Driving cessation and people with dementia

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This presentation

• Driving cessation, community mobility and the UQDRIVE program
• What is known about driving cessation and people with dementia
• Some directions for improving outcomes
What is driving cessation?

• Permanent retirement from driving.
  • “painful, awkward, difficult, embarrassing, sad, frustrating, tearful, ugly experience” (p. 68; Freund, 2003)
• Pathway to get there – prior life
  • Becoming aware
  • Making the decision
  • Stopping driving
  • Life after driving
Why is driving cessation difficult?

• Dual loss
  • Driving is transport:
    • Accessible, familiar, works well in our communities
    • Behaviour change- habits, new learning
  • Driving is symbolic, identity
    • The car, the licence, Meaningful roles and activities, self
    • Grief and loss – emotional support and strategies
Why is it difficult?

• Safety of self and community
• Staying involved and engaged in the community and activities
• Legal/formal processes and implications (licensing, insurance, assessments)
• Retired drivers choose everyday not to drive (so need to understand and accept — or environmental prevention)
What do we know about driving cessation for older people

- Associated with increases in depressive symptomatology not explained by age, health etc
- Reduced community engagement
- Reduced number of roles, reduced time away from home
- Increased risk of institutionalisation
- Reduced access to health care
- Pedestrian fatality risk
What improves driving cessation outcomes for older people?

- Planning and awareness
- Sensitive approach – right amount of information at the right time, making sure message is understood and accepted
- Gradual and voluntary cessation
- Maintaining perceived control (over the decision, over life)
- Having accessible and acceptable alternatives (knowing how to use them)
Improving outcomes of driving cessation for older people

- Talking with peers
- Managing grief and loss
- Focussing on very individual lifestyle goals
  - How to get to particular community destinations
  - How to start valued home based activities/roles
UQDRIVE

- University of Queensland Driver Retirement Initiative
- Focus is not on whether people should drive or not
- Improving outcomes when they stop
  - Helping awareness and planning
  - Improving safety with alternatives
  - Encouraging continued engagement in the community
UQDRIVE resources

- Awareness raising resources
  - Aims at people currently driving.
  - Brief, sensitive.
  - Contains information about driver safety and responsibility and advice from retired drivers.
  - Can be done as a presentation or brochure
  - Adaptable for local content
Intensive support groups

- Aimed at people who are stopping or have stopped
- 6 weeks, ½ day per week
- Led by health professional and peer leader
- Up to 15 retired and retiring drivers
- In community – discussion, activities and outings
- Setting individual goals
First graduating group
What is known about driving cessation and people with dementia?

• Difficult!
• Consensus that it is likely that all people with dementia will stop driving at some point.
• Arguments about when and how
• Particular concern about awareness and how involved driver (and carer) can be in the decision
Driving cessation and people with dementia: Major challenges

- **The system** – feel lost, confused, not in control
  - (even health professionals were not sure)
- **Everyone is different and complex**
- **The pathway varies** and many may be involved:
  - Retiring driver
  - Family member/carer
  - Health professionals
  - Process of dementia
Challenging issues

- **Meaning** of driving (also for carer)
- **Who is responsible?** (GPs, drivers, family, licensing body)
  - Who will be the “baddy”? Impact on rapport, how to find right time, right information for decision?
- **Battles** – ongoing conflict, unlicensed driving
Major challenges

- Symbolic losses
  - Identity and self esteem, masculinity
  - Family or others stepping in – betrayal, loss of face
  - Lack of opportunity to grieve
- Practical losses
  - Transport – getting from A to B, essentials
  - Being a passenger, pedestrian
  - Knowing you can go out
Major challenges

- Impact on carers
  - Loss of household transport
  - OR required to provide transport (stop working)
  - Can they judge driving performance fairly?
  - Are they listened to when they try to get help?
  - Left to explain, remind and police the decision
Major Challenges

• Limitations of alternatives
  • Shortage of accessible transport especially in regional/rural areas
  • May require new learning: Public transport use can be as complex as driving.
  • Even taxis and fairly supported transport can be problematic
  • May require escorted travel
Some current approaches

- Hartford resources

- Research indicate consumers heavily relying on Alzheimer's groups for support
- Some trialling of formal driving cessation support groups
- E.g Dobbs et al
Some thoughts about what is needed.

- **Review of system** – simplify, clarify who is responsible, particularly when driver might not be able. External ‘experts’
- **Ongoing education** and support
- **An individual creative** approach
  - What works for the person with dementia and their family.
  - What does driving mean?
  - Why are they still driving/ wanting to drive?
    - Habit, don’t remember they shouldn’t, reduced awareness, needs that aren’t being met
Some thoughts about what is needed

- Ongoing support for family members
- **Flexible** community/transport services
- Allowing people to **share their feelings** and their versions of events WITHOUT focussing on the facts.
- Support for staying active and involved
A case study

- Daughter – one of 5 children
- Her father lives alone, most offspring are in the same city but not nearby.
- Told to stop driving a few weeks previously at the GP when his MMSE score was 3/30 but possibly language issues
- Shocked and upset
- Continued to drive
What the family did...

- Organised for delivery of groceries, lifts to Dr etc
- Disabled car (but he fixed it)
- Argued with father over phone and in person (daughter very frustrated and scared)
- He became angry and refused to talk to them about it but continued driving.
- Family organised a visit from the local police to “scare him into stopping”
What happened next…

- He continued driving
- BUT now drove when it was dark, with his lights off, speeding through back streets because he was concerned that he was being targeted unfairly by the police.
Why was he driving?

- He was actually driving once a day only.
- At close of business, to the local fruit and vegetable shop.
- To get left over vegetables to feed to his guinea pigs.
What may have been a better way of handling the situation?

- Find out when and why of driving.
- See if this could be met in any other way:
  - Fruit and vegetable shop could be paid to give him a call and drop items in on way home (or use taxi to deliver it).
  - Community service/ volunteer could pick up veges or pick him up “on the way through” for the trip.
- Family members could help with this.
Summary

- This is a very challenging situation for all involved.
- We are balancing safety and quality of life and need to maintain the balance.
- Flexible, creative, sympathetic approaches may be more effective.
- May need to use different strategies all the time.
- Family feel stressed and unsupported.
Any questions?

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