

Get lost



Spatial disorientation in dementia



Prof Michael Hornberger sheds light on the link between spatial disorientation and dementia, highlighting the significance and impact of this in the real world.

Michael is Professor of Applied Dementia Research at Norwich Medical School, UK.

Getting lost in an unfamiliar environment is a common occurrence for the vast majority of people. For example, we can easily get lost and have difficulty finding our bearings when on holiday in a new town. This can be amusing, in particular when we pass the same place for the third time, but it can be also quite unsettling and distressing when we get completely lost. Such 'getting lost' scenarios are very common for people with dementia, who often have difficulties finding their bearings even in highly familiar locations. It might come as a surprise to many people that such spatial disorientation is a key symptom in dementia, since we would assume that memory problems are the key early symptom. Spatial disorientation is actually as common as memory problems, but is under-recognised since it is often not noticed by family members, and is rarely inquired about as a symptom by clinicians and healthcare professionals. To better understand why spatial disorientation occurs in dementia, we need to understand how the brain is affected by the dementia disease processes.

Dementia is an umbrella term for different dementias, with Alzheimer's disease accounting for 60-70% of cases with dementia. It is thought that Alzheimer's disease is caused by the build-up of two proteins (amyloid and tau) in the brain. The exact reason why these proteins accumulate and cause the disease is not yet fully established. However, once the two proteins accumulate, they start becoming toxic to the nerve cells and subsequently nerve cells start dying. It is this dying of nerve cells which causes the symptoms in Alzheimer's disease, since the brain cannot conduct its functions properly anymore once the nerve cells are gone.

Certain brain areas are more susceptible to the accumulation of these proteins and hence we see symptoms in Alzheimer's disease caused by dysfunction in those areas. One key area which is affected by this in Alzheimer's disease is the hippocampus. The hippocampus (Latin for 'seahorse', since its shape is akin to a seahorse) is an important structure for both our memory and our spatial orientation, along with other brain structures. When the amyloid and tau proteins accumulate in the hippocampus, our memory and spatial orientation become gradually faulty, and we increasingly experience problems recalling memories and finding our way around. This faulty spatial orientation has important diagnostic and real-world implications for dementia.

For dementia diagnosis, spatial orientation changes can potentially complement the reported memory problems, which helps to confirm the diagnosis. This is particularly useful, since many people report changes to their memory as they age, while healthy people would rarely report having problems with orientation. Memory lapses without any spatial disorientation should therefore reassure people that their memory changes are more likely to be due to healthy ageing than the start of dementia. Even more significant for dementia diagnosis is that spatial orientation changes might occur before memory symptoms emerge, since specific spatial orientation changes are known to be caused by the earliest



protein accumulations due to dementia in the brain. There is ongoing research in this direction, including from my own research group, as it would allow us to potentially identify people with dementia before they develop memory-based symptoms. An earlier diagnosis might then allow earlier treatments or even prevention strategies. Recently this has become even more important, as there is a new medication coming to the market which can slow down the processes of dementia. As such, earlier identification of dementia symptoms will become even more important in the future.

The other important diagnostic aspect for spatial disorientation is that it allows assessment of people on a 'non-verbal' level. This means that it is possible to assess people who have little formal education. This is becoming increasingly relevant, since predictions are that the largest future increase in dementia will be in low- and middle-income countries, where many people are still illiterate or have low levels of education. For now, none of the existing, commonly used verbal memory tests in the developed world can be used in these populations, whereas spatial orientation tests can. For this reason, spatial orientation has significant potential not only to change dementia diagnostics in developed countries such as the UK, but to have a true global impact. We are currently collaborating with our international partners to investigate the feasibility of spatial orientation diagnosis in these countries and populations, including India, Tanzania, and Brazil. And of course, spatial disorientation has real-world relevance for people with dementia, in particular in regard to getting lost and driving.

Going out and remaining independent remains a key aspect for people with dementia and their families. However, there is always a balance to strike between providing as much autonomy to a person with dementia while at the same time keeping them safe. Outings are an important aspect of this, since they allow people with dementia to carry out tasks such as local errands or walking the dog within the neighbourhood. Unfortunately, spatial disorientation can cause people with dementia to get lost even on such routine outings in local neighbourhoods. It is estimated that around 40,000 people with dementia get lost every year in the UK, but this estimate is based only on instances when the police are called to

help find the lost person. The actual number of people with dementia getting lost is therefore likely much higher, but most incidences are not reported since people are found by family, friends or neighbours. Not only are these incidents distressing to the person with dementia, they have also been shown to cause some of the highest levels of carer distress, since they do not know where their loved one is.

A potential solution to prevent such incidents, especially from a geospatial perspective, is to provide people with dementia with GPS sensors/apps which allow them to be located. However, very few people with dementia use such devices, even though there are dementia-specific products available. The reasons why so few people use GPS devices are varied: most people and their families are not aware that getting lost is an associated issue, and hence a GPS device is only purchased after an event occurred; for others the technology is still too complex to use, in particular the usage of geofencing options; and for others the privacy issues of 'tracking' their loved one makes them reluctant to use such devices. Regardless of these issues, we clearly need to raise more awareness that spatial disorientation can lead to getting lost episodes and highlight the technologies that are available to mitigate these instances. This is not trivial, since getting lost episodes commonly lead to harm, or in some extreme cases even death due to exposure or dehydration, for people with dementia. Or to put it differently, no person with dementia dies of their memory problems, but they might come to harm due to their spatial disorientation.

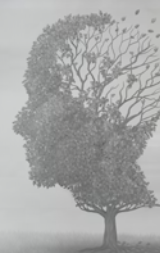
The other real-world aspect for dementia and spatial disorientation is driving. Driving requires a lot of spatial navigation and orientation. Most of us would probably think that finding your way these days doesn't pose that much of a problem given the nearly ubiquitous nature of in-car navigation systems. However, we also need to consider other spatial orientation aspects of driving such as the position of the car on the road, as well as judging distances to other vehicles, road users and objects when manoeuvring or parking. Anecdotally, people with dementia often have such difficulties which result at first in harmless incidents, such as hitting the bins in the driveway, but such minor incidents can often be the harbinger of future car accidents or even road fatalities. Indeed, older drivers are second only to young, male drivers in terms of having the highest road accident and fatality rates.

Importantly, current driving assessments for people with dementia often pay more attention to reaction time, processing speed and memory deficits impacting driving safety. Virtually no research has been conducted on how spatial orientation changes in ageing and dementia and the impact this has on driving behaviour and safety. We have ongoing projects with the Department for Transport,

the Road Safety Trust and Driving Mobility (the driving assessment provider for the Driver and Vehicle Licensing Agency) to investigate how spatial orientation changes are impacted in ageing and dementia and how this might inform future guidelines. Recommending that somebody stop driving can be a devastating blow and many people, particularly in rural settings, rely heavily on driving to live their lives independently. But at the same time, keeping these people and other road users safe must be weighed against this, and spatial disorientation in dementia is clearly a symptom that should be considered when making these decisions.

Taken together, I hope this brief overview of spatial disorientation in dementia, and particularly Alzheimer's disease, has given you an insight as to why these symptoms are not only important for diagnosis, but also for the safety of people with dementia. I am very grateful to have received such wonderful support from the RIN to help raise awareness, engage stakeholders, and identify funding opportunities to expand our research in this still neglected but important topic.

If you are interested in getting involved in our work, please feel free to reach out to Clare Stead at comms@rin.org.uk to start a discussion.



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