

Gabriel Tullio with parents Gabby and Rachele

IT TOOK just 15 seconds for Rachele Tullio's life to turn upside down on a Sunday morning in 2013, all the time needed for her to wake groggily from dreams to find herself in the middle of a waking nightmare.

Her son had been knocking at the bedroom door; that's what shocked her into wakefulness. In a moment, the 16-year-old was in the room, turning on all the lights. Standing at the end of their bed, Gabriel came with strange news: he had a bad headache, his arm felt funny, and there was something wrong with his mouth. His speech sounded slurred, his voice strained and anxious.

Then, without warning he collapsed on the floor as his mother cried out in sudden realisation: "He's having a stroke!"

Even muddled with sleep, the trio of symptoms had set off alarm bells for Rachele who, with husband Gabby, had recently completed a refresher first aid course as part of her school teacher's registration requirement.

Could an apparently healthy teenager be having a stroke? She couldn't be sure. But one thing was certain: the Tullio family had been plunged into a crisis – now Gabriel's life would depend on how they responded.

Rachele called an ambulance, despite some qualms she might be over-reacting. Better to be on the safe side, she figured. And she was right: after Gabriel was



REBUILDING *gabriel*

words **sarah hender** pictures **calum robertson**

rushed to the Queen Elizabeth Hospital by ambulance, a CAT scan indicated a deep bleed in the boy's brain. He needed urgent surgery – work that could only be performed at the Women's and Children's Hospital. Ominously, one doctor told the couple they should say goodbye to their son before he was transferred.

The crisis could not have been foreseen. Unknown to anyone, at some point early in Gabriel's development, blood vessels in his brain had been malformed. The condition, known as an arteriovenous malformation (AVM), is relatively rare, and found in less than 1 per cent of the population. The most common way people learn they have one is when it bleeds, a potentially fatal event that affects about three out of 100 people with a brain AVM every year. In about half of all cases, the bleeds cause permanent disability or death.

Such was the reality confronting Adelaide neurosurgeon Dr Amal Abou-Hamden in the middle of that night. "When I received the phone call about Gabriel in the early hours of the morning describing the situation, I knew that he would not survive unless we acted very fast," recalls the 40-year-old specialist, whose family moved to Adelaide from Lebanon when she was 14.

The boy needed an urgent craniotomy, an operation to remove a piece of the skull to enable the surgeon to remove the

Gabriel Tullio was millimetres from death last year after having a stroke. The 17-year-old, his family and medical staff talk about his recovery

haemorrhage and the malformed blood vessels that caused the problem.

"Surgery for the more complex AVMs has been likened to the dismantling of a time-bomb," says Abou-Hamden, a specialist in dealing with AVMs. "An AVM can bleed at any time even in the absence of surgery. Careful disconnection of the fragile tangle of blood vessels is essential to prevent potentially catastrophic bleeding with devastating consequences for the patient."

Hours of planning would normally be needed for such an operation – and Gabriel's was a complex case, even for an AVM. But there was no time. "The haemorrhage had extended deep into the brain and was causing a tremendous amount of pressure on the rest of his brain," the surgeon explains.

It took four hours of surgery before the worst was over. Four hours to remove a pool of blood pressing on Gabriel's brain and fix the tangled web of vessels which had caused the problem. Four hours that must have seemed like a night without end for Rachele and Gabby.

“SURGERY... HAS BEEN LIKENED TO THE DISMANTLING OF A TIME-BOMB

Then, it was done. When Abou-Hamden came to the tiny waiting room off the Paediatric Intensive Care Unit (PICU) where Gabriel's parents were waiting, she took off her cap, leaned on the doorway, and sighed. The news was good – she and her team had managed to keep Gabriel alive.

How close had they come to losing their boy, Rachele had to ask. Gabriel had been 2mm from instant death. Explains Abou-Hamden: "[The haemorrhage] was only millimetres away from compressing the brainstem, the part of the brain

that controls vital functions including heart and lungs function. Any further pressure on this critical part of the brain would have resulted in the arrest of these vital functions."

Rachele was relieved, yet stunned.

Only a few hours before, she and Gabby had been chatting with their son over a coffee in Henley Square, talking to him about how school was going, his future dream of studying law and a possible family holiday.

Later that night, when Gabriel asked Rachele for a back rub to relax after studying she thought nothing of it. She kissed Gabriel good night on the right side of his head. It was exactly where a piece of his skull would be removed a few hours later.

But, when Rachele walked into the intensive care unit, that was all hidden from her. There her son lay, attached to machinery, with tubes everywhere, his eyes swollen, and bandages wrapped around his head.

"It was at that moment I realised how sick my son was and how much I needed

life SAVER

words sarah hender



DR AMAL ABOU-HAMDEN is very happy for George Clooney's impending nuptials. "Thank God for George Clooney's fiancée Amal – at least my name is now sorted and they don't think I'm a male anymore," says the 40-year-old high achiever, who hasn't had time for marriage herself.

Abou-Hamden's family migrated to Adelaide when she was 14. Explaining her surname was always a bit of an issue at medical school. People would say "oh so you're half Arabic, half English?" It is in fact a full Arabic name, "Abou" meaning "father of". When she told her friends at medical school that "Abou" was the equivalent of a "Mc" or an "O" in front of an English name, it was inevitable she would be given the nickname "McHamden".

When the doctor took the phone call about Gabriel in the early hours of that April morning, she got enough information in that few minutes to understand that she had to get herself out of bed and into her car to head to hospital. Whilst driving in, the neurosurgery registrar on call was giving her information about Gabriel so that she could work out what she would need and she was giving him instructions about everything she might need in theatre. Once in theatre, the rostered nursing and anaesthetic staff were working towards the end of their shift.

"We probably went through two sets of staff during Gabriel's surgery, but as the surgeon you are 'it'," she says. "There have been times during long complex operations when you can be there for 10-12 hours and you can literally go through three sets of scrub nurses and anaesthetists while you're left standing."

Abou-Hamden is the only doctor in Adelaide who has undergone formal extra subspecialty training in vascular neurosurgery. There are a couple of other neurosurgeons in town who would have been able to operate on Gabriel but being such highly specialised surgery it was fortunate for Gabriel that he received care from a doctor most qualified to perform it.

Abou-Hamden saw a need for this specialist skill in her training as a neurosurgeon in Adelaide where she saw patients having to go interstate to receive this kind of specialist care. "It didn't sit well with me," she says. "You know, we were in a capital city. It was just not fair for Adelaide patients to go interstate for that. So I felt there was a need to bring back those skills to Adelaide."

Following neurosurgical training in Australia, Abou-Hamden did her post-graduate fellowship training in vascular neurosurgery and paediatric neurosurgery from 2008-2010 in Toronto, Canada. She returned to Adelaide and began as a consultant here at the end of 2010.

"There are a lot of things that are interesting in medicine but at the end of the day you can't help who or what you fall in love with," she says.

Perhaps this may explain why there



Gabriel Tullio with Dr Amal Abou-Hamden who performed the delicate operation on his brain to remove the haemorrhage and malformed blood vessels which caused his stroke

PICTURE CALUM ROBERTSON

has been no time as yet for marriage or children.

Abou-Hamden, Gabriel and his family have formed a close bond that the surgeon knows will always remain between them.

"I think whenever you have anybody go through such a harrowing experience, both for the patient and their family, and they are in hospital for such a long time after the treatment, you do form that special bond and connection with them," Abou-Hamden says.

"You know it's not like an elective case when someone comes in for their surgery and they go home within a day or two. You know this was a very difficult experience for the whole family and you see them every day. You do form a special bond," she explains.

"After cases like this – you're operating in the middle of the night and you're exhausted sometimes because you still have a full day's work the next day – and around that time, you just feel relieved when it's over. Then when you see the patient back to their normal life, back to their family, it absolutely gives you that great sense of reward and fulfilment. It makes it all worthwhile and it just drives you the next time.

"Every patient is special, every patient is important but you know you do have situations like this that are just that side of the norm where it was such a close call." ●

SIGNS OF STROKE – F.A.S.T.

FACE Check their face. Has their mouth drooped?

ARM Can they lift both arms?

SPEECH Is their speech slurred? Do they understand you?

TIME Is critical. If you see any of these signs call 000 straight away.

Other signs of stroke may include:

Weakness or numbness or paralysis of the face, arm or leg on either or both sides of the body;

Difficulty speaking or understanding;

Dizziness, loss of balance or an unexplained fall;

Loss of vision, sudden blurring or decreased vision in one or both eyes;

Headache, usually severe and abrupt onset or unexplained change in the pattern of headaches;

Difficulty swallowing.

Information: strokefoundation.com.au

these people in PICU more than anyone else in the world," she says. "I needed their expertise, their compassion and their reassurance more than anything."

Gabriel was one of 540 children admitted to PICU last year. It is a place for the toughest, traumatic cases: children recovering from brain surgery and cranio-facial surgery, injury caused by motor vehicle accidents or falls, and many other serious health problems which may result from respiratory illness, poisoning, diabetes or seizures.

That means the staff have great experience and skills in helping not only the patients, but their families.

Rachele was running on sheer energy with only two hours' sleep, sitting by her son's side, stroking him, talking to him. All of these different people, highly specialised nurses, were attending to him, doing paperwork and monitoring him. Every time they attended to Gabriel, in his unconscious state, Rachele noticed that the staff would speak to him telling him what they would be doing.

"There is always this unknown about whether a patient can hear when they are under sedation," explains Paul Knudsen, a registered nurse with PICU and the first of Gabriel's nurses attending to him.

"We take no chances. We are dealing with human beings and we would rather make them aware of what we are doing, conscious or not conscious, so they will not be scared."

Rachele was impressed as an observer and comforted as a parent by this gentle and respectful approach towards her son and other patients in the ward.

"This left a profound effect on me. I was a learner. I was learning from them. I was frightened. To see the care and compassion they showed my son with such a calm demeanour was a comfort. >>>

"I didn't realise at the time but it was touch and go then."

The silence of PICU was eerie. There were few sounds other than the regular beeping of the mechanical ventilators and monitors that towered over the patients. No idle chat happened here, it was a quiet, structured and professional environment.

Yet despite the serious nature of the work it was strangely not an unhappy place. The walls of the reception area were painted in a warm yellow. All the nursing staff were bright and upbeat, greeting families of patients with a cheerful good morning and introducing themselves to new shell-shocked families.

It would be natural to wonder how the nursing staff could be so seemingly untouched by the crisis that a family had been plunged into. After a short time, it was clear to Rachele that this atmosphere was, of course, deliberately created and was a significant factor in how PICU and its staff manage the day to day, both for the patients and their families and also for themselves.

It was not long before Rachele could see the impact of the nursing staff's cheery behaviour on herself and her son. It regularly rescued them from the intensity of emotions that threatened to be all-consuming. It took the pressure off, even just for a moment.

"These angels of light normalised for us what was an abnormal situation. There was a bit of humour. They would say 'so Gabriel, this is your mum. She's a good-looking sort, isn't she?' They were holding my hand without actually holding it," Rachele says.

It was a day to day existence.

When bad things happen to a child, more than anything, a parent looks for signs of hope that all will be well again.

Rachele saw early on that long-term hope is not something given out freely at PICU. How the early days of a critical illness or injury, particularly a brain injury will play out often requires a "wait and see" approach. That requires close monitoring after the initial stabilisation of a patient.

Yet parents long for a positive early prognosis so they can sleep at night. It seemed to Rachele that, in PICU, such words were kept in a secret locker, only to be opened once the doctor in charge gave staff the key. Before then, it was about celebrating the incremental achievements of the recovering Gabriel.

Knudsen says: "The first major celebration with a PICU patient is always when the breathing tube is removed and

As the nursing staff attended to all the tubes and lines connecting him to life-saving machines, Gabriel awoke. His very first words to the staff were "f*** off". Rachele's immediate reaction was relief.

"He'd managed to get the order of the words right. It was reassurance that cognitively he was functioning!"

There were other encouraging signs that Gabriel was back on planet Earth. Whilst on a drip, he began to ask for water, which soon became a regular shouting demand. On these occasions, the nurse would come over to him and say calmly: "Hi Gab I know you want water but we can't give it to you now. Very soon we can give you as much as you like." In response, Gabriel would say to them: "Listen, I have a job. I will PAY you if you give me some water."

As sedation was decreased and Gabriel's condition improved, his emotional state and his behaviour was not easy to handle at times. The nursing staff took it all in their stride. They had seen it all before. They gave Rachele and her family words of guidance about what was likely to come and how they should handle him.

"People with brain injury often wake up cerebrally irritated and they may say things they don't normally say," Knudsen says. "There might be short-term memory loss and so we have to keep repeating ourselves. We warn the families of what things to expect. We tell them to try and get a good sleep whilst the patient is in PICU as they need to prepare themselves for the long journey ahead."

By the end of Gabriel's first week in PICU, his doctor was able to open that "secret locker" of a longer term prognosis. The nursing staff were able to give Rachele and her family that reassurance that one day Gabriel would walk and when that happened they hoped that he would come back and see them.

"That's the best thing about our job," says Alkisty Moraitis, another registered nurse with PICU, "to be able to get patients through the process of being critically ill and then having them come back or hearing stories about what they are doing now. Often you leave work one day and wonder whether that person will be there tomorrow and then you come back and they are thriving, doing all these amazing things."

Now a little over a year on, at 17, Gabriel is recovering well. Since the stroke he suffers from weakness on the left side of his body. He walks with a limp and still finds it challenging to use his left hand for some daily tasks.

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the patient can breathe on their own". After that, there were the moments when Gabriel's eyes first opened, when he slowly turned his eyes, his first hair wash and even when his family first saw Gabriel missing a large part of his skull.

"These things were actually huge steps in the grand plan of reassembling a human being, putting my child back together again," Rachele says. "It was exciting to see their words come to fruition."

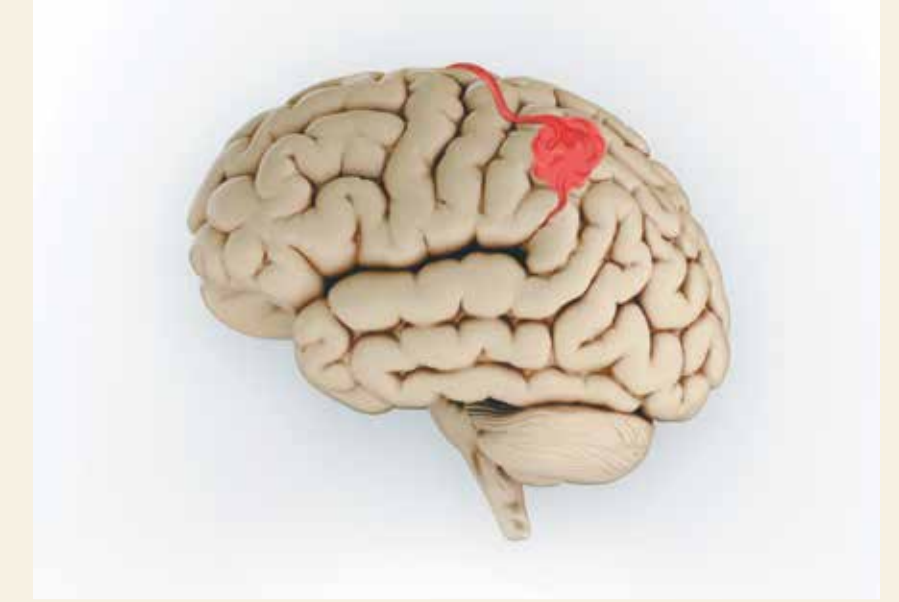
As Gabriel slowly rejoined the real world, there were some funny moments.

According to Abou-Hamden, most improvement is expected in the first few months after a stroke but improvements can continue for years afterwards.

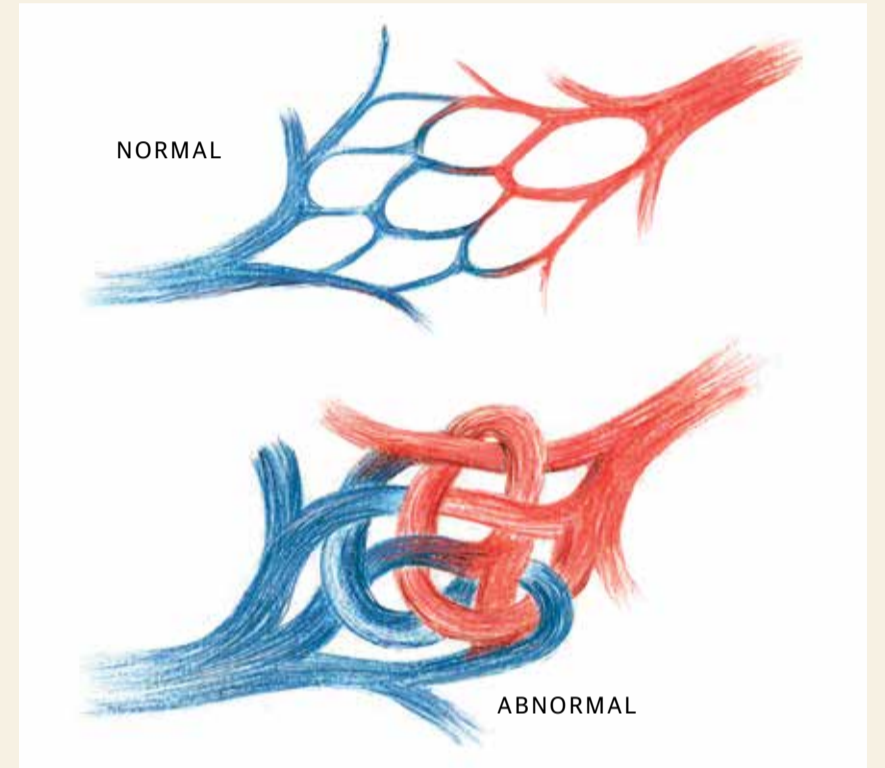
Gabriel spent two weeks in PICU and 13 weeks in total at the hospital. He is still receiving physiotherapy but is able to walk, talk, attend school and go to parties just like most teens. But he is different.

He says his first memory was not until three weeks after surgery.

"When I woke up it was as if I knew I had been there for ages, it was no shock,"



above A brain with an arteriovenous malformation **below** A normal and abnormal connection of the blood vessels



ARTERIOVENOUS MALFORMATION

Arteriovenous malformation (AVM) in the brain is a relatively rare condition, and found in less than 1 per cent of the population. It results from an abnormal tangle of blood vessels in the brain, which develops very early in life. The most common way people learn they have one is when it bleeds, a potentially fatal event that affects about three out of 100 people with a brain AVM every year. In about half of all cases, the bleeds cause permanent disability or death.

Panadol. "I did that at about 11.40pm and walking back from the kitchen to my bedroom I just started to feel a thump in my head. It wasn't like serious pain, it was just a thump but then gradually the pain started really kicking in. I sat on my bed to wait for it to die down but the pain was getting too bad for my liking.

"I was on my way to mum and dad's bedroom when I started feeling this tingling on my left side, my leg and my arm especially. It was just drooping, everything was a bit drooping.

"I was saying to mum and dad I've got this really bad headache, it's not going away and I've taken Panadol. I wasn't frightened, I was unsure and confused and more curious than anything.

"I was saying I can't feel my left side because after a while the tingling had died down into numbness. Then every couple of seconds it was getting harder for me to talk, my mouth was going numb. The last

he says. "My moods were all over the place. One minute I was happy and the next I was shouting my head off. I was pretty terrible to the nurses. They did an expert job of putting up with me."

His recollection of the stroke is haphazard. He doesn't recall going to Henley Square but remembers everything clearly from when they returned home at about 8.30pm. "After mum went to bed, I had a bit of a headache while I was on Facebook, nothing major," he says. A friend on Facebook told him to get a

thing I remember clearly was moments before I collapsed I was asking to go to the bathroom and I remember dad trying to help me up but then I just collapsed.”

Now, Gabriel has discovered a resilience in himself that he never knew he had. “I feel like I can deal with a lot of hard stuff now,” he says. “The stuff I thought was hard before seems like a breeze now. There are so many people that I met while in hospital that have been through worse. I feel grateful to be where I am.”

Gabriel’s previous ambition to study law is still a goal and he does not feel that it is out of reach for him. He is repeating Year II at St Michael’s College at Henley Beach having missed out on three terms of school last year.

“I’ve got greater expectations of myself than before the stroke. I have always had the usual dreams that everyone has of wanting to be successful and happy but now I think I’ve got a better chance of reaching my goals because I’ve been so close to losing it all.”

Gabriel has been back to visit the staff of PICU since leaving hospital and the nurses’ thrill of seeing him walking in was not lost on Rachele.

“These nurses have discovered what meaningfulness is,” she says. “It is a powerful meaning to save a child who needs them. These people are at the cusp of life and death. You realise that what they do makes such a difference to your life and has a ripple effect across the community who are connected to this person who they have saved. This says to me that love is alive.” ●

Gabriel Tullio, centre, with PICU nurse Paul Knudsen and neurosurgeon Dr Amal Abou-Hamden in the operating theatre at the Women's and Children's Hospital

