

Making medical decisions

December 13 2013



"You're asking me to make these decisions. How do I make these decisions? I'm fighting for my little girl's life [...] We shouldn't have been asked for a decision. [...] it was almost as if the responsibility was being passed over to us."

"I had no blueprint for dealing with it. I felt pretty helpless. I couldn't do anything. [...]"

We weren't told we had any role."

These are just two testimonies from [family members](#) who were involved in decisions about medical treatment for a relative in a vegetative or minimally conscious state that have inspired a new publication.

Serious Medical Decisions - the role of family and friends has been produced by the Chronic Disorders of Consciousness Research Centre, an interdisciplinary collaboration between Cardiff University and the University of York led by Professor Jenny Kitinger and Professor Celia Kitinger.

It comes in response to research by the Centre which found that families often do not know their role in making serious decisions for a relative who lacks the capacity to do so themselves, and that practitioners were not always clear about the Mental Capacity Act.

Professor Celia Kitinger of the Department of Sociology at York said: "The Mental Capacity Act spells out that clinicians should ask families for their views about what their relative would want in order to inform [treatment decisions](#). However 51 [family](#) members with a severely brain injured relative were interviewed for our study and often, they reported that they had never been asked about their relative's own wishes."

The booklet helps clarify the law in England and Wales and sets out the role of both family members and clinicians.

It describes the types of decisions that may need to be made including: whether to put 'Do Not Attempt Resuscitation' on the patient's records, how best to respond if the patient develops pneumonia, and whether continuation or discontinuation of clinically assisted nutrition and hydration is appropriate.

Professor Jenny Kitinger of Cardiff's School of Journalism, Media and Cultural Studies said: 'This booklet is so important and much needed –

not just for families, but for clinicians too. Family members have no right to make decisions for another adult. But, they must be consulted so that the doctors who are responsible for treatment can learn about the patient's own values and beliefs and factor that into their decisions."

Serious Medical Decisions was developed as part of the Royal College of Physicians' (RCP) working party updating guidelines on management of patients in vegetative and low awareness states. It will be distributed at the RCP conference on Thursday 12 December and ultimately, in hospitals and care and rehabilitation centres around the UK. It is also available [online](#).

Welcoming the new booklet, Stephen Allen, Chief Officer, Cardiff and Vale of Glamorgan Community Health Council said: "Most families find it difficult to talk about what they would do should they or someone they love be involved in an accident or suffer an illness that could potentially leave them in either a vegetative or minimally conscious state. You need to consider where would you go for advice and support at this critical time. In our view this booklet provides clarity on the processes both families and friends need to know and what the role of the clinicians will be at this important time."

Luke Griggs, spokesperson for Headway - the brain injury association added: "Having a loved one in a minimally conscious or [vegetative state](#) places an enormous strain on families, and making complex and difficult choices on their behalf with little knowledge and guidance is extremely difficult.

"Headway welcomes the RCP's new guidance for physicians, and in particular the information for families that will help them to navigate the complex legal system and have the confidence to make decisions that are in the best interests of their relative."

Provided by Cardiff University

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