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## Colin's story about his son John

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### Summary

- When John sustained a brain injury, his amnesia lasted three months.
  - Despite the challenges, John's father remained positive.
  - With a range of supports, John's life is back on track.
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Five years ago, Colin's son, John (not his real name), suffered a brain injury in a high-speed motor vehicle crash. Colin shares his experience and tips to help other trauma patients and their families in dealing with recovery, especially in the early stages post-trauma.

### Struggles with distance

We were at home, 300+ kilometres west of Melbourne, in Hamilton. John was in Royal Melbourne Hospital. That was part of the initial shock for us – distance.

So, in the very first couple of days, we had to pack, and had no idea just what we faced. We basically packed open-ended, and probably took more stuff than we thought we needed. That turned out to be wise because we had to be in the city for well over a week in that first period.

Accommodation for country folk in Melbourne can be tricky. I'm fortunate, I had a sister living at Nunawading and we were able to immediately set up base there. But then we stumbled upon some accommodation tips.

### City accommodation tips

We found out there was an accommodation facility available, just one block away from Royal Melbourne Hospital. It's there to cater for situations like ours – country people with a patient in the hospital.

We weren't told any of this earlier, we sort of stumbled upon it, and then it took a couple of weeks to set up. We ended up using that facility for well over four weeks, I believe, which was just so convenient, you know, in proximity to Royal Melbourne Hospital.

So, that would be the first thing I would suggest to people from the country who are travelling to the city: make sure you make enquiries as to what support is available for next of kin to stay nearby.

### Travelling from the country to Melbourne

But then it turned out we needed to travel regularly, Hamilton to Melbourne. I couldn't guess how many trips we made. I was still working. My wife (Betty) was teaching full time at that stage.

My job involves weekend work, being a relieving pastor in churches, so I was able to travel down to the city during the week and visit John. I'd take my computer so I could prepare and so on.

I'd travel down to Melbourne either on a Monday or Tuesday, and stay until Thursday. Betty was teaching, so we were living apart. Then Friday night, Betty would go down on the bus and train and then stay and spend the weekend with John.

We must have done that for nearly two months I suppose, travelling back and forth.

We were fortunate that as seniors we had access to senior travel vouchers. We had a number of people within our church community saying, 'How can we help you?'

And we just mentioned, 'Well, if you're seniors you get these travel vouchers. If you don't see that there's any way you are going to use them, we are able to.'

And so, we actually were on the receiving end of twenty, thirty, maybe forty travel vouchers that we were able to

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use. So, in effect, we were able to travel back and forth to be with John at no personal outlay from our point of view.

### **Staying positive**

Early on, when we visited John, he would recognise us, but he couldn't talk to us – he had a tracheal intubation in at the time and the first few weeks he couldn't talk to us. It took him nearly a month before he was able to write anything. Then, they were able to put in that little voice activator thing with the finger over the tube, and he could then start to make some audible sounds that we could recognise as communication.

However, he wasn't remembering anything. If we'd visited the day before, he had no idea. It took nearly one hundred days for his memory to start to gel – that's how long he had amnesia.

He was being tested every day by the psychologist to identify movement out of the amnesia stage. For the test, he had to remember twelve things, like his name, where he was, what had happened, dates, and so on.

His head doctor, Professor O, told us that normally amnesia clears up in about three to four weeks. John went on that way for nearly three months, which indicates the severity of the impact the accident had on his brain, in two ways. The first was the actual impact to his head during the accident. The second was the fact then that he didn't breathe normally for, well, we assume it was well over half an hour to three quarters of an hour, before they got breathable oxygen into his lungs.

One could easily be quite upset by the whole situation but that in turn would be passed onto John. So, we chose to stay at peace with the situation. We just took each day as it came, we kept a 'what will be the new thing he'll do tomorrow?' sort of attitude. And we were very rarely disappointed.

### **TAC assistance**

Our first experience with TAC's help was with travel and accommodation expenses. TAC came to the party and covered the cost of the accommodation facility at Royal Melbourne that we had paid for.

TAC also allowed, I think it was, five thousand dollars for travel. And because we were using senior vouchers, Betty and I weren't drawing on that, so we were able to, in fact, use that for airfares for John's younger brother, Jake (not his real name), who was in New Zealand at the time. TAC were quite happy that that fund went towards airfares for Jake to fly to Melbourne to be with John.

One time, about four weeks or five weeks after the accident, we were booked in to be away. We had a commitment to go to New South Wales for about two weeks or so. We were able to arrange with Jake's work in Auckland for him to come over again. So Jake spent most of that time visiting John, and caught up with friends in Melbourne too.

TAC picked up the tab for the airfares. Because Betty and I weren't directly using that travel fund, they accepted that Jake could use it. That was our first very generous introduction to TAC help.

### **Back to work**

Sixteen months after the accident, John started his return to work. I can't praise his workplace enough. They were just fantastic to hold his job for him.

Before that, at one stage I took John back for a visit. I don't think he was out of amnesia yet. But he was at a stage where I was allowed to take him out of Epworth hospital for an hour somewhere, and we hopped on a tram and I took him back to his workplace and they greeted him with open arms.

But he really couldn't remember much afterwards. It was only the fact that I took photos while we were there that reminded him. Photos were important while he had amnesia. We needed to have photographic records to show him, to say "Hey, you know, your auntie was here and you played pool with her," because he had no memory of ever doing that sort of thing, you know.

TAC had put in place a return to work plan, where he was slowly introduced back into the workplace. For the first week, it was something like a couple of hours a day. And then that built up to a full day, and then three odd days during the week, where he had the in-between day off. And finally he built up to a full return to work.

During that interim period, TAC were actually paying the workplace for the hours that John worked because they were treating that as his transition back to work.

Although the workplace paid John for the hours he worked, they were reimbursed by TAC in those early days for the transition, which was just amazing.

And later on, when he would need to take time off from work for physio, TAC would reimburse the workplace for putting someone else in his place. John could go off to his physio sessions and everything else he need back at the Epworth hospital. They were fantastic there.

### **John today**

You know, we're just so blessed that the damage was just physically on his jaw. The structure's been repaired; he's got fifteen implant teeth. And there's the memory side of things.

### **New challenges**

Moving forward, we found out that John struggled to handle money. He was getting paid into an account we didn't know about.

We had little hints at times, but he started to lean very heavily on drink to support himself and to keep himself going. So, he was spending a lot of his money buying alcohol. And this was creating a dilemma with his workplace, where he certainly must have turned up to work on some occasions under the influence of alcohol. His job involves driving other peoples' cars.

That was a major issue for the TAC. So they started to set up a team of carers who would spend time with John.

We also looked at how best to handle the whole money situation. In the early days I had received a letter from Professor 'O', addressed to the bank, stating I was to take responsibility for John's financial side of life, because he really wasn't in a position to deal with it himself.

So, the local bank here, where John had his account, happily set up a separate account on the basis of the authority I had from the doctor. We were then able to arrange for John's pay and everything else to go into an account that he wouldn't have access to. And now all his accounts, his bills, power, and all his meals now as well, are direct debited from that account.

And because he has no access to money, we've been able to basically close that avenue. But the urge to drink is still there, and we're looking at long term strategies to slowly, but surely, educate.

We give John Woolworths and Coles gift cards that can be spent in their stores. They can't be used for alcohol, for cigarettes, or to withdraw cash. So, he's still got the freedom now to go into the supermarkets.

For example, on Saturday night, after a big bike ride, he said he just felt like having an ice cream. And so, he was able to go down and you know, get himself a Drumstick or something like that. Well you know, that to us is a freedom you've got to have.

And so, those cards have really solved the problem for us in not giving him a five dollar note, because he'll only save it up until he's got ten dollars and then he'll go and buy something that he shouldn't. He can't, he can just get what he normally has access to at the supermarket.

### **Checking in**

As part of the drink concern, TAC helped us to set up an alarm system for John in his own place. He has to clock in every morning, press the button, before seven o'clock. We did this because we've had the situation that, if he did find money, and if he did get on to drink, he wouldn't turn up to work the next day.

We wouldn't know until the boss would ring up at say nine o'clock and say, "Hey, John hasn't turned up for work today". But we're so far away.

With the alarm in place, one Saturday morning, he did go off and forgot to press the button. We got a phone call then at 7:15 am from the team to say that John hadn't pressed the button. They asked if we'd made contact. It was just a matter of us ringing John on his mobile, and he said: "Oops, I forgot to press it".

And so, everything was okay. At least we knew very early on in the piece that the system was working and we were able to check that there were no issues.

### **Getting back into shape**

As a result of John's drinking, he started to put on a lot of weight and that was alarming for us. On the way home,

he'd stop and buy junk food. Well you can understand that happening, it was the easy option for him, so he got very overweight.

TAC began looking at a strategy to address it. One way was to get him more physically active, so they set up a gym membership for him for twelve months. Now, he goes off to the gym at least three times a week, which is terrific. They also linked him up with Professor 'C', who is an addictions doctor, who is now working with John, helping him out of his alcohol addiction.

As a result of being on the Light and Easy diet program, being off alcohol, and going to the gym, he's actually lost fourteen kilos.

### **The A team**

John has a team that cares for him. There's a physio, an occupational therapist, and others, all funded by TAC.

We have three-monthly meetings, and it was in a discussion at one of these meetings that the idea of the alarm system came up. I'm pretty sure it was Heidi, the psychologist, who came up with the suggestion. They made a submission to TAC to support setting up this facility, and it was approved.

We needed it because of our location. We needed an early indication of when John was under the weather, when he wasn't going to go to work, and that sort of thing.

### **Supports**

Our previous carer organisers from the TAC didn't really open up many avenues of support. But with our current one, we're blown away by the willingness to support.

We want to get John back into the very best shape and back to his normal life as much as possible. And they're not leaving any stones unturned in terms of the support.

There's the addictions doctor, John's medication, working with pharmacy, support packs and everything – all covered by the TAC. So certainly, I can't thank TAC enough.

The TAC has also enabled John to have regular contact with a group call Kinder Caring. They have allocated carers to be with John every day. They meet him at his workplace and go down to the gym with him. Most of them drive, so they take the car, and after John's gone to gym, they'll take him back to his flat.

John's got responsibilities at home. For example, on Tuesdays he's got to make sure he orders his Light and Easy. Thursday, after Light and Easy has come, he's got to sort it all through. The kitchen and the fridge have to be gone through. And if there are any food items there that are going to be out of date they need to be disposed of. And, so, these carers help him to work through that process, and to get it in place.

The occupational therapist is looking out for activities to get John socially going out more. Because he did withdraw in those early days. He'd just stay home and was, literally, doing damage to himself.

But now he's out and about. He went off to African drumming last week. He's linked up with a ten-pin bowling competition and that's every Wednesday, which he thoroughly enjoys. He has goals for the number of strikes and sets targets for himself.

It's giving him more reason to get out of bed, not just to go to work, because he's always loved sports. In fact, ten-pin bowling is an activity that over winter, he's able to really enjoy.

### **Cascading support**

We feel supported knowing that John now has company. He has somebody that visits him. We're able to go away for a weekend, a week or three, knowing that everything will be okay.

We still ring him every day. There's always a phone linkup at five minutes to seven. It's our regular time slot, so we always talk to John.

Coming up in a couple of months' time I'm due to go up to New South Wales for around three weeks. And again, we just feel that we've got freedom now, that we know things are being covered back with John at home base, and we've got strategies in place now to help there.

### **The future**

Certainly, we're wanting John to have little targets that he wants to achieve, you know. It's important that he's got

things to look forward to, to try to work up to.

And now, he has set himself a target that he wants to achieve. He's got a meeting with the Professor, and at their last six monthly meeting he said to John, "you know, you've got to lose some weight."

And John has told us, "my goal is I want to be one hundred kilos, and that's about to lose another six or seven kilos. I want to have lost that by the time I go to the surgeon." And so, we've actually been able to get him now to do a weekly weigh-in and record what he is weighing.

That's giving us a great deal of satisfaction too, that John's sort of taking this on board now and starting to want to improve and go forward.

**Interview courtesy: School of Public Health and Preventive Medicine, Monash University.**

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