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## Adrian Owen At the flimsy border between life and death

Jon Sutton meets Adrian Owen to discuss his new book, *Into the Grey Zone*

**What has surprised you most about your journeys into the grey zone?**

Working with people in the grey zone – and by that, I mean patients who hover at the border between life and death – I’ve been surprised by many things over the years, but perhaps most obviously that the relationship between what people appear to be and what they actually are is far less clear than we used to think it was. For many years, patients who would not respond to any form of external stimulation, like a request to move a hand or blink an eye, were presumed to be in a so-called vegetative state – ‘awake, but unaware’. When we showed in 2006 that fMRI could be used to reveal covert awareness in some of these

patients, it became immediately apparent what a grave error of judgement that had been.

**So what do we now know?**

That many of these patients harbour some level of awareness; indeed, some of them are completely conscious, locked inside their own bodies, yet unable to communicate with the outside world in any conventional way. Moving on to start communicating with some of those patients in 2010, again using fMRI, was another major milestone for us. I guess it was less of a ‘surprise’ at that stage, because by then we knew the patients were in there; it was just a matter of developing the technology to the point that we could





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open up a reliable channel of communication with them. But it was a thrilling achievement nonetheless.

If I were to get a little more philosophical about what has surprised me most about working in this area, I would have to say that it has convinced me more and more that we really are our brains. As I wrote in *Into The Grey Zone* [www.intothegrayzone.com], 'Your brain is who you are. It's every plan you've ever made, every person you've fallen in love with, and every regret you've ever had. Your brain is all there is. Without a brain, our sense of "self" is reduced to nothing.'

**Not all psychologists would agree with that.**

I know. Dick Passingham, who is a great friend of mine and someone I have respected for many years, recently pulled me up on this... he pointed out that there is a whole lot more to us than that. As well as our brains, we are our bodies and our past histories, he said. I replied that we can replace almost any part of our bodies and we will remain the exact same person. But swap out someone's brain and there is no question that they will cease to be them; their memories, their personality, their attitudes and beliefs, everything will change, including their entire past history (at least as they recall it). The very essence of them as a person will be for ever altered.

**Do you have any estimate of how many of these patients might be out there, awaiting that 'magic', to be 'found'?**

Improvements in roadside medicine and intensive care have led to more people surviving serious brain damage and ending up alive but with no evidence of preserved awareness. We don't know exactly how many vegetative-state patients there are, nor how many of them are trapped in 'the grey zone', awake and aware, but unable to convey that fact to the outside world. This is due, in large part, to poor or non-centralised nursing-home records. In the United States, estimates range from 15,000 to 40,000 vegetative state patients. Given that number, our findings suggest that as many as 7000 of these patients might actually be aware of everything going on around them. Such patients can be found in virtually every city and town in the world with a skilled-nursing facility.

**A while back I sent you my own draft 'Advance Decision' [available via our website], and while saying you do advocate them you cautioned 'Imagine again that you are aware and have to witness your own death just because you used to think that was a good idea'. How do you deal with that conundrum? Great question! The reason I said that back then was because I was beginning to realise that what most of us think we would want if we are unfortunate enough to end up in the grey zone, is not actually what we want when we get there. How many times have you heard (or said) 'I don't want to end up like that – pull the plug!' Through technology like fMRI we have been**

able to communicate with some of these patients and we now know that their lives are not necessarily as bleak as we might think they are. That's not to say that they are blissfully happy, but consider this example; my colleague Steve Laureys recently surveyed 91 people with locked-in syndrome—conscious people who were only able to communicate by blinking or vertically moving their eyes. They were asked to answer a questionnaire about their medical history, current status, and attitude to end-of-life issues. Contrary to what most of us might expect, a significant proportion of the patients (72 per cent of those who responded) reported that they were happy. What's more, a longer time in a locked-in syndrome was correlated with how happy this group said they were.

**Not everyone has been convinced by your work, pointing to physiological and statistical artefacts and cautioning against over-interpretation. How do you respond?**

This is a great question that gives me an opportunity to point out that I don't get to spend my whole life just doing cool science! In fact, I spend a lot of time managing people's expectations, juggling the demands and interests of doctors, patients and families and justifying the scientific conclusions we have reached to people who may not believe, or understand, what we have discovered. For me, this is the 'politics of science', and it's a necessary evil. We can't just sit in our ivory towers discovering stuff, writing about it in scientific journals and hoping that everyone will just take it at face value. I've generally found that it's very worthwhile taking the time to explain our findings, sometimes even running additional experiments to rule out artefacts or potential design flaws and usually the end result is a better understanding of the data and a more accurate interpretation of the results.

In many instances, it's been the criticisms that have driven me on towards the next big question. For example, I remember after the 2006 paper came out in *Science* a small, but vocal, contingent doubted our findings; they said that fMRI activity alone was not sufficient to conclude that our patient was conscious. This scepticism led directly to our next step – to actually communicate with a patient who was presumed to be vegetative. My reasoning at the time was 'if they don't believe the patient is conscious, what better way than to get the patient to tell us themselves!' But that said, overall, I have had tremendous support from both the scientific community and the public for my work, and I am very grateful for that.

**Very few psychologists – sorry, 'neuroscientists'! – can claim to have pioneered a new field of science. Do you put this down to vision, luck, a bit of both? I would never claim to have pioneered a new field of science – apart from anything else, I have worked with amazing students, postdocs and collaborators for many years and they have all contributed in great and small ways to the emergence of this field. In many**



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ways, my role has been to bring these people together – often from disciplines that might never normally talk to each other, like engineers, ethicists, psychologists and critical care staff. That's when the magic really happens!

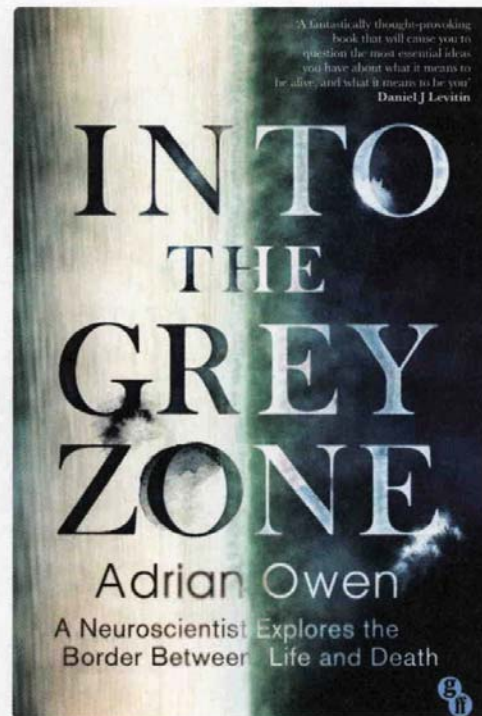
But I have also been very lucky; I trained in psychology in the late 1980s and that really equipped me well for the emergence of cognitive neuroscience and brain imaging. When PET and then fMRI came along in the early 1990s, I think I was really well positioned to get into those fields using sound psychological principles. In those early days that was really important, because there was a lot of really terrible brain imaging being done in the name of psychology! Then, having that solid grounding in brain imaging, allowed me to look beyond simply 'brain mapping', which is what I did for most of the 1990s, and find a real application for the technology in a clinical setting. I wouldn't say I ever had a 'vision' for any of this, but perhaps it helped to have a sense of knowing what I knew, and the foresight to try to apply that knowledge to novel situations and scientific questions.

So you're a psychologist – one of the last (as in, youngest) of the 'old guard' of British psychologists, the UCL/APU school. Familiar figures crop up in the book, such as John Duncan, Pat Rabbitt, Trevor Robbins. Can you understand us having a little pang of jealousy at seeing 'A neuroscientist explores...' on the cover?

I am very proud to have trained in psychology, and I think it provided me with many of the tools that I have used over the years to tackle the scientific questions that have interested me, from how to design a rigorous experiment to an appreciation of medical ethics. But there came a time when describing myself as a 'psychologist' no longer told people much about what I actually do. In fact, it often gave them the wrong impression entirely. One of the themes running through *Into The Grey Zone* is how the field that we now know as 'cognitive neuroscience' emerged out of psychology with a lot of help from brain imaging, and my career followed that very same path across the same time span. I am a psychologist at heart, but a lot of what I do is better described as neuroscience. I like to think that what I am best at is applying good psychological principles to neuroscientific questions, some of which may not seem very 'psychological' at all.

You and your teams have had so many successes. But, like neurosurgeon Henry Marsh in *Do No Harm*, you seem somewhat inevitably haunted by the failures. Peering into your past girlfriend Maureen's brain, only to see 'darkness. Quiescence. A void', or being bold enough to ask John 'Do you want to die?' and getting inconclusive results.

I don't think I am haunted by the failures, but ups and downs are the reality of science, particularly when you are pursuing a single, burning question over many



**Dr Adrian Owen**

is the Canada Excellence Research Chair in Cognitive Neuroscience and Imaging at The Brain and Mind Institute, Western University, Canada. [Into the Grey Zone](#):

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[www.intothegreyzone.com](http://www.intothegreyzone.com)

A review and extract will appear on our website ahead of the book's UK publication in September

years. The problem is, in the scientific papers, readers often only get to see the highlights... the net result of several experiments and the summary of what we think it all means. I'm not talking about the tendency not to publish negative results – that's a different type of problem – but rather, all the ideas that never got off the ground, all the unfortunate twists and turns that got in the way of the science. In our case, patients dying (or recovering) just as we're about to make contact with them is a fairly common occurrence. Of course, our first thoughts are with the families, but I can't pretend that these things aren't also scientifically disappointing because often it sends us right back to the drawing board.

Writing the book gave me the space and the freedom to write about these things and express how they make us, as scientists, feel. Of course, the science is in there in a way that I hope everyone will be able to understand, but there's also a lot about the process of doing science, the ups and the downs, the triumphs and the failures, the setback backs and the



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sense of sheer exhilaration that I still get when we do occasionally make a break-through. What I really wanted to convey in *Into The Grey Zone* is what it's actually like to be a scientist, set against a backdrop of the scientific discoveries themselves and, of course, the incredible stories of the patients and their families.

**That really does come across in the book, which is beautifully written. Where did that come from?... Did you find it easy? Did it surprise you?**

I resisted requests to write *Into The Grey Zone* for many years, because I wasn't really sure that I could do justice to the patients and their extraordinary stories. I have written hundreds of scientific papers, but this required a different kind of approach. Fortunately, our research has received plenty of attention from the media and the public over the years, and this has given me a reasonably good sense of how to write for (and talk to) the non-expert, and that made it much easier than I expected.

One side note that might be of interest to your readers; I began writing these stories against a backdrop of the relevant neuroscience, focusing on the anatomy of the brain, the function of various regions, and so on, but quite quickly realised that wasn't where my heart was and that wasn't going to be a very easy book to write. About two chapters in, I realised that it was the psychological aspects of the scientific journey that fascinated me most, why we think the way we think and why that is such a critical and vulnerable part of the human condition. Once I'd found that voice, it became much easier to keep writing.

**You dedicate the book to your son, saying 'In case I'm not here to tell you the story myself'. That struck me as a little fatalistic! Then I realised you had returned to that point in the acknowledgements...**

I'm glad you noticed that. It was always my intention to dedicate the book to my son Jackson because it was written during the first three years of his life, in between (and sometimes during!) nappy changes, midnight feedings and many, many sleepless nights. The story also covers a period of my life that in many ways defines who I am now as a person. When I read a book dedication, I always feel a bit short-changed when there's no explanation. 'For Jackson' doesn't tell you anything and why this book is for Jackson. I added 'In case I'm not here to tell you the story myself' because I hope that one day he'll read it and understand something about my life that won't be obvious from the daily interactions he and I share as father and son. I hope I'll still be around to add additional colour, of course, but something I have learned from working in this area is that there is absolutely no way to predict that. As I wrote at the end of the book, 'working at the flimsy border between life and death, the sheer fragility of every human life is hard to ignore'.

**Have you found a growing need for some 'light relief'**

**in other areas of your personal and professional life?**

I have never been a terribly serious person and I have always pursued things that interest and entertain me. But it's tough to try to fit it all in. One way is to just combine the two. I play guitar and sing in a band called Untidy Naked Dilemma (<https://youtu.be/b7oShriLYVA>), made up entirely of neuroscientists and that's been an incredibly important part of my life for many years. In various forms, the bands I've played in have performed all over the world, often at academic conferences that many of the members of the band were attending.

From time to time, I'll also do a fun scientific study with someone who is an academic friend rather than a regular collaborator, just because we can and because it's fun. Richard Wiseman and I, who have been close friends for more than 30 years now – we were psychology undergraduates together at UCL between 1985 and 1988 – recently published a study together pointing out that about 80 per cent of the time, pictures of the human brain are presented facing to their right (that is, we mostly get to see the left hemisphere). Why that is we do not know, but it's one of those quirky little things that Richard spotted and we decided to write an academic paper about it. It's wonderful to have the freedom to do things like that with your friends, especially after 30 years in the field.

**In any area like this, dark humour can be a defence mechanism, and there's a bit of that in the book. The locked-in patient subjected to one Celine Dion album springs to mind. What would be your own torture track – something by your own band maybe?**

If I were ever unfortunate enough to find myself in the grey zone then I am fairly sure that my students would put me straight into the fMRI scanner and ask me to 'imagine playing tennis'. Although it might well help them work out whether I'm in there or not, after all this time saying those words, I'm not really sure I ever want to hear them said to me!

There is quite a bit of humour in the book, and that was always intentional. Despite some of the awful things we have to witness on a day-to-day basis, funny things do happen, and I included them in the story because that's the reality of the situation and I wanted to remain as honest as I could to that reality. I can imagine that people might think it's terribly depressing working closely with people at the border between life and death, but there are plenty of funny moments, surprising moments, joyous moments and exhilarating moments, and I really wanted that to come through in the pages of the book. When you're working with people who are living with terrible life circumstances it's important to keep some perspective, or it really would be very hard to go home and sleep at night.

Oh, and it would have to be the 'The Final Countdown' by Europe, mostly because it haunted my undergraduate years at UCL (it was #1 in the UK charts in 1986), but also because the cruel irony would be simply too much to live with...