

December 2012

Dear TIME participant or referrer,

I am writing to wish you Happy Christmas, and to thank you warmly for taking part in the TIME Project, which is about to reach its 10th anniversary year.

The study remains highly active, with well over thirty referrals to the study in the course of the year from around the UK. We have also been receiving regular contacts from throughout the world via our website.

We are extremely grateful to everyone who has taken part in or referred to the study. We realise that we have been asking a lot of our participants this year because two big current projects, by Serge Hoefjeizers in Edinburgh and Kathryn Atherton in Oxford (pictured below), got properly underway at around the same time. These studies are trying to answer key questions about why people with TEA sometimes continue to forget information more rapidly than expected once the 'attacks' of memory loss have been stopped by treatment. Kathryn's study focuses on the possibility that a disturbance of brain activity during sleep may be important. Serge is looking in detail at the rate of forgetting during the day, and the possibility that recently formed memories may be more vulnerable than usual to interference by newly learned material. We hope that these studies are not too arduous, but they are time-consuming, and we are indebted to you for all the time you have given up to one or other, and, in a few distinguished cases 😊, both of these studies. Serge and Kathryn will begin analysing and describing their results fully in the course of next year. By the time next Christmas arrives, I should be able to let you know what we have learned from their work.

During 2012 we have completed or published several scientific papers based on the research that you have made possible. Fraser Milton's study of brain activity during recollection of the past will soon appear in the journal 'Neuropsychologia'. Chris Butler has completed a further paper describing newly obtained results from the brain scans we performed in 2003-6 which we hope will be published in the journal 'Epilepsia'. We were invited to submit a paper by 'rising stars' in epilepsy research to the journal Epilepsy and Behaviour, to which Chris, Fraser and Mils Muhlert all contributed: this will appear soon. If any of you would like to see copies of these papers, please let me know and I will gladly send them on to you. We have also been involved in producing a major book, a multi-author review of all that is known about the interconnections between epilepsy and memory (Epilepsy and Memory, Oxford University Press, 2012). We hope that this will be a useful survey of the area. It largely owes its existence to you, and the work on TEA that you made possible, as this work this inspired us to organise a conference, in 2009, which later gave rise to the book.



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We are developing collaborations with other groups involved in related work. Colleagues at The National Hospital for Neurology and Neurosurgery in London are using a version of our forgetting test in a study of memory disorder, and we are planning a joint study with a leading psychologist of epilepsy based in Berlin. Colleagues in Buenos Aires are planning to study aspects of the autobiographical memory problems in TEA.

In the course of this year I have been in touch with two people with epilepsy in the US who have independently thought and written a lot about memory problems from which they suffer, closely linked to those that occur in TEA. In particular they have noticed a loss of memory for autobiographical events of which some of you are also keenly aware. This kind of loss also occurs in some people with other types of 'temporal lobe epilepsy'. My US contacts have launched a confidential e-discussion group to allow others with similar problems to share their experiences and learn from one another. *If anyone would like to join this group, please send me an email and I will put you in touch with them..*

We are updating our website at present as this has become an important way of accessing the study, and it is visited a lot. We will include a link to a project donations site, hosted by the University, as fund raising for the project remains a challenge. This is absolutely not a request to you for to send a Christmas a gift to the TIME project ☺, but if you encounter someone looking for a worthy cause to which to make a donation, please send them to our website.

We are very grateful to the growing number of participants who have agreed to donate their brains to the project, and we will be in touch with new recruits about this in due course. This provides the best opportunity to learn about the changes in the brain that give rise to TEA and the memory problems that occur with it. But we are also glad to say that so far no donation of this kind has reached us!

Once again, we are extremely grateful for your help which has made this project possible. If any of you are keen to help us plan our future work, or have any queries or suggestions, please drop me a line.

We wish you a very Happy Christmas and 2013

Adam Zeman

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