

Ictal asystole: a diagnostic and management conundrum

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Appendix A: Ictal asystole – the patient perspective

This information was kindly provided to us by patient two from the case report.

Signalling question	Patient's response
What has been your overall experience with this condition?	<p>“My first seizure was a shock but in hindsight not a surprise as I had been having episodes of ‘déjà vu’ for several years prior. I had collapsed in 2009 and underwent several tests both for neuro and cardiac causes. No abnormalities were detected at that time.</p> <p>After my seizure, I was admitted to hospital overnight and then went for tests to look for what may have caused the seizure. I was started on antiepileptic medication and was told I had epilepsy. I stopped driving but carried on working. I had some other tests including a heart trace monitor for two days. When I was wearing the monitor, I passed out again. When I handed the heart trace back to the clinic later that day, one of the doctors called and explained that my heart rhythm was too slow during the symptoms and that I needed a pacemaker. I went in and had the procedure the next day.</p> <p>The doctors now thought it was the abnormal heart rhythm that caused the seizure and not epilepsy, so they took me off the medication and told me I could reapply for my driving licence. But six weeks later, I had another seizure even though I had a pacemaker; so unfortunately the problem has been epilepsy and an abnormal heart rate.”</p>
How did it make you feel when you were first told you had a diagnosis of epilepsy?	<p>“My first thought was about not being able to drive and losing my independence. I was also very aware that my seizures happened in front of colleagues and loved ones so I felt very vulnerable and the thought of losing control is frightening even now.”</p>
How did it then make you feel when you were then told you didn't have epilepsy?	<p>“I felt fantastic!! I could reapply for my licence and I was ‘fixed’. Ok – I had a pacemaker but that gave me a sense of security that it would trigger if my heart went too slow. So no more seizures – I felt relieved by that.”</p>
How did it make you feel when you had a seizure whilst off medication thinking that you didn't have epilepsy?	<p>“I was extremely disappointed and frustrated as I had been given two diagnoses - then one was excluded but then it reappeared with no warning. I was also upset for my husband as he witnessed the second seizure and that might not have happened if I had kept taking the medication.”</p>
What has been the impact of having a diagnosis of epilepsy on your life? What would you like to see done better for others who may have a similar diagnosis to yours?	<p>“Epilepsy has not really changed my life very much (....except for the driving part) but I'm used to coping with medical conditions so I have learned to ‘just get on with it!’ My hope is that the medication continues to control the seizures so I don't have any more. In future, I would hope to see more collective decisions made about diagnosis and management for people with more than one symptom or diagnosis.”</p>

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