

Rising to the challenge



It's amazing what support and determination can achieve. Here, four inspirational people talk about overcoming the challenges of epilepsy to reach their goals.

A father-daughter team

These days Paul Wade stashes his keys and mobile phone in a bum bag so he doesn't forget where he left them. But he'll always remember his first seizure. It was in Buenos Aires, 1993, and he was 32, the celebrated captain of Australia's national soccer team. He was just about to run onto the field in a World-Cup qualifying match when he collapsed in front of the Socceroos physio.

Tests revealed a scratch on his brain causing epilepsy. "I instantly went into panic mode because I didn't know what epilepsy was. I didn't have a clue. It's not pleasant."

Paul hid his epilepsy for years as he moved on to work as a soccer commentator. "I didn't want to lose my job on television or playing soccer," he says. "I thought everyone would discriminate against me."

But his secret was revealed in the most public way possible - he had a seizure

while broadcasting a live interview in 2001. Eventually, Paul was offered the chance to undergo brain surgery to stop the seizures. The invasive treatment involved injecting a radioactive substance that travels to the brain to see which part was causing the seizures. Then a piece of Paul's brain the size of two matchboxes was removed. The operation was a success and Paul walked out of the hospital after just seven days. He hasn't had a seizure since although his short term memory was affected.

Paul, who now works as a motivational speaker, sports coach and commentator, credits Epilepsy Action with providing invaluable support through his ordeal. "It was mainly them that helped me. Not physically but certainly they helped give me a bit of mental strength."

"Facing epilepsy is bad enough but facing it on your own worse. Even if they're just there to lend an ear. It's scary for an



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adult - I can't imagine what it's like for a little kid.”

But Paul did learn what it's like for a little kid when his daughter, Brianna-Lee, was diagnosed with epilepsy.

“I was giving show and tell in Year 2,” says Brianna-Lee. “I just all of a sudden saw black-and-white dots like when your TV goes funny. Then I kind of blacked out.”

Brianna-Lee, now 15 and a keen soccer player, says her father's support and understanding helps her manage life with the condition. “Dad knows what I'm going through because he's been through it.”

Talking with other young people has also helped put things into perspective. Brianna-Lee attended an Epilepsy Action camp for teens where she learned to ski. The camps provide an opportunity to stretch beyond mental and physical boundaries, and get to know other kids

in a similar situation, supported by supervisors and volunteers.

“The camps I've been on have really boosted my confidence and also Dad, he explains things so well, he makes you feel so good about yourself. No matter what, he always has the solutions. He's always been there for me.”

Like to hear more from Paul Wade? For information about his motivational presentations for businesses, schools or community groups, email pwade@sportseg.com.au or visit www.sportseg.com.au and click on 'Paul Wade Skills for Life'.

Brianna-Lee Wade (above) loves physical challenges like playing soccer and skiing on the Epilepsy Action 2006 Winter Youth Camp, where she says “everyone knows where you're coming from. It kind of comforts you.”



Graham Cowley believes complete honesty with friends and family (far right) is the “wiser approach.”

Sheer determination

At 61, Graham Cowley is a retired lawyer, founder of one of Sydney’s largest law practices, and former vice chair of the world’s largest group of law firms. But his success is a far cry from what he expected when, aged 13, he had his first seizure in class at a Sydney high school.

“My only memory of the seizure was waking up dazed and frightened,” says Graham. At first, “I was convinced epilepsy was the beginning of an inevitable route to a lunatic asylum, being locked up. I was fortunate that the first neurologist I went to see, now a lifelong friend, dispelled those myths.”

Not every doctor gave such sound advice. “In second-year law school at Sydney University I had seizures and the local GP was quite adamant I’d have to give up uni and because of

the stress I’d have to drop out,” he says.

Graham believes his sheer determination and a refusal to let discrimination hold him back have contributed to his many achievements. “Having a seizure is devastating. You feel lousy for days. You’ve bitten your tongue to death, you feel like you’ve had a king hit. It’s hard to have seizures and just say, ‘to hell with it, I’m getting on with life.’ I think I came to the early realisation I didn’t have much choice. It was either go under or stay on top.”

He also adopted what he calls “a wiser approach” – complete honesty about his condition with family, friends, colleagues. Even so, he confesses that “always in the back of your mind, you think, ‘I hope I don’t have a seizure addressing a room of lawyers in New York.’” While that never happened, Graham – having



“There’s progress,” says Sebastian’s mum, who adds that help from Educator Darren Midgley has contributed to “big improvements.”



Sebastian’s school days

It may not be brain surgery, but for Sebastian Hurrell, 5, starting school was an enormous challenge that he’s successfully overcome.

“I think socially it’s been very difficult for Sebastian,” says his mum, Hannah McCrimmon-Hurrell. “That’s probably been the biggest impact of all. I guess it’s because he can’t keep up with play and children don’t understand him because he mumbles. They ask questions like ‘why doesn’t he answer

me sometimes?’”

Sebastian has an intrusive form of epilepsy where his arms fly up unexpectedly. He also has tonic clonic seizures characterised by stiffening, loss of consciousness and jerky movements. So it was important everyone in his life understood the implications of the condition.

Epilepsy Action Educator Darren Midgley met with the family and made presentations at Sebastian’s school covering types of sei-

zures, first aid and social impacts. Darren will go back this year to answer the kids’ questions about epilepsy, which is a huge support to Sebastian’s social integration.

Meanwhile Sebastian continues improving in a supportive environment. “He’s had delays in his learning,” says Hannah, “but there are big improvements and every term we set goals with his teacher and special education support person. Every term he’s met his goals, so there’s progress. It’s just slow.”

been seizure-free since age 22 - was "massively disappointed" to have another one at 58.

When he's not playing tennis, reading or spending time with the five-year-old grandson "I dearly love," Graham now volunteers his time and skills to chair the Epilepsy Action Board. "I'm very happy about that," he says, "because I realise how tough it is for people. There's an emotional tug, having epilepsy myself, that makes it that extra bit special."

"I came to the early realisation... it was either go under or stay on top," says Graham (with son Kim, wife Diane and daughter Amber).



Communication is the key

Whether it's talking openly with family, structured presentations from Epilepsy Action Educators, informal chats on a ski camp, or strategic discussions with co-workers, honest communication can be an important coping strategy.

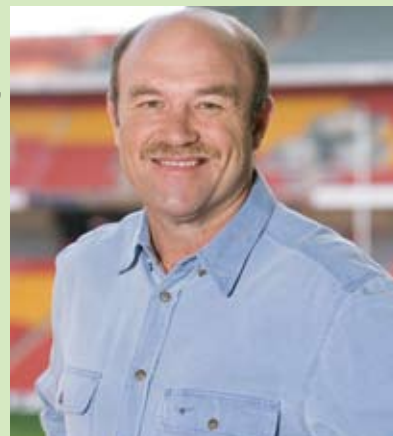
For Paul Wade, 'coming out' allowed his director to cover for him during the fateful live interview when he had a seizure. "The director had said we'll have a contingency plan if you have a seizure," he says. "They cut to a part of the crowd to try to distract from my voice. People don't mind, they can deal with it."

And for Graham Cowley, it goes beyond practical planning: it's a matter of pride. "I've made no bones about it with anyone in my life," he says. "I thought that was the smartest thing to do - why be ashamed? It's like being ashamed of having cancer."

“
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Fast facts **Surgery**

This February ex-rugby league star and TV commentator, Wally Lewis, joined ex-Socceroo Paul Wade and underwent a three-and-a-half hour operation to control his epilepsy. Here we take a brief look at this treatment option.



What is epilepsy surgery?

Surgery is an alternative treatment available predominantly to those with partial seizures, one of the more challenging forms to control. Surgery offers a chance to significantly reduce seizures or become seizure free.

Who is suitable?

Surgery may be considered when medical treatment has been unsuccessful and:

- Seizures come from only one small area of the brain (focal seizures).
- Seizures are particularly debilitating or dangerous such as tonic, atonic seizures (drop attacks) and status epilepticus (prolonged seizures).
- Seizures occur many times a day making normal life impossible.
- The cause of the seizures may be worsening, eg a tumour.

Would I need tests?

Prior to surgery, a large number of tests are conducted and a one-to-two week period in hospital may be required to record seizures. These tests can include:

- Videotelemetric EEG or continuous EEG recording and video monitoring for a period of time to record seizures.

- Magnetic Resonance Imaging (MRI) scan, which records detailed pictures of the brain and is effective in identifying brain abnormalities.

What next?

The decision to operate is based on the results of the tests and the person's choice. Some may decide against it and others may be told that it's not an option for them.

Preparing for surgery

When preparing for surgery, it's important to:

- Stay healthy.
- Take the medications as prescribed by the doctor.
- Stop smoking.
- Stay well informed through the surgical process.
- Ask lots of questions.

Life after surgery

For those who can have it, successful surgery means seizure freedom, or a drastic reduction in seizures and medications, opening the door to many new opportunities.

Major epilepsy centres at public hospitals offer information about epilepsy surgery or contact Epilepsy Action for a more in-depth factsheet.