

## Why ignoring fainting could be fatal: That 'funny turn' could be a warning you have a life-threatening heart condition

By [Jo Waters](#)

Julie Fear and her 18-month-daughter Naomi were sitting on the sofa playing when, without warning, the toddler suddenly pitched forwards and fell, hitting her head hard on the floor.

It was a nasty bump yet, when Julie picked her up, Naomi wasn't crying - she was completely silent.



Naomi Fear (right) her mother Julie and grandfather John Watts all had pace makers fitted

'Her face was like a waxwork dummy, there were dark shadows under her eyes, her lips were blue and she was so perfectly still, I thought she was dead,' recalls Julie.

'I panicked and rushed to my neighbour's house with her, but by the time I got there, she had come round.

'Later, as we drove to A & E in an ambulance, I felt relieved Naomi was still alive, but was dreading the diagnosis.'



Syncope Trust And Reflex anoxic Seizures

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That's because she, too, suffered from blackouts. These had had a significant impact on her life and health - not least because the strong drugs she was prescribed didn't work, causing debilitating side effects. Julie feared her daughter would face the same fate.

But like many thousands of others who suffer blackouts, Julie didn't realise her condition was entirely treatable. More importantly, the right kind of treatment was vital - it could save her life.

Every year more than 200,000 people are hospitalised after suffering a sudden blackout and fall. Usually it's assumed they've fallen because they're old and frail. Others end up being diagnosed with epilepsy.

But often the real cause is actually an arrhythmia - where the heart beats either too slow or too fast.

This causes a lack of blood flow to the brain and temporary loss of consciousness, known as a syncope.

It is a deeply worrying problem, as an untreated arrhythmia, while also extremely debilitating, can lead to sudden cardiac death.

There are 100,000 sudden cardiac deaths in Britain each year and experts estimate 80 per cent could be prevented with the right treatment.

## *The human costs of misdiagnosis are huge*

'Around a third of "falls" in the elderly are probably a blackout, causing a collapse,' explains Dr Adam Fitzpatrick, a consultant cardiologist and electro-physiologist at Manchester Royal Infirmary.

'And of these, around 30 per cent are candidates for a pacemaker, but they are not always being treated because they are not having the appropriate investigations.'

As a result, elderly patients 'mostly end up in orthopaedics and the reason why they fell is never discovered', adds Trudie Lobban, chief executive of the charity Arrhythmia Alliance.

Dr Fitzpatrick's own research suggests up to half of those who suffer from blackouts actually have a heart problem, including arrhythmias.

Heart arrhythmias are detected with an electrocardiogram (ECG) - a test which records the rhythm and electrical activity of the heart.

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'It's vitally important that patients who've had a blackout are given an ECG to rule out an abnormal heart rhythm,' says Dr Fitzpatrick.



Feeling faint: Regular blackouts could mean you have an underlying heart problem

'But only 30 per cent of GP practices have these machines and even then they are not properly financed or supported to provide the service, even though general practice is probably the best place to use ECG screening; A& E can be very busy and ECGs can be neglected.

'Most neurology clinics are often not geared up for them, either.'

The problem is not just that patients are being misdiagnosed. Even when correctly diagnosed, many arrhythmia patients are not being given the best life-saving treatment.

'While drug treatments - betablockers and other medication which controls electrical impulses in the heart - work for some, many don't do as well on them and continue to have blackouts,' says Dr Fitzpatrick.

'These patients need to be referred on to a cardiologist to have implantable cardiac devices fitted, such as pacemakers, which regulate the heartbeat by delivering electrical impulses - one of the most effective treatments - but this isn't happening in a lot of cases.'

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Britain has one of the lowest rates of pacemaker implants in Western Europe. At around 450 per million population, this is significantly lower than the 900 to 1,000 per million performed in countries such as Germany, the Netherlands, France and Belgium.

'Pacemakers can improve quality of life and also save lives by preventing sudden cardiac deaths,' says Lobban. 'There is no doubt that in many cases - possibly thousands - failure to receive a pacemaker can be fatal,' adds Dr Fitzpatrick.

This is not, for once, about lack of money. Rather the problem is misdiagnosis, and reluctance among doctors - both GPs and casualty doctors - to refer patients for pacemaker treatment.

'There is a lack of awareness among doctors working in acute medicine, including a lot of junior doctors, about who is a suitable candidate for a pacemaker,' says Dr Fitzpatrick.

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Misdiagnosis: Many people are wrongly diagnosed with epilepsy when they have fainting fits (posed by model)

Julie Fear's family experience epitomises many of the problems with diagnosing and treating arrhythmia.

She'd suffered fainting spells since childhood and, aged 12, was diagnosed with temporal lobe epilepsy - recurrent seizures caused by sudden bursts of electrical activity in the brain.

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This diagnosis had a huge impact on her life. 'It affected every aspect,' recalls Julie, now 45 and a database administrator. 'I'd wanted to be a policewoman, but taking epilepsy medication affected my concentration and I didn't get enough O-Levels.

'I lacked confidence and constantly worried about having an attack. Mum wouldn't even let me lock the bathroom door. I couldn't go to discos like most teenagers because I was concerned the flashing lights would trigger a blackout.

*'It's vitally important that patients who've had a blackout are given an ECG to rule out an abnormal heart rhythm'*

'If I was invited for a sleepover, most parents didn't want me to come when they found out about my epilepsy as they didn't want the responsibility.

'Then, when I had children, I constantly worried about collapsing when I was alone with them - especially when they were babies. I worried I might drop them on the stairs or that they would drown in the bath.

'My medication never stopped my fainting spells and made me feel spaced out, so after four years, I stopped taking it. Whenever I went to the doctor to say I didn't feel right, I was told I was stressed or depressed - my symptoms were never properly investigated.'

'I really didn't want Naomi to go through what I'd experienced,' recalls Julie, who lives with her husband, Andrew, 46, a prison officer, and their daughters, Melissa, 23, Zoe, 20 and Naomi, now 17, in Portland, Dorset.

'My dad suffered similar fainting spells as a child, but appeared to grow out of them and I was hoping Naomi would be like him, rather than me.'

## DO YOU NEED THE ELECTRIC HEART TEST?

THE classic symptoms of an arrhythmia blackout (syncope) are a temporary loss of consciousness for a few seconds or minutes, sometimes accompanied by twitching of limbs and incontinence. Very often the patient turns deathly pale.

The only obvious differences between this and an epileptic seizure is with a syncope the patient may have some memory of passing out and recover quite

quickly. After a seizure, a patient will usually have no memory of it happening and may be confused and drowsy for up to 40 minutes.

The charity STARS recommends that all patients who've had a blackout have a 12-lead ECG heart rhythm test (where leads are attached to the chest and limbs) to check for abnormal heart rhythms before they undergo neurological investigations.



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After her fall Naomi was diagnosed with anoxic seizures - caused when blood flow to the brain stops or slows due to shock, fear, abnormal heart rhythms, or even a hot bath.

Anoxic seizures affect around 1 in 1,000 people and the majority (75 per cent) of children will outgrow the condition.

'The doctor described it as a simple fainting spell and said she'd probably never have another and I felt so relieved. However, when she came home from hospital, Naomi had several blackouts in just a few days.

'Eventually, she was tested for epilepsy but the tests were negative. The specialist insisted she was having anoxic seizures and kept saying she'd probably outgrow them.

'I didn't feel I could challenge his diagnosis.'

But Naomi's fainting spells continued radically for the next ten years.

'Sometimes she'd go for months without having one, but then have several in a week.

'Each was so scary I feared it would be her last. Her lips would go blue, she'd turn white as a sheet, her arm would shake, and she'd arch her back and most times wet herself, too.

'She found it very difficult to cope with and would get terribly upset, especially if it happened at school. She hated children crowding round her to look.

'By the age of eight, though, the attacks seemed to be less frequent and we hoped she was outgrowing them at last.'

In December 2001, Julie's own fainting spells worsened and she began having several attacks a month. She was put back on epilepsy medication, which again failed to control her symptoms.

*'I was offered an implantable  
pacemaker and haven't had any  
blackouts since'*

After one attack, Julie's husband remarked on how similar her symptoms were to Naomi's and suggested they do their own research.

On the internet the couple came across the charity Syncope Trust And Reflex anoxic Seizure (STARS) and realised Julie's symptoms were a perfect match for syncope.

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'I spoke to STARS who advised me to go back to my GP and ask to be referred to Professor Chris Mathias, a specialist in neurovascular medicine at St Mary's Hospital, London.

'He agreed to see me, but it wasn't straightforward - we had to appeal to a panel for funding for the referral outside the area and that took a year, then I waited another nine months for an appointment.'

She eventually saw Professor Mathias in September 2002; tests confirmed her fainting spells were due not to epilepsy but to syncope caused by a slow heartbeat.

She was offered an implantable pacemaker, which was fitted in 2004. She hasn't had any blackouts since.

Shortly after Julie's diagnosis, her father John Watts, 70, from Wyke Regis, Dorset, also suffered a recurrence of his childhood blackouts.

He says: 'It's only because of what happened to Julie I was aware of syncope and was able to ask to be referred to the right specialist.'

John was diagnosed with the same type of arrhythmia and given a pacemaker. In 2006, Naomi, then 14, experienced a recurrence of her blackouts for the first time in years.

The family assumed these were 'just' her anoxic seizures, until after one blackout when her teacher accused Naomi of being drunk.

Naomi says: 'I felt so humiliated, I came home in tears and asked Mum if I could be investigated for syncope - I'd seen what a difference having a pacemaker made to her life and wanted to know if I needed one, too.'

*'We could have died at any time because of this condition - why did nobody think to test us?'*

Tests showed Naomi had the same problem. 'At one stage my heart stopped for 45 seconds. When they asked me if I wanted a pacemaker fitted, I didn't hesitate.'

One was duly fitted in July 2007 and she's had no blackouts since. In a minority of cases arrhythmias are genetic - but it's not standard practice to screen all family members if someone in the family is diagnosed.

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Even if Naomi's family is unusual in having so many cases, their misdiagnoses are far from unique.

Around 30 per cent of adults and 40 per cent of children who are diagnosed with epilepsy actually have a heart arrhythmia. In his own research Dr Fitzpatrick has found a high number of blackout patients have heart problems.

Two years ago he set up a multi-disciplinary rapid-access blackouts clinic which has seen more than 350 patients referred by physicians, A & E doctors, neurologists and GPs.

Half had abnormal ECGs, suggesting they had heart problems; 20 were subsequently fitted with pacemakers and three with defibrillators, another type of cardiac implant.

Only 2.5 per cent needed investigating for suspected epilepsy. A misdiagnosis of epilepsy reflects the fact that the symptoms of heart arrhythmia blackouts and epileptic seizures are similar - both involve abrupt loss of consciousness, involuntary twitching of the limbs and incontinence.

However, there are differences, and last month STARS and the Arrhythmia Alliance launched a checklist for patients who suffer blackouts and their doctors to highlight awareness of these symptoms and speed up diagnosis.

The key is having an ECG, says Dr Fitzpatrick. 'Taking a detailed history and an ECG can stop a patient who has suffered a blackout from being wrongly diagnosed as epileptic and ensure they are directed to the right specialist for any further investigations or treatment, such as a pacemaker.'

Although Britain's new pacemaker implant rate is improving – up 3.5 per cent on the previous year in 2008 - we would have to increase the number of new pacemaker operations by 13 per cent a year for the next six years just to catch up with where comparable European countries are now.

Perhaps surprisingly, our low implant rate is not down to 'a question of resources', explains Professor John Camm, consultant cardiologist at St George's Hospital, London.

'It's historical - pacemakers got off to a slow start after their introduction in the UK in 1961 because some physicians and cardiologists didn't believe they were the right treatment for certain electrical problems in the heart. It was new technology and invasive in nature. The first devices were far from reliable.

'But there is also now a problem with physicians failing to refer patients with symptoms on to cardiologists - they simply reassure them and don't feel they warrant a pacemaker.

'It is often difficult to know if a slow heart rhythm is life-threatening. The death threat is usually not immediate, but some way off - years maybe. The physician is not being callous, but does not recognise the unpredictability of some slow heart rhythms.'

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But for Julie Fear and her family, and thousands more like them, the human costs of misdiagnosis are huge.

'I do feel we've been lucky as a family to survive,' says Julie. 'But equally it scares me that any one of the three of us could have died at any time because of this condition. Why did nobody think to test us?'

'And why did we each have to fight for a diagnosis when we all had the same symptoms?'

- For more details, call 01789 450564 or visit [www.stars.org.uk /diagnosis/blackouts-checklist](http://www.stars.org.uk/diagnosis/blackouts-checklist)

Read more: <http://www.dailymail.co.uk/health/article-1232210/Why-ignoring-fainting-fatal-That-funny-turn-warning-life-threatening-heart-condition.html#ixzz0YXi7JPQj>

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