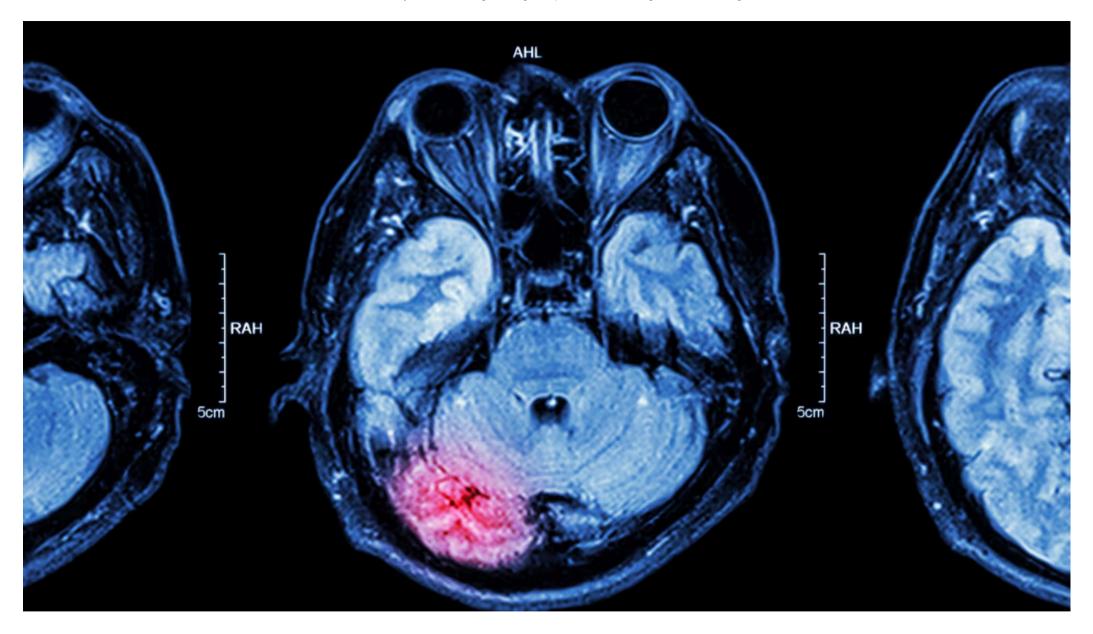


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Why is it so hard to get the right help from ACC following a concussion diagnosis?

By Fiona Terry

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James winces in pain waiting for an ACC staff member to answer his call. Migraine-inducing hold music echoes from his cellphone: ironically, Elvis's words, "We're caught in a trap," on repeat. With debilitating concussion caused by a blow to the head from a basketball travelling at high speed, 18-year-old James (not his real name) struggles to stay focused. Intense headaches, noise sensitivity and fatigue make finding the answers he needs from ACC unbearable.

It's taken 50 minutes just to get through, followed by a further 30 minutes of more hold music while on transfer to the department dealing with concussion, the Assisted Recovery team, so James can find out what treatment services would be included under ACC.

Nearly three weeks after James's visit to the emergency GP his symptoms were not improving. The Assisted Recovery team member promised a reply by email that day. Nothing came. Two days later, James and his mother repeated the lengthy holds and transfers. This became the new normal as they tried to navigate the processes of ACC, the state-owned insurer for accident and injury claims.

Even a recommendation by James's GP for ACC to assign a case manager to help simplify the process was eventually declined, with no explanation or way of appealing the decision.

Yet research shows getting early treatment for concussion improves the chance of full recovery. Frustratingly, James isn't alone in finding the ACC system difficult to navigate, with delays to treatment the consequence.

"My colleague and I spend around a fifth of our working week on hold to ACC," says Emma-Jo Sanders from the Top of the South branch of support charity Brain Injury New Zealand (BINZ).

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Concussion is a form of traumatic brain injury (TBI). TBIs occur as a result of an external force to the head or body, which causes the brain to shake inside the skull. They range from mild to severe, with the vast majority categorised as "mild", which is commonly known as concussion.

ACC says it accepted 47,000 injury claims related to concussion in 2024. This is a jump. Research in 2021-22 led by AUT associate professor Kelly Jones at the National Institute for Stroke and Applied Neurosciences, estimated at least 40,000 New Zealanders sustained TBIs every year.

Rates have climbed since ACC launched its concussion guidelines for community sport last year. ACC acting head of client recovery Hannah Coombes says claims accepted for sports-related concussion rose from 10,712 in 2023 to 12,045 last year, suggesting awareness of concussion is slowly building.

Jones, who's also vice president of BINZ, says, "There's a common misconception that if you have a head knock but don't black out, your brain is fine. That's incorrect. People can have a mild traumatic brain injury without that happening."

Long-term consequences

As well as noise sensitivity and loss of consciousness, other symptoms of concussion include confusion, memory loss, headaches, balance problems, fatigue, cognitive difficulties, speech problems, and irritability.

"Falls are the leading cause of traumatic brain injury in New Zealand, accounting for 48%," says Jones. "Unfortunately, the label 'mild' implies it's not a significant injury. We know many people recover well; however, some with a mild TBI have longer term implications."

Jones was involved in a study funded by the Health Research Council of New Zealand that showed nearly half of adults experiencing a TBI still suffer four or

more persistent post-concussion symptoms a year or more later. These symptoms include headaches, fatigue, forgetfulness and poor concentration.

The study authors note that despite previous perceptions that the symptoms of mild TBI resolve quickly, evidence is emerging that people experience "an array of longer-term difficulties".

The question now being asked by many is whether ACC staff understand this when dealing with concussion sufferers.

"It's not uncommon for ACC to decline treatments that specialists have advised clients receive."

Stacey Mowbray

"We certainly hear there's room for improvement around navigating ACC processes and that's where it could be helpful to visit the Brain Injury New Zealand website," Jones says. "We also get feedback from those suffering from TBIs that they strongly advise to have a support person to help with navigating recovery – including with the ACC system."

Claims to ACC can include payments for those unable to work and sessions with occupational therapists, physiotherapists, psychologists and speech language therapists. These services are contracted out by ACC to specialist providers.

Revolving case managers

Auckland GP Lara Courtenay accidentally walked into a tree as she rushed to work while texting and it led to a life-changing concussion. Her symptoms from the incident in late 2020 included fatigue, severe vision problems, headaches, light sensitivity and communication and balance difficulties. Diagnosed with a mild TBI, accessing care via ACC felt like a constant battle, she says. "There was one

point where my psychologist sessions were about how ACC were treating me," says Courtenay, who is now back at work full time.

"The really sad thing is, from a GP's perspective, I'm sure there are others out there who are severely mentally distressed because of this."

Initially unable to work, she found getting her weekly ACC compensation payments straightforward and her first case manager very understanding. After eight months, though, a new case manager was assigned – Courtenay had more than five in total over four years. "The others seemed ill-equipped in understanding the needs of people with brain injuries. For a while I was also assigned to the Assisted Recovery team, where you can't even get hold of one person."

She recalls spending lengthy periods on hold when needing to liaise with ACC staff – for instance to find out what treatments would be funded, or discuss the return-to-work programme. She also remembers repeatedly having to explain her complex situation again to new ACC staff, while having limited energy.

This not only caused distress, she says, but delayed getting the right medical help.

"In the end, it just gets too hard and you give up. What people with brain injuries need, though, is ACC asking how to support them, especially when [some people] can't even navigate a computer system or check emails."

Courtenay had been struggling as a single mum to care for her daughter, including getting her to school. She desperately wanted to get back to work.

"I couldn't drive but initially nobody from ACC told me I could get help with transport or eye rehabilitation, for instance, because my biggest problem was eye function. I found those things out only because after eight months I decided to switch to a new service provider, Active+, and the occupational therapist there was just incredible – she saved my life.

"As time went on I felt like ACC was trying to find reasons to stop my support and the way they'd speak to me about my symptoms was so dismissive. They would tell me I was fine and then I would see a specialist privately who'd confirm I still needed recovery time and assistance.

"As a doctor, I felt really sad for patients, thinking if this was happening to me – and I have medical knowledge – then there's a lot of injustice out there."

At the Brain Injury NZ office in Nelson, Sanders sees many clients who've persevered unsupported because they couldn't face dealing with ACC, she says.

"Even when they do get through on the phone, the way they're spoken to often is dehumanising. Sometimes you do get staff who are very understanding and patient, but others can be dismissive and abrupt. So many don't seem to understand that people with concussion can have memory loss, problems with cognitive processing, and difficulties speaking or finding words."

"My colleague and I spend around a fifth of our working week on hold to ACC."

Emma-Jo Sanders

One client BINZ is advocating for is Gary, from Nelson, who has debilitating symptoms following severe concussion from a bicycle accident nearly a year ago.

"Gary initially had help but ACC were trying to push him back to work," says Sanders. "Sadly, his employer of 18 years had let him go as his ongoing symptoms included blackouts, which meant he couldn't continue in his role with machinery.

"He has a GP letter stating he can't work, but ACC wrote to him saying they were ceasing his compensation."

Gary's former employer reached out to BINZ on his behalf.

"It's hard enough navigating the ACC system without concussion," adds Sanders, who also coordinates regular social groups across Nelson Tasman and Marlborough to help TBI sufferers connect.

Sanders has some knowledge of dealing with ACC following a TBI. Her mum Janet had a motorbike accident when Sanders was small. "I grew up with the battle she had with ACC" she says.

"The vast majority of people with concussion get put with the Assisted Recovery team. That means you don't have a case manager, but whoever answers the phone or email on the day, and you'll likely have to explain the situation all over again."

Navigation difficulty

David (not his real name), who works in the finance sector in Auckland, has battled ACC since he was badly injured in a jet-ski accident three years ago. He spent more than two months in hospitals and a specialist rehabilitation unit before returning home, still severely disabled. He also suffered multiple broken bones and nerve damage.

"It's been hard with ACC," says David. "I'm on my fifth case manager. My first lasted around nine months and that wasn't a good experience because it felt like she hadn't read my file and never understood my injuries, especially my brain injury.

"Once I'd returned home, ACC contracted a service provider for an occupational therapist, physio and psychologist. However, there was so much to do in the way of organising appointments with specialists I also really needed help with that, but there was none. It was so difficult navigating that with my brain injury, speech difficulties, memory problems and fatigue. I felt like I was going in circles with ACC and not being heard."

David believes staff shortages were behind the revolving case managers. But one of them provided excellent help. "She checked in on me, chased specialists for appointments, understood my injuries, and gave me information on what I needed to do. She would make things easier for me, which with a brain injury is all you want. She was absolutely amazing."

David's brain is still recovering and despite living with fatigue, headaches and pain from his other physical injuries, he still desperately wants to increase his work hours from part time to full time.

Brain injury support group Headway, set up in 1981, has been campaigning for change with the ACC system for those with TBIs for many years.

"It's really unfair and impractical that someone with a concussion is treated through the ACC system like someone with a twisted ankle," says CEO Stacey Mowbray. "The challenges and needs for support are so much more complex.

"If I had a twisted ankle, and needed to talk to ACC and I'm on hold, that's annoying. For those with brain injuries though, that is damaging to their recovery."

She recalls a young client phoning ACC to organise a taxi ACC had committed to paying for.

"It was painful to hear his interaction with the ACC staff member. He was trying to communicate but treated with complete disrespect, not given time to explain himself."

Mowbray is concerned many ACC staff dealing with TBI patients don't understand the injury.

"A while ago, I wrote to ACC offering for us, as an organisation specialising in education, to provide clear training but they said it wasn't needed because they have their own. It's heartbreaking to think it could work so much more smoothly if there were changes, but that's just not being recognised."

Following an independent review in 2016 of ACC's dispute resolution procedures, a new service, WayFinders, was established to help people navigate the organisation's complex and confusing processes.

Since 2019, it has provided free, independent advice. In 2023, a kaupapa Māori navigation service, Te Ara Tūhono. was added. These are independent but funded by ACC.

"They have specially trained staff and the power to escalate claims quickly, but many people are unaware of them," says Mowbray. "The fact they exist highlights the problem of the system."

ACC's processes

In response, ACC's Coombes says the main promotion of WayFinders is via "client-facing staff". "Clients can also appoint someone else, such as friend or family member, who can communicate with us on their behalf about their claim."

Asked why training being turned down, Coombes says an e-learning module teaches staff about TBIs during their induction. This covers how different types of injury affect different functions in the brain and everyday tasks.

"There is also a facilitated training session that expands on this initial training."

She adds the 47,000 concussion claims accepted in 2024 made up just 2.35% of the 2 million claims for last year. "It's important to remember that concussion claims make up only a small portion of overall claims.

"Our systems and teams are designed to support a wide range of injuries, including concussion, within this broader context."

Mowbray emphasises that in some circumstances ACC's system does run smoothly.

"We have seen cases where it works. We've seen case managers who do it well because they understand concussion, know their clients, and are willing to help by informing them about their entitlements.

"We've seen beautiful relationships – but not enough of them.

"We are so lucky as a country to have the best rehab providers and world-leading researchers and to have ACC, but it's not a perfect system. It wouldn't take a lot, though, to change it – just some tweaking and a bit of education."

"I'm really grateful we have ACC but there are problems with the system that so badly need to be fixed."

Joy Webb

Mowbray would like to see ACC create a dedicated team to assist those with TBIs.

"Clients could dial an ACC number taking them straight to a team trained in supporting someone with a TBI. That team could have ongoing relationships with organisations like us and researchers. That could bring massive change in outcomes."

Headway, which focuses on community education such as in schools and workplaces, also runs a peer support programme, Making Headway. This aims to help people gain skills and connections to live well with a brain injury. "Research shows links between concussion and mental health issues, loneliness and isolation, with an increased rate of suicidal ideation linked to brain injury," Mowbray notes. "ACC doesn't fund peer support but our community tells us how important that is."

Registered nurse Joy Webb says attending these Headway events and meeting others proved life changing. She has ongoing symptoms from a moderate

concussion after being knocked off her bicycle by a car in February 2023.

The former Ironman athlete tried returning to her job gradually but was unable to sustain working in a medical environment that required responding to mild emergency situations – a job she'd been dedicated to for 33 years.

"The person assigned to me by ACC was so pushy about me increasing my working hours, even my boss had to step in to advocate for me," she says.

Because she had acute light sensitivity, ACC requested Webb attend an appointment with a neuro-ophthalmologist. His recommendation was for special glasses but ACC declined the request.

Four months later, in October 2024, a neuropsychologist report – also organised by ACC – fully endorsed the request for special glasses, costing \$1273. Webb called ACC the following month but was informed her case manager had changed and a new one not yet assigned. "They said they were short staffed and that someone would be in touch in due course."

Webb heard nothing more — until the day the *Listener* contacted ACC about her case. On the same day, a new case manager phoned Webb and promised to look into her request for glasses. ACC's Matthew Goodger told the *Listener*, "We have been in touch with Joy to apologise for not contacting her sooner."

Webb says, "I'm really grateful we have ACC – without it I'd have been very stuck – but there are problems with the system that so badly need to be fixed."

Mowbray says it's not uncommon for ACC to decline treatments that specialists have advised clients receive. "We question who makes those decisions within ACC. If you pay for an expert's report, why would you not then act on that expert's advice?"

Asked why ACC would decline treatments that specialists have advised for clients, Hannah Coombes says ACC could not provide general comment on

specific cases.

Road to recovery

The promising news is that the brain can restore and repair itself even many years after an injury, says AUT Professor Alice Theadom, director of the Traumatic Brain Injury Network.

"Its ability to adapt and build new pathways, learn new skills, even in very old age, is incredible. I reassure people their brain can recover many years after injury – we just need to provide it with the right environment."

Like Kelly Jones, Theadom thinks the label "mild" TBI for concussion is misleading.

"It isn't necessarily mild in terms of its impact on people or those around them but the trouble is it's an invisible injury, which makes it a challenge when trying to manage it."

Theadom started researching concussion 15 years ago. "We identified a number of issues in terms of people's cognitive functioning, their work, the impacts on their income and ability to maintain social relationships.

"The faster someone can access the right help, the faster the recovery. But our research showed lengthy delays between people seeking medical attention and being seen by a concussion service." Research by one of her PhD students found this gap was, on average, 55 days. "By that 55-day mark, people were struggling at work and their family relationships were strained. In many cases over that period their symptoms actually got worse.

Shocked by the delays in getting help, Theadom led a working group to reduce that. Working with ACC, trauma clinicians, GPs, physios, sports physicians, and cultural advisers, the group formulated the Brain Injury Screening Tool (BIST) for health professionals. Once completed, BIST gives a recommendation of whether the person is likely to require prolonged recovery and needs to go to a concussion

service. It also provides recommendations for educational advice for patients and their follow-up care.

A four-year trial starting in 2021 across four primary healthcare organisations and involving 100 GP practices proved hugely effective, with delays in people being seen by a concussion service reduced to 17 days, says Theadom. As of March 2024, ACC reported 869 BIST assessments had been completed, with patients funded for a GP appointment and two follow-ups.

There are hopes this tool will now be rolled out nationwide. It's also currently on trial in some hospital emergency departments.

BIST has also improved clinician confidence, says Theadom. "We've made the process of referring directly to concussion service providers much easier for clinicians, because before it was very cumbersome."

Direct referral from medical professionals means patients avoid needing to navigate ACC first.

When it comes to research and the healthcare system on offer, New Zealand's really punching above its weight, says Theadom.

"The concussion service available to ACC clients is one of the best in the world," she says. "I'm told what we have is far in advance of what's available elsewhere. We just need to reduce the barriers to getting good access to it."

For 18-year-old James, after initial delays, a good recovery programme was developed, but only after help with navigating ACC.

"We were really grateful to have had access to an expert concussion team in the end," says his mother. "If putting that team into place had been left to ACC, I wonder how much worse his symptoms would have become in the meantime."

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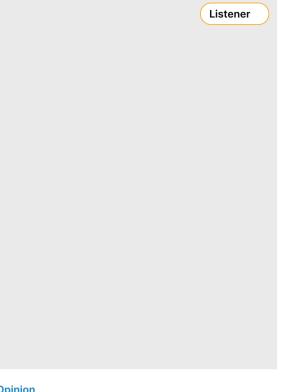
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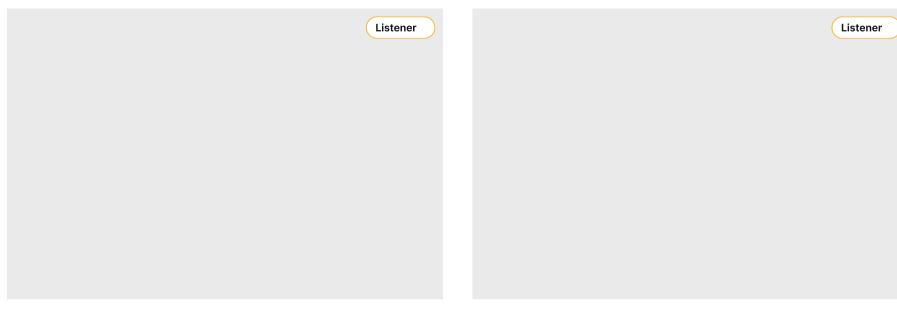


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