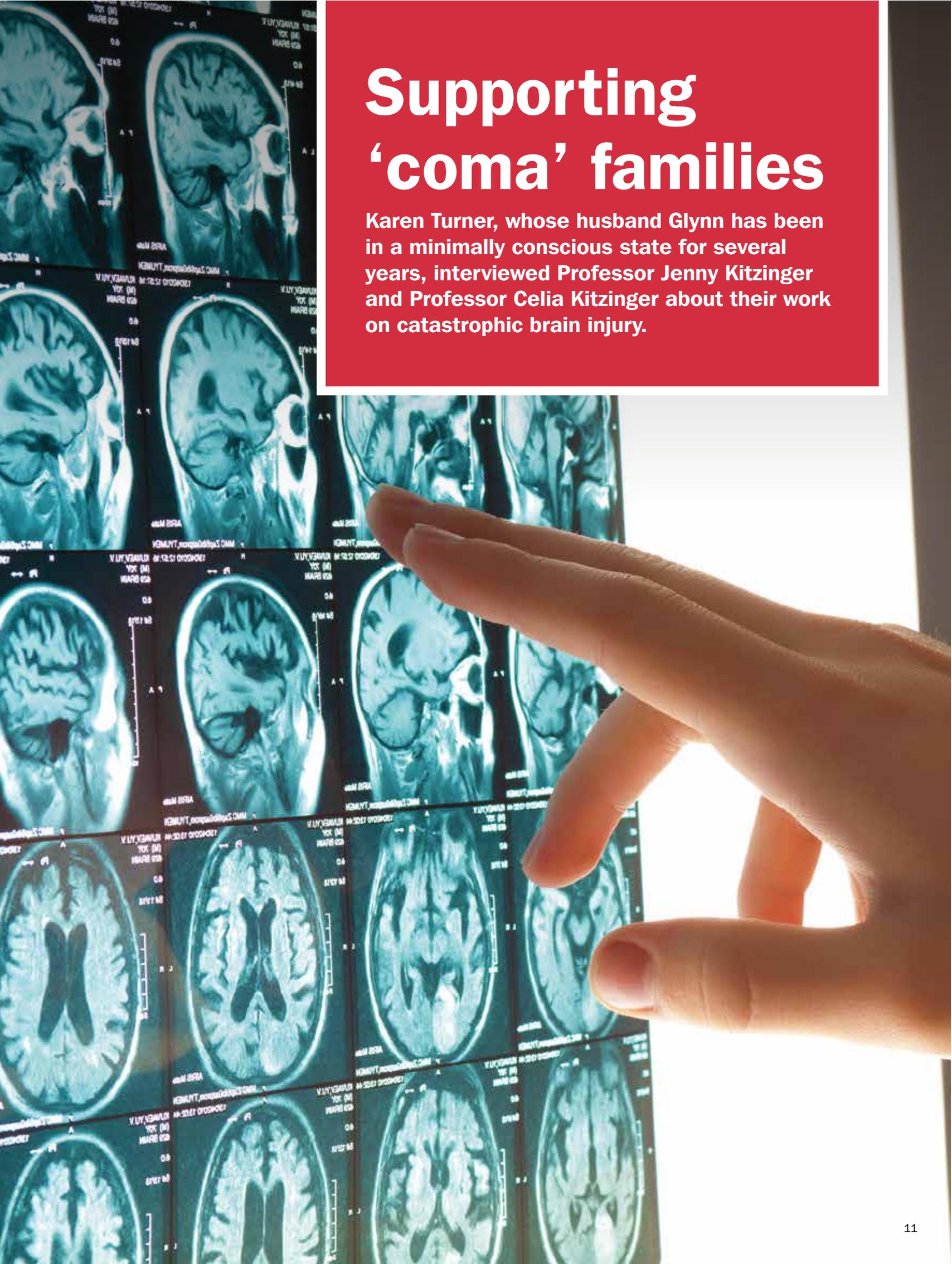


# Supporting 'coma' families

Karen Turner, whose husband Glynn has been in a minimally conscious state for several years, interviewed Professor Jenny Kitinger and Professor Celia Kitinger about their work on catastrophic brain injury.





Karen Turner talks to Professor Celia Kitzinger about how the work of the Coma and Disorders of Consciousness Research Centre is helping the families of coma patients.



Professor Celia Kitzinger asks Karen Turner about her experience.



Professor Jenny Kitzinger films the research interviews for the project (clips available on [healthtalk.org.uk](http://healthtalk.org.uk))

Professor Jenny Kitzinger and her colleague (and sister) Professor Celia Kitzinger are co-Directors of the Coma and Disorders of Consciousness Research Centre (CDoC), a joint initiative they set up between Cardiff and York universities, involving colleagues across law, philosophy, history, sociology, health sciences and other disciplines. The Centre explores the social, legal and ethical challenges of the vegetative and minimally conscious states.

The two sisters set up the research centre after their own experiences of what happened to their sister, Polly, who was catastrophically injured in a car crash near Brecon in 2009.

They went on to do interviews with over 65 family members with experiences of having a relative in a coma, vegetative or minimally conscious state and have used their research to inform over a dozen co-authored, peer-reviewed publications and also to create an online resource. The resource is on the [healthtalk.org](http://healthtalk.org) platform (<http://bit.ly/1HchkbX>); it summarises their research findings, alongside showing filmed interviews, to provide support for families and training for professionals.

When Cardiff University awarded this initiative the 2015 Innovation and Impact Award, Karen Turner, from Ipswich, wrote in highlighting how the Kitzingers' research had been invaluable for her: *"As the wife of someone who is in a minimally conscious state, and has been for the last five years, I know that this is a very lonely experience for myself and my children. This research is giving families the opportunity to speak*

*out, tell it like it is, and feel that they have a voice. We are surrounded by experts who care for our relatives but they haven't got the lived experience we have and don't really 'know' what we go through emotionally and practically. Research like this not only helps the families but gives the professionals the opportunity to look beyond the patient to the whole family."*

Karen spoke to the sisters about their ground-breaking work.

**KT:** Why did you start doing research on coma and disorders of consciousness?

**CK:** After Polly was injured in 2009 she was first in a vegetative and then in a minimally conscious state. During that time, and still now that she's regained consciousness but with profound multiple neurological disabilities, there were real problems with her care. Occasionally it was individuals who we felt acted inappropriately, but mostly it wasn't any one individual's fault. Mostly it was the system. Doctors seemed ignorant about the law and even lawyers that we consulted did not seem to be clear about what could be done. We were left in limbo without any way of advocating for Polly's clear values and beliefs. We knew as a family what Polly would have wanted but because this didn't fit with what the doctors were doing, we were ignored when we tried to get Polly's voice heard. We hadn't fully appreciated before that next-of-kin have no rights to make treatment decisions in this situation and it was a bit of a shock.

**JK:** A few months after Polly's accident I applied for, and was eventually appointed as, a Welfare Deputy by the Court of Protection.

This is an official role that was created by the Mental Capacity Act 2005. This meant that I could make some decisions on Polly's behalf, however I still could not refuse some of the treatments I believed she would have wanted to refuse. Even with decisions that were within my legal powers I continued to be overruled by people who didn't understand what a Welfare Deputy was. We've since had an official apology about this, but it's too late to make a difference to Polly.

We hope our analysis of the situation, and research we went on to do with a wide range of families, can make a difference to other people, and we have fed our findings into policy documents such as the House of Lords' scrutiny of how the Mental Capacity Act is working in practice.

**KT:** How can the online resource support families?

**CK:** We wanted to give families accurate information about their role in medical decision-making, which is telling medics what the patient would have said in this situation if they could. The online resource explains how families can ask for Best Interests meetings, and how they can make sure that their relatives' wishes, values and beliefs from before the accident are taken into account.

**JK:** Alongside this we wanted to communicate some accurate information about coma to replace media emphasis on miracle recoveries so we've included discussion of what recovery from a prolonged coma usually means and videos with leading professionals in the area. We've

also gone on to work with artists to develop some creative representations of long term 'coma' in art, music, poetry, even a puppet show. ([www.buff.ly/1VgbvSW](http://www.buff.ly/1VgbvSW))

**KT:** What happened to Glynn led me to make a living will, an advance decision, to protect myself and my family in the future. What can be done to encourage other people to do this before disaster strikes?

**CK:** Living wills, now known as advance decisions to refuse treatment, are a way in which you can refuse in advance any treatment you don't want to have in the future when you might not be able to refuse it. I co-founded a charity, Advance Decisions Assistance ([ADassistance.org.uk](http://ADassistance.org.uk)) to help people write them. If Glynn or Polly had written one they could now be at peace. All that is needed is to write something like "If I am diagnosed as being in a vegetative or minimally conscious state by two appropriately qualified clinicians X weeks after the precipitating incident I refuse all treatment aimed at prolonging my life". Signed, dated, witnessed, and with a statement saying "I maintain this refusal of treatment even if my life is at risk as a result", this is a legally binding document.

The problem is that although the law permits this, there's been very little government support promoting advance decisions. They're not for everyone, but those who do

want them are being denied the opportunity to write them. We covered advance decisions in our online resource (see section on end of life wishes on our [healthtalk.org](http://healthtalk.org) resource) and we're trying to spread the word, via the charity and also through the Before I Die Festivals we organised both in Cardiff and York. It is very important that people feel more able to talk about dying and death.

**KT:** Your work has helped the Royal College of Physicians (RCP) develop new guidelines on prolonged disorders of consciousness. How are they helping medical practitioners and families work closer together in deciding treatment options?

**JK:** The guidelines are available online via the RCP and can be invaluable because they provide a map, with signposts and directions as to what should happen and to what timescale, after a person is in a prolonged disorder of consciousness. For families who've felt lost in the wilderness, alone without a compass, that's really important. And for doctors, who may themselves be unsure of some of the issues, it's a crucial reference document. Working with the RCP we ensured that there was clear information in the guidelines about doctors' duties to consult with families. We have also created some additional booklets based on the guidelines to make them more accessible to families, and help them hold doctors

to account – they are all available on our research centre website at [www.cdcc.org.uk](http://www.cdcc.org.uk).

**KT:** Does the Coma and Disorders of Consciousness Research Centre work have any implications for considering whether the law concerning permanent vegetative state (PVS) and minimally conscious state (MCS) patients need to be changed?

**CK:** Yes, and we're trying to change it! The main problem we're addressing right now is that the law says that artificial nutrition and hydration cannot be withdrawn from a patient in a permanent vegetative state without a court hearing even if everyone, all the family and all the doctors, believe it is in the patient's best interests to withdraw such treatment and the patient had been clear they would not want to be sustained in PVS.

Nobody wants to go to court, not the clinical commissioning group or trust, not the doctors, not the family. The process of applying and getting to court can be intimidating and is time-consuming and costly. This means that patients go on receiving treatment for months or (usually) years after family members have come to believe that this is not what the patient would want. We are working with a multi-disciplinary team of lawyers, doctors, and other experts to find a way of streamlining the court application process and making it less stressful for everyone concerned.

The [healthtalk.org](http://healthtalk.org) resource about vegetative and minimally conscious states topped the Information on Ethical Issues category in the 2015 BMA Patient Information Awards.

The reviewer for the BMA praised the team for creating: "a profoundly honest and singular resource which will offer wisdom, empathy, insight and support to others... of great value to both families and clinicians." They added: "In over five years of reviewing for the awards this is the best resource I have seen."

The resource was used by over 4,000 people within months of launch and has also won awards for its impact on policy and society.



L to R: Margaret Kellas (Patient/Family Representative member of the Advisory Group), Professor Jenny Kitinger, Professor Celia Kitinger and Gunars Libeks (Patient/Family Representative member of the Advisory Group) at the BMA Patient Information Awards

# CHALLENGE

## CARDIFF



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Jo Oliver talks to Professor  
Valerie O'Donnell

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Walford Davies

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Ester Coma Bassas on affordable  
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