and allowed to drive, it is not possible to predict for how long that patient will remain a “safe driver.” That patient may experience a sudden deterioration the day after the assessment and thus be no longer a “safe driver.” Another issue that needs to be considered therefore is, how often should the patient’s driving skills be evaluated. The following is a partial list of available resources:

#### a. Evaluation by Driver Rehabilitation Specialists (DRS) or Occupational Therapists

This comprehensive evaluation takes several hours to complete and encompasses a thorough clinical assessment followed by a Behind The Wheel (BTW) assessment. At the end of the evaluation patients are classified into one of the following categories (Silverstein et al., 2016):

- Continue to drive with no restrictions.
- Drive with restrictions, such as only daytime driving, no highway driving, limit speed and distance.
- Patient needs periodic review.
- Patient should no longer drive, assistance with community mobility may be recommended.

#### b. Tests of cognitive functions, single and composite

Several single tests and composite batteries of tests are available to evaluate the patient’s fitness to drive (Bennett et al., 2016; Molnar et al., 2006). A systematic review (Bennett et al., 2016) of 28 such tests, however, shows great variability in determining the relationship between test result and safety to drive, lack of consistency and even conflicting results especially when single tests are used.

The Mini–Mental State Examination (MMSE), in particular, is not sufficiently sensitive to differentiate safe from unsafe drivers (Bennett et al., 2016). Composite batteries of tests on the other hand show more consistency in establishing fitness to drive, especially if the various tests evaluate different cognitive domains. Unfortunately, however, none of the composite battery of tests examined in that review was able to discriminate sufficiently between “safe” and “unsafe” drivers. There is therefore a

need to develop a test or battery of tests to accurately and consistently determine capacity for safe driving.

- c. Fit2Drive algorithm (Tappen, Ramos, Newman, & Newman, 2017)

This free web-based algorithm takes into account patient's age, gender, MMSE score, and Trails B Test, in seconds and projects the probability of passing and on-the-road test.

- d. Driving Decisions Workbook—Roadwise review

A self-administered test developed by the American Automobile Association (AAA) and available online or by request from the AAA.

- e. The Driving Decisions Workbook

A self-administered test, available online and developed by the Transportation Research Institute at the University of Michigan.

- f. American Geriatrics Society and Pomidor (2016)

Free brochure available on the web, developed by the American Geriatrics Society, in conjunction with the U.S. Department of Transportation's National Highway Traffic Safety Administration (NHTSA) 2016.

- g. Useful Field of View Test (UFOV) (Edwards et al., 2006)

Can be used to identify deficits that may impair driving and can also be used to improve driving safety.

- h. State Licensing Agencies

Given that regulations, policies and laws vary by State and local jurisdiction and are subject to change, health care professionals should seek legal advice. Some, but not all States, have mandatory reporting requirements. Association of Driver Rehabilitation Specialists

- i. AMA Physician's Guide to Assessing and Counseling Older Drivers, Second Edition, 2010
- j. Simulated driving available at certain driving license offices.
- k. Driving with instructor available in certain districts.

- 7. Withdrawing driving privileges

The decision to revoke someone's driving privileges is a difficult one. It should not be taken lightly. The need for physical independence, particularly in rural areas, must be weighed against the possible harm that may result from driving, even if it is limited to local shops, Church or friends' homes.

Particularly difficult situations arise when the patient lives alone or with a spouse/partner who is physically disabled and not able to drive. In these instances, the only means of getting to stores and other places is by driving. Revoking driving privileges socially isolates the person. Safety, however, must be weighed against the need for social independence and the potential risk to other road users.

It also should be remembered that in many instances, especially in rural areas driving is the only means for the patient to continue living independently at home. Sometimes, the patient's spouse, partner, or caregiver is physically disabled and therefore relies on the patient with dementia to go shopping and keep the couple living at home.

Withdrawing driving privileges of older people, especially those living in rural areas socially isolates the patient and has a profound impact on the patient's self-esteem and ability to socialize. Withdrawing someone's driving privileges therefore has several ramifications and many implications that have to be taken into consideration and balanced against safety.

As the legal issues surrounding driving privileges vary from State to State and by local jurisdiction and are also subject to change, it is recommended that clinicians be familiar with the *modus operandi* of the particular State where they practice to avoid being subject to a third-party lawsuit (AGS, 2016).

- 8. A positive spin to transitioning from "driver" to "passenger"—changing the goal from "withdrawing driving privileges" to "ensuring transport independence" (AMA, 2010; Silverstein et al., 2016)

Withdrawing driving privileges is quite traumatic. Most patients vehemently resist it because of the status and advantages of having driving privileges. However, the potential nefarious consequences of allowing a patient with dementia to continue driving are so significant.

As sooner or later most patients with dementia will no longer be able to drive because of the hazards involved, a subtler, more gentle approach would be to change the goal from "withdrawing driving privileges" to "ensuring transport independence" and addressing it very early in the disease process with the full cooperation of the patient and family, in a way similar to selecting a person to have Durable Power of Attorney and addressing end-of-life issues. At that stage the patient, knowing that this will not be implemented immediately, but only when he will no longer be able to drive safely, will be more agreeable to entertain various options which even may include relocation.

Furthermore, this goal will be more readily accepted if reassessed whenever the patient's general condition is reviewed. It, therefore, becomes an integral part of the patient's management, on-going evaluation, and follow-up as opposed to being an isolated action that has



punitive implications. Most importantly, discussing this goal early in the disease process, long before it needs to be implemented keeps the patient in the driver's seat, in control of the situation and retaining his dignity. He will stop driving when the time is right.

Driver cessation support groups are being developed to assist with the transition from driver to passenger (Silverstein et al., 2016).

## Summary

1. Getting lost in familiar territory is often the first sign that driving may not be safe.
2. Driving skills are compromised by dementia and the aging process. Sooner or later most patients with dementia will not be safe driving.
3. A number of resources are available to assess safe driving. The unpredictable rate of deterioration of patients with dementia limits the usefulness of these tests.
4. Driving privileges have to be revoked in some patients with dementia. Health care professionals should be aware of the legal process involved as regulations differ from State to State and there also may be some local variations.
5. When driving privileges are withdrawn, triggers that may elicit a wish to drive should be removed, confrontations should be avoided and not allowed to escalate and arguments should be avoided.
6. Changing the goal from "withdrawing driving privileges" to "ensuring transport independence" is a less traumatic approach.
7. Driver cessation support groups are being developed to assist with the transition from driver to passenger.

## Authors' note

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