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# JOIN DEMENTIA RESEARCH NEWSLETTER

## SPRING 2018

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The recent headlines suggesting there may be a link between head injury and dementia has generated considerable interest. We are therefore pleased to introduce as guest editor for this edition Dr Neil Graham, Alzheimer's Research UK Clinical Research Fellow, to tell us about the link between sport, head injury and dementia and the research done in this area to date.

**Professor Martin Rossor, National Director for Dementia Research at the National Institute for Health Research**

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Although it is generally accepted that severe traumatic brain injuries increase dementia risk, it is not clear how repeated mild head injuries during contact sports relate to long-term outcomes. It seems that the total severity and quantity of impacts is likely to be important, with concussion symptoms less helpful. Many of the symptoms reported in chronic traumatic encephalopathy (CTE) overlap with other conditions, such as psychiatric problems, and we lack the tools to make the diagnosis during life. It's therefore entirely unclear how common the condition is.

Improved diagnosis and the prediction of outcomes after brain injury is the key focus of my work supervised by David Sharp at Imperial College and Jonathan Schott at UCL (University College London), using the latest sensitive imaging techniques and blood tests. Models of head injury are providing an ever-improving mechanistic understanding, relating damage to long nerve fibres to subsequent neurodegeneration. Well-designed retrospective studies in specific groups, such as retired footballers in the UK (the FIELD study), should help us to better understand the effects of repeated heading. Looking forwards, big data studies will clarify the signatures of normal ageing and different types of dementia, as several studies worldwide are tracking patients' progress over time after injury.



This collective effort should both improve outcomes for patients after injury, and assist individuals to take informed decisions about sports participation, protecting cognitive health for the future.

**Dr Neil Graham**  
**Clinical Research Fellow (Alzheimer's Research UK / Imperial Health Charity)**  
**Imperial College London**

## LATEST JOIN DEMENTIA RESEARCH STUDIES

### Medication Management in Older people: the MEMORABLE study



Poor medication management can limit the benefits people obtain from their medication. Taking many tablets makes managing them more difficult, and it's more likely that someone could forget or choose not to take them. It also increases the risk of side-effects.

The MEMORABLE study aims to improve the way older people, including people living with dementia, are able to manage their medications, particularly

where this involves taking a lot of different medicines.

*(In the picture: Dr Ian Maidment, Chief Investigator of the study)*

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### Deciding about research on behalf of someone else: the DECISION study

Due to problems with their memory or understanding, some people may be unable to make their own decision about whether or not to take part in research studies. When someone is unable to decide, their family and friends may be involved in making a decision on their behalf. This could be difficult, and support might be needed.



The DECISION study aims to improve understanding about how family and friends make decisions on behalf of the person they care for.

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### The Multimodal Imaging in Lewy Body Disorders (MILOS) study



Lewy Body Disorders share many symptoms with more widely known conditions such as Alzheimer's disease, which means misdiagnosis is common. However, Lewy Body Disorders are currently under-studied compared with many other forms of dementia and can react negatively to certain medications for Alzheimer's disease. Therefore, better diagnosis and treatments need to be developed.

The Multimodal Imaging in Lewy Body Disorders study aims to fill this gap, providing a better understanding of the causes of Lewy Body Disorders.

*(In the picture: Dr Li Su, Chief Investigator of the MILOS study)*

## A DAY IN THE LIFE OF A DEMENTIA RESEARCH NURSE

“Being a dementia research nurse is very varied, no two days are the same. My job satisfaction is knowing that through these studies, I will be making a positive difference to participants living with dementia”.

Emily King is a dementia research nurse at the Royal Hallamshire Hospital in Sheffield. She qualified as a nurse in 2009, having worked on care of the elderly wards, she developed an interest in dementia and did a Masters in dementia studies.

At the end of each day, she enjoys knowing she is making a difference to the lives of people with dementia.



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## ALZHEIMER'S PATIENT ENCOURAGES OTHERS TO TAKE PART IN DEMENTIA RESEARCH

Martin Wallis is a retired pottery shop owner from Honiton, Devon. After having been diagnosed with Alzheimer's disease, he decided to take part in a clinical trial at Royal Devon and Exeter NHS Foundation Trust.

Before joining the study, Martin said he was unable to read or write and had been told he was not allowed to drive following his dementia diagnosis two years prior.

Now he can read again, and is writing a book about his life.



“Having just been told there was no cure for my condition, I was delighted to be offered such an opportunity [to take part in research]. The trial has given me a new hope for life”.

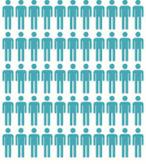
“There is a cure out there,” said Martin.

“One of these trials has to click soon. I can't recommend taking part in research enough”.

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*If you'd like to read the full version of the stories featured in this newsletter, please request a copy from any of the charity helplines overleaf.*

## JOIN DEMENTIA RESEARCH IN NUMBERS



**34,201**  
total volunteers



**67,668**  
screenings



**9,377**  
participants that have enrolled  
in studies to date



**27%**  
of volunteers have  
participated in a study



**199**  
Studies have recruited



**102**  
Studies currently open  
to recruitment



**957**  
trained researchers  
using the service



**191**  
NHS, University & commercial sites  
have used the system

*Statistics accurate as of 31 March 2018*

## GET IN TOUCH

To update your information on Join Dementia Research, please call one of the helplines:

**Alzheimer Scotland: 0808 808 3000**  
**Alzheimer's Research UK: 0300 111 5 111**  
**Alzheimer's Society: 0300 222 1122**

*Calls to Alzheimer Scotland are free, calls to other Helplines cost no more than a national call from any type of phone or provider and calls are included in any free call packages on landlines and mobiles.*

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