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Nick Fox, Professor of Neurology
LOSING MY MIND

Professor Nick Fox is revolutionising treatment of early onset dementia. His team is improving the accuracy of early diagnosis in order to radically improve treatment. This is his story.

“ONE THIRD OF PEOPLE WILL BE AFFECTED. THE PRICE OF NOT DOING SOMETHING IS TOO HIGH”

Nick Fox, Professor of Neurology at the Dementia Research Centre

Even though I see this disease on a professional level every day, I still find the stories heartbreaking,” says Nick Fox, Professor of Neurology at the Dementia Research Centre. “I recently diagnosed Alzheimer’s disease in a person aged 50. They’ve got it because they carry the gene – and therefore their three children and brothers and sisters all have a 50% risk of developing the disease.” It is hard to imagine how painful it must be to receive this diagnosis knowing it will affect not only your own health but that of your entire family – but Professor Fox still has it to deliver.

Fox specialises in early onset dementia, research that is made possible with the support of philanthropists. He emphasises that dementia at any age is devastating. However, those who are at a life stage where they also have to deal with the demands of a job and a young family face a particularly hard journey, as do those whose families carry a gene that makes them more susceptible.

Fox’s research is focused on improving the accuracy of early diagnosis. “There is often a misconception that we diagnose ‘dementia’. But dementia is a very non-specific term. It’s no more specific than saying ‘brain failure’. We need to be able to detect whether problems are due to Alzheimer’s disease, or frontotemporal dementia, or vascular problems.

“We have to move in the way that cancer research moved 20 years ago – becoming more specific, more precise in what we mean. Only then can we tell people what the future holds and identify the best treatment.”

His work couldn’t happen without the patients and carers in his clinic who offer to be research subjects and the technology that enables Fox and his team to track the progression of the disease. Sophisticated brain imaging is key – allowing them to both pick up early changes in the brain and to track the progression of those changes.

“By tracking progression, we can make trials more efficient,” says Fox. “Memory tests are a very subjective measurement – they are influenced by mood, or interactions with the examiner, and they don’t tell you whether you are shifting the underlying diseases at the brain level. You may just be getting a symptomatic benefit – in the same way that coffee can wake you up but it doesn’t do anything about your sleep deficit.”

Members of families carrying a known gene are being given treatments before they have symptoms in the hope that the intervention will be more effective – and Fox is now working with the children of families he first met when he started as a PhD student, 23 years ago. His team is also looking for both blood-based and cognitive biomarkers of the disease, to try and understand the full measure of its impact.

Fox is also closely involved with the proposal for a Dementia Research Institute (DRI) at UCL. This will, he says, “be focused, bring the world’s finest minds together to beat the disease. It will have everything it needs to fight one of the biggest medical challenges of the 21st century – from the most up-to-date brain scanners and imaging equipment to cutting-edge laboratories for experimental medicine, and wards for patients who want to help trial the very new therapies that are being developed in those labs. It is expected that the first scientific programmes of the DRI will be up and running by 2017.

“We’ve seen what progress can be made against HIV and certain cancers when we’ve done research that is fully integrated and properly funded,” says Fox. “We’re at the stage now where there are lots of exciting developments and we need to transfer those into finding treatments. We are only going to do that if we make a major resource push. It’s really exciting that we may be able to pull together researchers who have been scattered around UCL and elsewhere, and bring them together into one concerted effort. That will require a lot of resource but the goal is absolutely achievable.”

Philanthropy has the potential to make a huge difference to the care and treatment of patients with dementia. For example, UCL’s strategic partnership with major supermarkets channels money raised from the 5p charge on plastic bags into dementia research. Fox says this is essential, because: “Dementia is the problem of our age. One third of people my age will go on to have dementia. Every family will be touched by it in one way or another – either by having to care for someone or by having a partner with dementia. The price of not doing something is too high.”

Dementia costs the UK economy more than twice as much as cancer, and three times that of heart disease, every year. Despite this, combined charitable and government investment in dementia research is just £1 for every £12 invested in cancer research.

Philanthropy at UCL helps enable Dementia Research at UCL to get further, faster. To find out how you can support UCL Dementia Research visit: www.ucl.ac.uk/dementia/support or text DRI16 £5 to 70070.

Paul had been aware for a while that his wife Sylvia, 66, was taking a long time to do the weekly shop and coming back without items – even when they were on the list. But when Sylvia forgot that she had attended her nephew’s wedding just two days previously, the couple sought help from their GP.

“That was back in 2006, and the initial diagnosis was depression,” says Paul. But Paul, 71, felt that more action was needed and Sylvia was eventually referred to Professor Fox and his team at the Dementia Research Centre. After a series of tests, Professor Fox diagnosed Alzheimer’s disease, three years after Sylvia first showed symptoms.

“It was sad to finally be told, but not a shock,” Paul says. “We have had a wonderful life with the children and four grandchildren and we were resigned to this being ‘the drop of rain that falls into everyone’s life’. Sylvia has always been very positive and happy – and still is.”

Sylvia is now on two different anti-Alzheimer’s drugs and an anti-depressant, and the couple are adjusting to the changes that the disease brings. “I have to think for two,” says Paul. “She needs reminding each day what day it is and what’s going on. After a bit of prompting she can usually remember what happened yesterday though not always. She never forgets who people are and has no problems communicating.

“We have lived in our farm for more than 30 years, so it’s very familiar to her. Professor Fox suggests staying put for the foreseeable future to keep things the same as possible. She is not very motivated to do anything but enjoys doing the things I suggest. The most difficult thing is packing to go abroad to see our daughter. Imagine putting something in a case, then putting something else on top of it and immediately forgetting what is underneath – an annual ordeal for both of us!”

The couple have been involved with research at Queen Square since diagnosis, involving a few days at the DRC each September, having MRI scans and all sorts of memory and cognitive tests. Paul is also being tested, as part of a control group.

“We are very fortunate to have Nick Fox as our consultant,” says Paul. “He is one of the country’s top experts and has become a friend. Anything we can do to get on top of the dreadful disease is important to us. It may not help us but future generations must not have to endure this.”
Thank you for partnering with UCL to achieve great things. To talk more about how your philanthropic support can transform our shared ambitions into impact, contact Lori Houlihan Vice-Provost (Development) on 020 3108 3801 or lori.houlihan@ucl.ac.uk

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