

Science AMA Series: I'm Michael Hornberger, a professor of applied dementia research at the University of East Anglia in Norwich, UK. My research is focused on spatial disorientation in dementia and how patients get lost. AMA!

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Abstract

Hi reddit! My team's research is focused on measuring spatial disorientation, i.e. getting lost in everyday environments, in dementia. To investigate these symptoms we use virtual reality and real-life tests with the patients, which demonstrates to us what makes patients get lost. We can then use this information to potentially predict which patients are at a high risk of getting lost. Getting lost is not trivial, as every year in the UK alone around 200 dementia patients die of exposure when lost. Investigating the causes of the symptoms and how we can treat them is therefore vital to guarantee the safety of our patients. I look forward to answering lots of interesting questions about dementia and spatial disorientation, including the causes, potential future treatments of the symptoms, and the work that my team is doing at UEA, during this AMA. Thank you everyone for your thoughtful questions today - it's been a great first AMA experience for me! Unfortunately, I did not have the time to answer all your questions, however if you're interested in learning more about my research, I hope you'll consider watching a lecture that I'm giving in London next week. It will be streamed live to the UEA Alumni Facebook page here: <https://www.facebook.com/ueaalumni/videos/1253772841326955> Michael

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Science AMA Series: I'm Michael Hornberger, a professor of applied dementia research at the University of East Anglia in Norwich, UK. My research is focused on spatial disorientation in dementia and how patients get lost.

AMA!

MICHAEL_HORNBERGER [R/SCIENCE](#)

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Michael

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Hornberger, a professor of
applied dementia research at
the University of East Anglia in
Norwich, UK. My research is
focused on spatial

What is the best way to deal with someone with dementia? Correct them, or go along with their delusions?

[Anchorali15](#)

Thank you for your question. In general, we recommend that it does not help to confront someone with dementia, ie correcting them, unless the person is putting themselves in danger. So, usually it is best to go along with particular symptom of the patient. For example, a very common symptom is repetitive questioning, where the patient asks the family the same question over and over again because they have forgotten, which can be very straining on the family. We usually recommend then to either distract the person with dementia or try to have memory aids for them they can use themselves, or in some cases not to tell them about upcoming appointments so that they do not ask all the time when the appointment is.

Is there any way of identifying people that suffer from dementia?

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What has happened with the worst case you've seen?

Are there different levels/grades of dementia??

Thanks.

[Hurinal](#)

Thank you for question. Yes, there are signs to identify people with dementia. Most commonly are memory problems, in particular if someone asks for the same information again and again. The other common symptom is that people get lost even on familiar routes, such as shops they have been to many times. If you spot any of those symptoms, then your first point of call should be your family doctor. There are different stages of dementia. Most commonly, clinicians stage dementia by severity of symptoms, ie mild, moderate, severe. Mild dementia is mostly characterised by someone being still very active but having significant memory problems and having problems doing more complex activities (eg finances). Moderate dementia mostly leads to more symptoms, such as changes in behaviour/personality but also sometimes language or walking problems. People at this stage are usually less active than before and have problems doing the most simple tasks in the household. Finally, the severe stage of dementia is characterised by patients becoming very dependent, for example they cannot dress anymore and have problems going to the toilet. They also are less communicative and in the end stages are mostly bedridden.

Is it possible for young people to get dementia? Why is it more common among old folks?

[hahasTooOften](#)

Thank you for your question. Indeed, it is often overlooked that even younger people can develop dementia, although this is very rare. We currently do not know why the disease only starts in later life in most people, however we know that age is the biggest risk factor for developing dementia. So, the older you become the more likely you are to develop dementia. Dementia itself is caused by the accumulation of proteins in the nerve cells, which start clumping together and therefore becoming toxic. This causes the nerve cells to die. One theory is that this protein accumulation takes time and that only with ageing the disease develops as the body is not as responsive in removing these proteins from the nerve cells.

what are the signs that a patient with demensia is near the end

[iamlyndsie1](#)

Thank you for your question. I am afraid there is specific answer to this question at the moment. The end stages of dementia are still very poorly understood. Most commonly, dementia patients will bedridden in the last stages and have problems eating & drinking, which causes them to loose a lot of weight. This will make them very weak and compromises their immune system. So, many dementia patients die actually from an infection as the body is so weak in the end.

What's the furthest one of your patients have traveled in search for their home?

[bozzy253](#)

Thank you for your question. The short answer is that we do not know. We are currently planning studies were we ask some patients to wear GPS trackers to see where they travel. Unfortunately, some patients get so badly lost that they die due to exposure and are found by either the police or

members of the public, which is very tragic. Such deaths are more common in cold winter or hot summers, when there is a danger to die of hypothermia or dehydration.

[The mortality rate due to neurological diseases is increasing](#). What factors do you think underlie this trend? What do you see as the areas likely to provide the greatest improvements in morbidity and mortality for dementia patients? Improved primary care? Pharma? Genetics? Preventative care?

[p1percub](#)

Thank you for your question. There are several factor which influence this increase of dementia, the main ones are: i) people living longer and since the biggest risk factor to develop dementia is age, we see more and more people having dementia; ii) we are better identifying dementia today. In the old days, people would have often considered dementia to be part of normal aging, which it is not. So, often dementia patients would not have seen a doctor but would have been taken care by the immediate family; iii) the increase of cardiovascular disease (heart disease, stroke) also impacts on dementia rates as people with cardiovascular diseases have a much higher chance of developing dementia.

There is currently a concerted effort to have a much bigger emphasis on dementia prevention, in particular by reducing the cardiovascular risk ("What is good for the heart, is good for the brain" is a common slogan). So, if you have good cardiovascular health, by exercising regularly, eating well, not smoking you will also reduce your risk for dementia.

What tips would you give to help minimize the effects of wandering so that dementia patients can stay in their homes for as long as possible and prevent being placed in long term care facilities?

[emi_687](#)

Thank you for your question. Yes, this is an important question as we want to have people living in their own home as long as possible, because it usually provides the best quality of life. Problems with wandering are the biggest problem with patients who live alone as they are most of the day alone. In such cases, we recommend to people to discuss with their doctors whether door alarms should be installed. These door alarms can be remotely monitored via mobile etc and there are several commercial providers for these services. Similarly, there are GPS trackers which patients can wear, however we find often that patients either forget to put them on or deliberately take them off, as they feel monitored. So, it is good to discuss this with the whole care team. For carers living with dementia patients, we usually recommend to have more simple door alarms which ring a bell when the front door is open for example. So, it makes them aware that someone is opening the door. These alarms are very simple to install and give peace of mind. In more severe cases, we sometimes suggest to lock the doors when they are inside the house and carry the key with them, so that the patient cannot leave at any moment. Still, there is clearly much more research needed to investigate the best methods to avoid unsafe wandering.

Can you give us a sense how much "getting lost" behaviours come simply from poor visuospatial awareness, and how much comes from poor frontal function for planning and problem solving capability? Or even from poor impulse control (more frontal)?

[ALR3000](#)

Thank you for your question. At the moment we do not know how much visuospatial awareness contributes to getting lost. The human navigation system consists of different brain regions, which have

different functions and interact with each other. Visuospatial information is only one part of the navigation system and it is therefore unlikely that people get lost only because of visuospatial problems. Frontal planning and impulsivity problems usually contribute little to navigation, it is more the temporal and parietal brain areas which are the main centres for navigation and those brain areas are also severely affected in Alzheimer's disease.

What do you mean by "getting lost"? Do you mean like literally just getting lost, like not knowing where they are and what to do, or something else?

[falconiform34](#)

Thank you for your question. Yes, I mean literally getting lost in familiar places. Of course we all get lost in new places, for example if you travel to a new place you have never been before. However, in dementia patients get lost even in places and routes which they have known for many years. In some cases, this getting lost can be so severe that they even get lost in their own house, ie they have to open each door to find the bathroom as they have forgotten where the bathroom is. As ekser said below, patients getting lost can be extremely distressing for the patient and their families and it often involves search parties or even the police. Here in the UK we have convinced the police that the missing person register should clarify whether someone has a dementia or not and there are also plans to implement a protocol for the police what to do in such cases. There is clearly an urgent need for that but we are only at the beginning to change this.

Thoughts on trazodone and dibenzoylmethane studies? If the human studies go well wouldn't that put you out of a job?

[daffie999](#)

Thank you for your question. Well, I wish they would put me out of the job! ;) Seriously, I hope that these drugs will prove successful as we need urgently some treatment for this devastating disease. Only the clinical trials will tell though whether they are successful. The current findings are all in animals and we do not know how they will work in humans.

Hi Michael, and thank you for doing this AMA. I have two questions for you:

1. Can you comment on how plastic dementia symptoms are in elderly patients? Is it possible for patients to see improvements in their dementia over time with certain behavioral or pharmacological interventions? I imagine this may vary depending on the patient history and other co-morbidities (such as AD or PD).
2. In the context of wandering or getting lost - what is motivating the behavior in these patients? Can you talk a bit about whether you have been able to gain insight into what is driving these urges to wander in patients through the course of your interviews?

Thanks!

[SirT6](#)

Thank you for your questions. Re 1) With most dementias you see only a gradual decline over time, however other dementia have a more fluctuating progression, ie some days are much better than others. It is currently not clear why that is the case. However, you can definitely improve dementia patients in the short-term with non-pharmacological therapies, such as music therapy. These therapies improve patients for short while and improve their quality of life but the disease still progresses further.

So, dementia is different from stroke, where you have one time event and then the brain can use its plasticity to re-generate as much function as possible. By contrast, in dementia the brain is fighting a losing battle as the disease always progresses and therefore any plasticity is nullified over time. re 2) The getting lost is not particularly motivated or an urge in the patients. It has more to do with brain's navigation system being affected in the patients and hence they are getting lost when they are on the way to somewhere. However, some patients can be very restless and start truly wandering. It is currently not clear what motivates this restless behaviour.

I once read this article, not sure if its fact or fiction, but just to confirm -is it true that if you sleep more than 8 hours a day it can possibly lead to dementia ?

[_izziyy](#)

Thank you for your question. This is a 'chicken or egg' kind of question, ie which one comes first. We often see sleep problems in our patients but it is not clear whether the sleep problems caused the dementia or whether the dementia caused the sleep problems. So, I am afraid the jury is still out as to how sleep changes might contribute to the development of dementia. Finally, just to say that sleeping on average 7-9 hours is perfectly normal.

Have you studied people with vascular dementia and, if so, do you see a difference in the quality or severity or progression of dementia between vascular and Alzheimer's, for example?

[cyborg-waffle](#)

Thank you for your question. Yes, we study people with vascular dementia as well. Vascular dementia patients have usually more of a step-wise progression in their disease. This means they stay pretty much the same for some time before they progress. By contrast, Alzheimer's disease is usually more a gradual decline, with constant changes. However, this is a only a generalisation as individual patients can show different progressions.

Some dementia patients seem to remember the past much better. Would moving dementia patients to their childhood home be beneficial?

[squidistic](#)

Thank you for your question. I do not think this would help, in fact it might actually quite confuse them as the house has very likely changed quite a lot. So, it would be very puzzling for them to see the house but everything is different, which would further underline their confusion with the world. However, it can be good to have some elements of their childhood/early adulthood in their life, such as specific songs or movies.

How come dementia can cause someone to forget where they are but not how to walk, or speak? Different parts of the brain? If so, why does dementia effect the parts it does? Are there any treatments you would like to test but are illegal (drugs or methods)?

[Davidjhyatt](#)

Thank you for your question. You are absolutely right, the brain areas affected are different. However, most dementia patients will loose over time the ability to speak or walk as well as the disease progresses through different brain areas. Why dementia starts in particular brain areas but not others

is, surprisingly, not yet understood but is currently investigated a lot. I do not think that any illegal drugs would have the potential to treat dementia, as their effects would not impact on the disease.

What about normal (neurotypical) people who get lost frequently and have issues with spatial navigation? Have you researched them at all?

[mbinder](#)

Thank you for your question. This is a very good point, which also concerns us a lot. There are many urban myths out there how people get lost but scientifically we understand still very little how normal people navigate. We have therefore a science project called Sea Hero Quest (www.seaheroquest.com) which uses a mobile game to measure navigation behaviour in healthy. We can use this data then to diagnose and treat the spatial navigation symptoms in dementia. Feel free to check the game out, which is freely available on the App stores.

Thank you for doing this AMA!

Do you know a lot about whether the cognitive processes that contribute to getting disoriented or lost are different in dementia patients than in a cognitively healthy individual? Does it relate to other aspects of dementia, like becoming disoriented in time or trying to cover confusion by inventing details?

[neurobeegirl](#)

Thank you for your question. Very good question, maybe have a look at my answer to the previous question (by mbinder) where I talk about this already a little bit. Also, check out our Sea Hero Quest project via Google, which tries to answer this.

Hello- thanks for doing this AMA! I'm interested in the pathophysiology behind spatial disorientation, and whether multiple types of dementia present with this problem. I've read that spatial disorientation is not a memory problem, which would rule out medial temporal lobe atrophy. Do you normally see patients with spatial disorientation that have frontal lobe atrophy? I'm also wondering whether certain types of dementia are more likely to involve spatial disorientation. Are there any treatments that help with this issue?

Thanks for your time!

[Austion66](#)

Thank you for your question. Very good point. Spatial disorientation is actually mostly caused by medial temporal and intra-parietal changes. However, it is currently not clear how far these overlap with episodic memory. In a way, it would make sense to have some overlap as many of our memories involve locations. In terms of pathophysiology, this is very interesting and one of the reasons why we started researching this as we think these spatial symptoms are much more specific to Alzheimer pathology. See for example our paper in Cortex, Tu et al. 2015. So, other dementias, at least in the early stages show rarely spatial disorientation problems and we think therefore this could be a much more pathophysiological cognitive test for Alzheimer's. Frontal lobe patients show usually no problems in simple navigation tasks; they are only affected when they need to do a lot of planning and organisation of the route which is handled by frontal regions. There are currently no treatments for this symptom, unfortunately.

How much do we know about how those who suffer from dementia and their ability to become lucid for shorts periods of time?

[LactoseWill](#)

Thank you for your question. Indeed, this is a good question. Unfortunately, we do not know what really goes on in people with dementia once they lose the ability to speak. So, I am afraid at the moment we do not know what makes them become lucid. We only know that playing music can trigger lucid moments in some patients. See for example this project in Scotland: <http://www.playlistforlife.org.uk>

How do you think the public can be more aware and more able to help people in these situations? Is there a guide like the 'act fast' campaign when someone suffers a stroke? How can we help?

[mrsgardom](#)

Thank you for your question. This is a very good point. In fact, I have currently a PhD student who is investigating this exactly. We are working with the police and safeguarding board to create information for an awareness campaign for professionals and lay people. We are only beginning at the project but we are realising that this is urgently needed to make people aware.

Can dementia get healed or slowed?

[alphaman63](#)

Thank you for your question. I am afraid at the moment dementia can neither be healed or slowed.

What can we do to keep them happy and safe? And is there a trade off?

[Conservative_Pleb](#)

Thank you for your question. This is very difficult to answer as it depends usually on the individual and their needs. I would recommend you consult the Alzheimer Association pages, which have excellent information on this. <http://www.alz.org/>

What have you learned about the role environment and architecture play in the treatment process? Could we design better rooms/buildings that would help dementia patients?

[oldsnappy](#)

Thank you for your question. Indeed, we know that improved environment and architecture can reduce spatial disorientation, in particular in care homes. In particular, clear color coding of floors or doors, as well as having pictures on the doors of the person living there or the function of the room can greatly help people to stay oriented. At home this is more difficult but you can still put pictures on the doors and we would also recommend that patients do not leave the house after dark as one can see familiar landmarks much less, which can cause disorientation.

I've heard listening to music can significantly improve movements and help improve some connection/memory, is this true?

[foolhardy1](#)

Thank you for your question. Yes, indeed music can lead to significant short-term improvements. There are several projects ongoing in this direction worldwide. Here a good example:

<http://www.playlistforlife.org.uk>

What specific kinds of tests, VR or real-life, are you performing to determine the level at which a dementia patient could get lost?

Is there one test, for you, that sticks out as being the determinant of whether they have a high-risk of getting lost?

Thank you!

[might-ochondria](#)

Thank you for your question. We are using a combination of tests, real-world, tablet-based and VR-based. It depends mostly which setting as a busy clinic does not allow a VR setup but we can do these in the lab. We developed one test (Supermarket test) which has been very successful and is now used quite widely in different studies and consortia. The test is freely available to clinicians and academics. If you are interested I would recommend reading our relevant publication (Tu et al., 2015, Cortex).

Do you have any advice on when to make a move between just having visiting nurses at a patient's house to a full-time care in a facility?

[Am_ugly_and_proud](#)

Thank you for your question. This is a very difficult question to answer as it depends a lot on the individual needs of the patient and their carer. So, in short there is no gold standard when to do this best. I would suggest to discuss it with the treating clinicians and nurses as they will know the individual best.

How likely or often is it that depression precedes dementia? Do people without mental illness / personality disorders fare better in avoiding Alzheimer's? Truly scary to read about it, even though I'm not a senior citizen, simply because of the rates in the older population. Thanks and best of luck in your research.

[anustretch](#)

Thank you for your question. The relationship of depression and dementia is not yet completely clear. However, often patients can present with depressive symptoms which turn out to be dementia, although some patients have 'only' depressive symptoms and will not develop dementia. On average, if you do not have a mental illness you fare better in avoiding dementia.