



**Getting back into the community.
We meet Rex Hoare, page 4**

Shine

Sharing stories, ideas and news across
Lifetime Care and Workers Care.

Winter 2019



Glen Clarke

Welcome

We are pleased to present the winter edition of *Shine* for 2019. In this issue John, Glen and Brett share their experience after sustaining a severe workplace injury, and Rex, Barbara and Jane and the Barclay family talk about life changing direction for them and their family after a motor accident injury.

In a first for *Shine*, Michael a Lifetime Care participant together with his partner Eimear have written their own story of what life looks like after Michael suffered a stroke following a serious cycling accident, and the trying road back to work as an academic at the University of Queensland and life in general.

Thank you to all of those who have been part of this issue and shared their story with *Shine*.

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Glen Clarke still lives in the area where his father and grandfather ran beef and dairy cattle in the Macleay Valley, north of Kempsey.

Glen worked on the family farm and as a truck driver when he left school – then at 21 started his own trucking business. He married, had four children, bought the farm across the road and, along with his wife, ran beef cattle, grew crops and operated a transport business delivering building materials to Sydney. Life was full.

Never a sick day

“At 41 I’d never had a sick day in my life. Then in February 2003 my life changed forever after a heavy vehicle accident on a trip to Sydney”

Glen was flown to Royal North Shore Hospital with a punctured lung, head trauma and broken ribs and shoulders. He’d also sustained a T7-9 complete spinal cord injury.

He spent the next eight months in hospital and rehab.



The hardest part of the injury is getting your mindset right. Your disability is still there but you’re not thinking about it the whole time.



“

I thought I'm not getting any younger and I need to get out there and give it a go.

”



Glen riding a handcycle at Narrabeen Lake.

“I resented not being home, close to my family, but in retrospect I realised that I needed that time to learn so many things about functioning with my disability – showering, toileting, dressing myself, using a wheelchair, building upper body strength, using public transport, driving, shopping, even socialising.

“When I got back to the farm, there were some things I could still do like spray weeds and help with the cattle on a utility vehicle. That sense of being able to contribute to the family was very important to me psychologically.

“I had lots of frustration and anger. Patience was something I had to learn.”

Glen in the Victorian high country with Disabled Wintersport Australia.



Retraining

Glen retrained in software accountancy, worked part time for a number of transport companies in town, then in 2017 started his own small logistics business using local subcontractors.

“It lets me work from home and I can still do a job I have experience in and am passionate about. Also, I have a lot of neurological pain so this enables me to manage my pain level.”

Glen keeps himself busy. He has been on various committees relating to disability and gives driver-awareness talks for children through the local Rotary Club.

“I talk to the kids as an accident survivor, and the effect it has on everyone involved. If I can make a difference to their awareness of accidents then that's great.”

About three years ago Glen went to the Victorian high country with Disabled Wintersport Australia.

“I'd never been skiing before but I learnt using a sit-ski. I now go every Father's Day – it's a ton of fun. And a great group of people! I thought I'm not getting any younger and I need to get out there and give it a go.”

Glen has also been to Sargood, the resort at Collaroy for people living with spinal cord injuries, and learnt to use a handcycle, snorkel, fish and play golf.

Opening the mind

“The thing I like about these places is that they've opened my mind to more things that I can do that aren't readily available in some country areas. Also I don't have to rely on family and friends all the time. I know they'd help, but it's a barrier for me.

“The hardest part of the injury is getting your mindset right. Your disability is still there but you're not thinking about it the whole time.”

“The main focus since the injury is keeping my mind busy. It's important for me to contribute to my family and society and remain positive, but I now know I can do it in a different way.”



Rex Hoare

Rex at the helm of the *James Craig*.

Rex Hoare lives on Sydney's lower North Shore with his wife Lynette and three children. A traumatic brain injury nine years ago hasn't stopped him being an enthusiastic conversationalist.

Rex worked as a systems auditor. He was an active parent, was a surf lifesaver at Warriewood, sang tenor in a choir and played the trombone in a band. Music was a big part of his life.

In 2010 while travelling on his motorbike to see a client, the then 51-year-old was hit by an SUV driver who hadn't seen him.

"I've got no recollection of it," says Rex. "The first thing I remember is waking from an induced coma at Westmead Hospital."

Rex had sustained a traumatic brain injury. After five weeks in ICU, Rex spent another two months in the Royal Rehab's Brain Injury unit at Ryde. His physical injuries healed, but the brain injury has led to lasting behavioural and emotional changes. His balance has also been affected.

Rex's goals after he returned home were to get his driver licence, and to get back to work.

He managed the licence, but work proved more difficult. "Work for Rex was very much a social thing as much as an intellectual and vocational one," explains Lynette.

He went back part-time with his old employer but it didn't work out. "It wasn't that I couldn't do the work," says Rex. "It was more that I had trouble reading situations and acting appropriately."

Other job attempts ended similarly.

Getting back to music

Re-engaging with community activities was more successful. Rex returned to the Willoughby Band playing another of his instruments, the baritone horn. "It's like a small tuba," he says.

"My long-term memory isn't affected too much," says Rex. "I can still sight-read music."

"Rex went back to the band almost straight away," says Lynette. "Bands are a very caring community."

He also plays with a trombone ensemble called the 'Bones of Contention' and an 18-piece swing band.

And if the bands weren't enough, Rex has rejoined the Willoughby Symphonic Choir, which rehearses weekly and puts on three or four concerts a year.

He has re-joined the Warriewood Surf Life Saving Club where he'd been a patrol captain when his children did Nippers. "They were very accommodating," Rex says. "Each year I've got to get my proficiencies again."

Rex has also become a volunteer guide on the *James Craig Tall Ship*, welcoming visitors aboard the ship and sharing historical and restoration information. "I've done the crew training, although they won't let me climb because of my balance. I try to go there once a week. The social contact is very important for me."

Support for icare

He is also a member of one of icare's Participant Reference Groups which provide forums for participants to share experiences and insights. "They are a great bunch," says Rex. "I'm always interested in seeing what other people are doing."

“ I always say that every day above ground is a good one. I'm really lucky to be alive at all. ”

"Rex is fortunate," points out Lynette. "A lot of people with a brain injury get quite depressed. Rex was anxious at first, but not prone to depression. Apart from work, the things he did before the accident he's been able to pick up pretty quickly afterwards."

"I always say that every day above ground is a good one," adds Rex. "I'm really lucky to be alive at all."



Brett Newman

“ I have a great network of friends. I can do most things myself, and even when I can't, I don't get frustrated. I don't mind asking someone to help me. ”

Thirteen years ago on a work trip, Brett Newman broke his neck in a swimming pool accident and became a quadriplegic. Yet he still has an independent and active life.

Brett grew up at Picnic Point in Sydney's south-west with his mum and a younger brother.

“It was a pretty normal childhood,” he says. “I was an active kid. I played a lot in the bush, and became good at swimming.”

At 20 the travel bug got to him and Brett went backpacking through Europe for three months.

Work for us!

“When I came back I was working at Woolworths in Revesby and the lady across the road at Flight Centre said, ‘You're wasted there. Come and work for us’.”

So he did and, in 2006, Flight Centre sent Brett and 30 other staff members on an all-expenses-paid holiday to Cairns. “The second night everyone went for a swim in the pool. I dived in off the boardwalk. It was a metre and a half deep - but I just went in wrong and hit the bottom.

“I'd dived safely into pools a thousand times. But I heard the crunch and knew I'd broken my neck.”

Brett sustained a high level (C6-7) incomplete spinal cord injury and spent eight months in Sydney's Royal North Shore Hospital and in Royal Rehab at Ryde.

“I accepted the injury and my situation. I thought that's happened, what do I do now? What are my expectations? I didn't go down those dark paths of depression.

“I was lucky in having a good network of friends.

“Everyone brought me baked dinners - I reckon between Mum and my friends I only had about ten hospital dinners in that time.”

In rehab Brett learnt to swim again: “I do freestyle, with paddles on my hands and a snorkel - because it's hard to roll and turn my head.”

Poster boy

Brett had a number of operations to reassign the tendons in his hands to still-active muscles to give him more hand control.

“I think I became the poster boy for tendon surgery,” laughs Brett. “Before the operations I couldn't close my hands, couldn't dress myself, couldn't pick up a knife or fork or my phone. Now I can do everything except do up buttons on a business shirt!

“And I need much less care - about two hours a morning to help with showering, getting dressed and cleaning.”

In 2012 Brett moved into a unit he'd bought in Surry Hills near Oxford St. In the same year he got a job in a busy government call centre where he manages a team of 14.

He still travels a lot and earlier this year he went to the west coast of the USA.

“I can manage most of the travel myself,” he says. “But it's easier if I travel with friends.”

And he still swims - three times a week - and on weekends often attaches his wheelchair to a handbike to cycle around Centennial Park.

At 35 Brett feels he's in a good place. “I have a great network of friends. I can do most things myself, and even when I can't, I don't get frustrated. I don't mind asking someone to help me.”

“ I accepted the injury and my situation. I thought that's happened, what do I do now? What are my expectations? I didn't go down those dark paths of depression. ”

Barbara McLaren: recovering against the odds

Barbara is a Lifetime Care participant

Barbara McLaren has an infectious laugh and still speaks in a clear strong voice. The 87-year-old led a full and active life with her husband just north of Sydney. Then four years ago that all changed.

Shine met Barbara, her daughter Jane and granddaughter Freya at the aged-care home where she now lives in Kurrajong.

Barbara grew up in England. She studied linguistics, went to Bible College and also studied agriculture. She loved farming and animals.

In London she met and married a Kiwi anthropologist, Peter McLaren.

"I wouldn't go to live in New Zealand," laughs Barbara. "He didn't want to live in England. So we settled on Australia."

Barbara and Peter came to Sydney in the early 1960s. They settled in Frenchs Forest but spent a lot of time in Papua New Guinea following Peter's research into PNG tribal rites. They had two children, Bruce and Jane.

Barbara is a devout Baptist and was one of the founders of the Covenant Christian School in Belrose. She taught at the school and wrote for a Christian School magazine.

"She had a calling," says Jane. "An unwavering faith in God. It's always been a constant in Mum's life."

Move to the bush

In 1982 the family moved to a 25-hectare block of land in the Colo Valley just north of Sydney.

"We were surrounded by bush. It was a great place for us kids to run free," says Jane.

The family lived in the house on the block while Barbara and Peter built a large mudbrick and hardwood lodge. Barbara wanted to build something for church groups to use as a meeting place and a retreat. "Building the lodge was a real community activity," says Jane. "It took about ten years to finish."

Barbara and Peter ran the lodge for 20 years as a non-profit business.

By 2015 they were in their eighties and coming up for 50 years of marriage. Barbara was well known in the Hawkesbury Valley, a respected member and mentor in the church, and still helping every week at the local public school where Freya was a student and Jane was teaching. She developed learning programs used by other teachers. "I was working with children who needed extra help - managing to bring them up a level," says Barbara.

While Jane had taken over most of the management of the lodge, Barbara and Peter still played an active role.

One Sunday in August that year, Barbara went to a function in Bilpin. She was driving home when her car was hit head-on by an out-of-control four-wheel-drive on the wrong side of the road. Three passengers in the other car died at the scene. Barbara appeared to have suffered only a broken ankle but, due to her age, was airlifted to Westmead Hospital as a precaution.



Three generations: Jane, Barbara and Freya at Barbara's aged-care home.



“Everyone came to say goodbye,” says Jane. “It was a very emotional time as we thought we were watching Mum slowly die.”

“Freya and Dad and I went down to Westmead,” says Jane. “We just went into overdrive as a way of coping. Mum’s ankle was a bad fracture needing surgery but it still seemed a miraculous escape from such a serious accident.”

“Then four days later Mum had a stroke. We were told it was a massive brain bleed and she would never be able to speak or feed herself again. She would never be fully conscious and would only exist in a vegetative state.”

The family made the reluctant decision to withdraw life support. “Everyone came to say goodbye,” says Jane. “It was a very emotional time as we thought we were watching Mum slowly die.”

Recovery against the odds

Barbara’s son Bruce, who was living in the United States and about to fly to Sydney, rang to say goodbye in case he didn’t get to Sydney in time. “We put the phone on Mum’s chest as Bruce was talking,” says Jane. “She seemed to be trying to speak and there were tears in her eyes.”

The doctors were still not hopeful of any recovery as the scans showed no brain function, but slowly Barbara rallied. Jane and Bruce took up residence in her room in the palliative

care unit, feeding her drops of water off a spoon to keep her hydrated. Soon Barbara was taking juice and within two weeks eating chicken and vegetables.

Jane puts the recovery down to her mother’s brain being fashioned by an active and busy life full of strong social engagement. “Mum had the most athletic brain for any 84-year-old you could imagine. She was constantly exercising and training it.”

Barbara continued to make a strong recovery. She was in Westmead Hospital for five weeks, then Jane and Bruce found a small aged-care home for her in Kurrajong, only about 35 minutes from her home.

Sadly, six weeks after Barbara’s accident, Peter died of a heart attack at home at the age of 87.

Adapting to her new life

Barbara’s brain injury has caused her to lose much of her reading and writing ability.

“I had been such an avid reader,” says Barbara. “And I was furious that they were now giving me children’s books to try and read!”

She can still read short sections of books, but now finds it easier to listen to audio books on a tablet.

As Jane says: “At 87, she doesn’t need to write essays. And anyway, what’s wrong with audio books?”

“And she still writes cards on birthdays,” adds Freya.

Barbara has found new friends in the home. She can walk around using her frame and enjoys meals in the dining room where she talks animatedly with other residents.

“And she still knows how to tell people off!”

And she goes out for appointments. “Bruce, especially, enjoys pushing Mum in her wheelchair around town,” says Jane.

Jane still runs the family lodge, but now as a function centre. “When I took over managing it about 12 years ago, I renovated it and opened it up for weddings and functions.”

Barbara says she’s used to being in the aged-care home.

“I’m happy here. I still have friends from church who visit from time to time. I tell Jane she doesn’t have to visit me every day. She can just ring me for four or five minutes and that’s fine.”

Freya says she thinks her grandmother is actually getting better.

“She looks younger than before the accident.

“And she still knows how to tell people off!”

John and his i-limb: “Don’t tell me I can’t”

John Coster is a Workers Care Program participant



John Coster’s new arm turns heads in his home town of Wauchope on the NSW Mid North Coast.

“There’s not too many blokes walking around with a robotic arm,” he jokes. The prosthetic arm, called an i-limb, is giving him more capability and independence, but takes some time and practice to get used to.

“I am thankful for the technology available at present – 20 years ago it would have been fake looking skin on a bit of wood or something with an awkward harness, so I must look at the pluses on the end of every minus. That’s my main saying in life – I’ll make a minus into a plus.”

John was injured four years ago in an accident at work at a timber yard. He lost his right arm above the elbow, and several fingers on his left hand were also severed. Although the fingers were reattached during surgery his left hand is still severely impaired.

Innovative surgery

He has had surgery (called targeted muscle reinnervation) to reassign the nerves in his arm. And an updated version of the i-limb has now been fitted that lets him control the i-limb better by just thinking about the action he wants to perform. “It’s working well and I’m going ahead in leaps and bounds,” says John. “The technology is evolving so rapidly – I’m aiming for an electronic elbow with the next model.”

Strength to strength

John goes to a personal trainer in Port Macquarie to build up his shoulders to support the weight of the 3kg-prosthetic which sometimes leaves welts on his skin. Despite this discomfort, John persists with his training. “I’m not going to give up,” he says. “There’s people worse off than me.”

The move to Wauchope was only six months before John’s accident. “The injury segregated me a bit. I moved up here for a sea-change, and because I was seeing more doctors than I was seeing anyone else” he found it hard to meet people. “I like to think I am a big enough character, even though I am an introvert” and the situation would have been different if not for the accident.

i-limb

The i-limb is the first upper limb prosthesis which allows the wearer to change grips with a simple gesture. It uses Bluetooth to connect to his iPhone, so he can instantly choose from up to 24 different grips with a tap of a button on the app screen. He got his first i-limb at the beginning of 2015 and has recently received the new model. “I can design my own movements.”



“

icare has put me in a position where I can determine when, where and what... not someone else.

”

“From day one they said I couldn’t have a prosthetic arm without a harness, but I said don’t tell me you can’t, and I have proved them all wrong. I have rewritten the books because they all said that you can’t wear something that heavy with a silicone sleeve on your arm and use it.”

Green thumb

Before his injury, John was always a physical person, working out regularly and taking pride in his strength. He spent many years creating and looking after cemeteries, flying all over the world to consult on designs in places such as Mongolia and China. He won awards for his landscapes and gardens. “This was a passion for me, and I was good at it. That is where my passion for gardening comes from. There are simple things that I struggle to do every day – I find a way around the problem, but the frustrating part is that they can take so long.”

John loves gardening and wanted to be able to work in his garden again soon after his injury happened. “From day one I wanted to. Bit by bit, I’m getting better and better.”

A little bit easier

Having an i-limb helps him to achieve some of the simple tasks in life. “It’s never going to be the same, but it’s going to make life that little bit easier, help me enjoy the things I like to do, as a hobby, like gardening. I used to love furniture restoring but I have to be careful because my left hand is not that crash hot.”

“I’m a very determined person. If I’m given a tool to use, then I’ll learn how to use it properly. The injury has changed my whole way of thinking. There’s ways around it, so I aim to get back into my furniture restoring with this technology. I’ll also have to teach my left hand to do what my right hand used to do.”

A lot smoother

After the accident John was first managed by a workers compensation scheme agent before transferring to the icare Workers Care Program where he has received support from icare coordinators Damien and Nadine, and his current case manager Liz Brownlee from Wise OT Solutions.

“It’s a lot smoother,” says John. “I still must go through some hoops, but it’s much better than before. But there is a long way to go yet. For a while, the doctors ruled my life, and now icare has put me in a position where I can determine to a certain extent when and where and what, not someone else.”

Giving back

In the future, John wants to be able to use his experiences from before the accident to be able to teach other people with disability or young people. “They are going to send me to be assessed to use an excavator and backhoe again. This is something that I used to do, and I’d like to be able to see if I can do that again. I want to be the best I can be with the tools that are available.”

John is keen to continue to learn and explore the different functions of the i-limb so he can do more of the activities he enjoys. “I’m going to keep plodding away around the house and the garden, with my dog and best mate ‘Buster’ so that it looks magnificent.”

Finding a direction

John is part of a mentoring program with other people with disability, but he doesn’t like the word mentor, or being described as an inspiration. “I’d tell them there is always light at the end of the tunnel and that you are the only one that can make it work. It doesn’t matter what tools they put in front of you, you are the only one that can make it work. You’ve got to have the drive. All I can probably do is give someone direction. I think direction is more important.

On the end of every minus, there’s a plus.”

The Barclays: keeping the family together

Renee is a Lifetime Care participant

Lorna and John with their Damara sheep on their property on the edge of Armidale.

Three years ago, Renee Barclay was severely injured in a road accident and now requires full-time care. Her parents Lorna and John talk to *Shine* about the family's journey.

"John and I were both in the Navy and we moved around a lot," explains Lorna Barclay. "I left work when we had kids. We lived in Adelaide for about eight years and before that in Canberra. We came to Armidale in 2014. The heat of Adelaide was getting me down and as our daughter Renee was going to university, we wanted a uni town. "At first we had a small house in town. But Renee has green thumbs; she just loved planting things, and in Armidale we could afford more space so we ended up moving here on the edge of town with seven and a half acres. "We planted some fruit trees and plane trees. We also have 14 Demara sheep. They mow the back lawn - they're wonderful trouble-free mowers!"

Renee, who was 35, lived with her parents and her two school-age children - Ayesha, and Ethan. When John and Lorna settled in to the new property they bought a caravan.

"We were going to travel around Australia - do the whole grey nomad thing," says Lorna. "We also had plans for a small extension to the house - a sort of granny flat for ourselves - so that Renee and her children could live in the main house."

The shortest day

But about three months after they moved to the property - "it was 21 June, the shortest day of the year and bad winter weather," says John - Renee was walking along the highway and was hit by a large 4WD.

She sustained a severe brain injury as well as multiple fractures and lacerations. Renee was airlifted to St George Hospital in Sydney. She was there for some months before moving to Royal Rehab at Ryde.

"I was going down to stay with her once a month for a week at a time," says Lorna. "I had her kids here and was looking after them as well."

It wasn't until late 2017 after ten months at Ryde that Renee was able to come home to Armidale.

Aged-care home to family home

The brain injury means that Renee is not able to walk or talk and requires 24-hour care. As her needs were so high and she couldn't be properly accommodated in the family house, the only available local accommodation with the necessary level of care was an aged-care home in town. However, John and Lorna were distressed at the idea of Renee spending the rest of her life in an aged-care home and both Renee's children found it difficult visiting her there. "And she's too young to be stuck with octogenarians all day," says Lorna.

Lorna and John met with icare's Home Modifications team and a plan was developed to enable Renee to return to the family house. In consultation with John and Lorna, icare agreed to build an extension to their home as separate accommodation for Renee. The extension includes a modified kitchen and bathroom, access for a power wheelchair, a ceiling hoist to move Renee and space for the two support workers who work in shifts to look after her.



It's sporadic, but if she's able to speak once or twice, surely she will do it again. It gives us hope.



“ She understands a lot and little things make her laugh – especially off jokes! There’s a comedy program on TV that she watches – she laughs in the appropriate spots. ”



Renee in her new flat with parents Lorna and John.

“They did a really good job,” says Lorna. “They weren’t intrusive. They built the extension separately before joining it to the main house at the very end.” Life for John and Lorna, however, continued to throw up challenges. While Renee had been in hospital, Ayesha, still a teenager, became pregnant. Lorna thinks that “with her mum so badly injured, maybe Ayesha was trying to fill a void, and getting pregnant helped with that”.

When Renee moved into the extension in May 2018, she was at last back with her family and now in age-appropriate accommodation. Care can be coordinated on the one site, family relationships could be rebuilt, Ayesha and Ethan can visit their mother easily and, when Ayesha’s baby Rose was born, Renee was able to cuddle her new granddaughter in her own home. For John and Lorna, that was special.

Coordinating the team

With two support workers needed for Renee at any time, there can be 15 or more of them on the roster each week.

“They’re a mix of uni students, and doctors and nurses from overseas studying for their Australian qualifications,” says John. “Unfailingly they are all excellent. We’ve been very lucky.”

As well as the support workers, there are a range of professionals working with Renee, from the Lifetime Care coordinator to a rehab case manager, a physio, dietician, registered nurse and speech pathologist.

With Renee now settled into her own flat, John and Lorna feel they can relax a bit. “But we’re the admin staff aren’t we,” laughs Lorna, “we’re the coordinators. And we feel we still need to monitor things, to make sure everything is running smoothly. There are so many people involved that little things can sometimes go wrong.”

“Although we’re not looking after Renee directly we are looking after everyone else now, including Renee’s two ferrets, and our son – who lives in Hong Kong – we’ve got his two cats as well,” says Lorna.

“And Ayesha in her wisdom has just bought a puppy the size of an elephant. Ayesha is good at looking after Rose, although we still need to look after Ayesha. But she’s 16, so she knows everything!

“Ethan is on the autism spectrum. He’s more than half way through primary school but can’t read or write. His teacher is wonderful and is trying really hard with him, but she’s got 25 other pupils to worry about as well. We’ve tried to teach him to read but we’re not really getting far.”

“ It gives us hope. Her brain is definitely functioning. ”

“One of Renee’s support workers also has an autistic son and relates well to Ethan who often goes in to chat to her.”

Ayesha is now pregnant with her second child.

“We’ll manage it!” says Lorna.

Hoping for improvement

John and Lorna still hope for an improvement in Renee’s condition. “It must be frustrating for her. She does try and write her own name. And when she was in Ryde she wrote down our names – ‘Lorna and John’.”

“She understands a lot and little things make her laugh – especially off jokes! There’s a comedy program on TV that she watches – she laughs in the appropriate spots.

“She’s talked briefly a couple of times, once to one of the support workers, asking for a cup of tea – ‘white and two sugars’! The other time she mentioned something about birds. It’s sporadic, but if she’s able to speak once or twice, surely she will do it again. It gives us hope. Her brain is definitely functioning.”

Michael Gard: Reflections on stroke recovery

Written by Michael and Eimear

Michael is a Lifetime Care participant



Michael Gard, 54, was senior academic at the University of Queensland when he suffered a stroke after a cycling accident. He and his wife Eimear have written their own story about his recovery.

Michael: The date is Boxing Day, 2015. I am riding in Yamba. I take a route I have taken many times before. I ride to Angourie and I am returning to Dad's house when I am knocked off my bicycle by a car. I come-to with a man and a woman telling me to lie still. I'm thinking, "Shit! Am I injured?"

Eimear: I am in Ireland. Michael's sister rings around midnight. The trauma of the head injury has caused a clot and he had a stroke in his sleep. I can't breathe. I frantically begin packing. Then, I realise I need a flight. I wake my family and one of my brothers drives me to the airport. I cry all the way from Ireland. Mid-flight, I get another message to say that Michael is being taken by chopper to the Gold Coast Hospital. Surgical intervention might be necessary.

Michael: I'm in the hospital trying to brush my teeth with my deodorant. I know who I am, but communicating with the world is a different matter. I cannot talk, read or write. Eimear takes the deodorant and hands me some toothpaste. I keep brushing. Later she hands me my guitar. I know Eimear and am very glad she is here. I do not know what to do with the guitar.

Eimear: He pushes my hair behind my shoulders, does up a button that has come undone. These kind of casual and familiar interactions signal to me that he is still in there. I create a poster of the alphabet and one of numbers. I need to help him find his words. I'm neither sleeping nor eating. I am drowning in forms. One of the doctors has said he has global aphasia and his prognosis is poor. The doctor is wrong. From that day on, I mistrust anyone who claims to know with any certainty if or how he will recover. They don't know Michael.

Michael: I'm now in the Princess Alexandra Hospital in Brisbane. There are people here that are much worse off than me. Eimear is with me every day. I also see speech, occupational and physio therapists. I escape to a café on a busy road. Eimear rings. Somehow, she figures out where I am. I am grateful for all the help from those in the Geriatric and Rehabilitation Unit (GARU). When Eimear arrives on discharge day, I am sitting on the end of my bed with my suitcase packed and hat in hand.

Eimear: My excitement at having him home is tinged with fear about whether we are ready. His speech is still coming along, but it's his processing that worries me. He turns on one of the gas cooktops, but tries to light another. He tries to alphabetically sort his records, but struggles with the J-K-L letters. I learn quickly that quietness is our friend, and we need to avoid noisy places. We go on long drives in the country.

Michael: The first difference between hospital and home was fatigue. In hospital, your life is structured. But when I went home, it changed completely. It was up to me to create structure. I remember the first Friday. I got out of bed and tried to get my



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day under way. By 9am I gave up and went back to my private heaven – my bed.

I was interested in whether music might help my language. After all, I could sing before I could talk. With a music therapist, Rebecca Eager, I tried learning lyrics and melodies but progress was slow. It seemed that as my speech improved I lost my ability to sing. One day, I got lost in Brisbane where I have lived for years. I misplaced my travel card. I didn't know where I was and I had no confidence to try to talk to anyone.

Eimear: I worried when I left for work. Was he going to be ok? I was glad on the days the therapists came, because I knew at least some of the time I was away, there was someone else with him. I didn't want him to feel alone or to get too comfortable in our small house. Everything I had read said he needed to be out in the world communicating, practising his speech.

Michael: I felt safe at home. I wasn't ready to socialise with people. Eventually, I visited cafés and tried to read. Under some pressure from Eimear, we got a dog, a Cairn terrier I called “Niccolò Machiavelli”, who some people thought looked like me! When I took Mac for walks, I was often stopped by people telling me how cute he was. Walking became a means of exercising and also an opportunity to practise small-talk with people.

Eimear: After a year, he said he was ready to go back to work. Genevieve Lee, the case manager arranged through icare, was incredible. She met with therapists and his work supervisor and, together, they agreed on a workplan. At this stage, his language was much better but he still found conversations with one person difficult and couldn't speak in front of groups.

Michael: I returned to work part-time at University of Queensland. I started very slowly but I pressed on. My colleagues were superb. They understood my difficulties and dealt with them sensitively. By my second year back at work, I was able to give a conference presentation (co-written by Eimear), in front of a delegation of 30 people.

Eimear: Michael is as proud and determined as he ever was. Giving up has never been an option for him. He has worked hard for every “new” word, conversation and relationship. We have lost friends and found some. We have gained all sorts of perspective on life – what matters and what doesn't. Michael's attitude made everything easier. Somehow, he sidestepped the anger, self-pity and depression, I was told to expect, and would have understood. I respect and love him more every day.

Michael: I am making good progress and still fighting to get back to as close to “normal” as is possible. I remain in therapy, and committed to improving my speech, reading and writing. Rebecca Dewberry, my good-humoured speech therapist, continues to help me. Three and a half years later, and I am still improving. I am trying to write for myself, but academic English is like another language, and I need help. What I also need now are programs for people going back to high-level work but the cupboard is fairly empty. I am forever grateful to everyone who has helped me on my journey: therapists, hospital staff, great friends. I spend a lot of time alone and I need this. But I need also a village. Not a city, but a village.

We lost Dad last year. Vale Ralph Kenneth Gard. I have returned to riding that route from Yamba to Angourie and back. Most of all, I am thankful for my angel, Eimear Enright. Our recovery is continuing.

Tell us your story

Do you want to write your own story like Michael and Eimar? It only needs to be short, and we can provide help. Contact the *Shine* team shine@icare.nsw.gov.au.

Personal safety devices to promote independence

Are you or your carer concerned about your safety and wellbeing in the community? There are a range of wearable devices that can help. They can promote independence for the wearer, and peace of mind for families and carers. These are known as personal safety devices, locators or alarms and may be a pendant or a watch.



Above: mCareWatch is an example of one type of device.

There are many different brands, but most offer a similar range of features. They are simple to set up and connect the device to your family member or carer's smart phone, then they can support you through an app on their phone. Some devices can link to a 24/7 monitoring call centre.

Location tracking

Location tracking works by using GPS, mobile towers and Wi-Fi and provides a map position of the wearer. You can set up a pre-set safe zone, and if you leave this area an alert is sent to your carer who can check in with you.

SOS Alert

If you're lost or feeling overwhelmed, you can press a button to send your own SOS alert through the device, which makes a call to your carer or a call centre to get help.

Falls detection

If you've fallen and aren't moving for some time, the devices will detect this and send an alert and your location to your carer or a call centre to get help.

Reminder alerts and health tracking

Many devices also offer customised alerts such as medication and appointment reminders, and health tracking such as heart rate monitoring.

How do I find out more?

icare can fund these devices for suitable participants. This would usually be assessed by an occupational therapist. Speak to your icare contact person for more information if you think one of these devices could help you or your family member.

See how a personal safety device works

Watch our animation for a simple demonstration. Go to <http://bit.ly/PersonalSafetyDevices>



Technology testers needed

Are you interested in trying out some new and innovative technology? The icare foundation has invested in Remarkable, an organisation that supports startup businesses making a difference for people with disability.

Positive impact

Remarkable runs an accelerator program that provides training, mentoring and seed funding to help early stage startups bring technology products to the market that have the potential to positively impact the physical, social and economic inclusion of people with disability.

It's important that startups continue testing the technology they are creating. Remarkable startups are looking for people to test and provide feedback on specific features, before they are released to the general public. Some of the startups that Remarkable are currently supporting are developing products that empower those with learning disabilities to become more confident, independent readers; virtual reality experiences; and a trusted platform to connect a family's therapists, educators, support workers together to provide them the ability to track and share goals and progress.

Interested?

If you're keen to try out some emerging technology or know people that would, or you have any questions about what is involved, please email us at shine@icare.nsw.gov.au and we can connect you with Remarkable.

For more information on Remarkable, visit their website www.remarkable.org.au



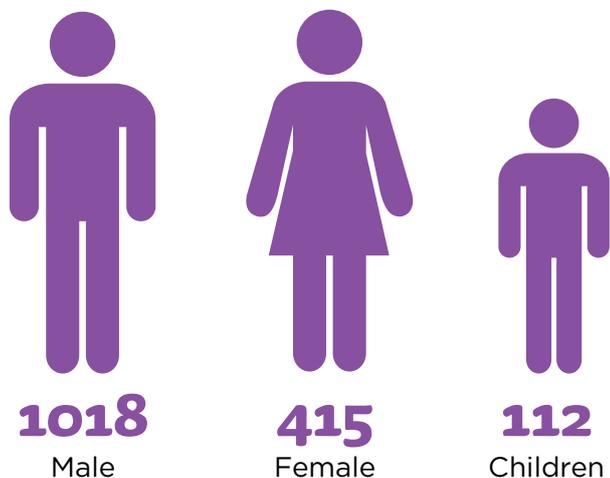
Remarkable startups, stakeholders and investors at a recent pitch night at icare.

About Lifetime Care and Workers Care

We thought you might be interested to know more about who Lifetime Care and Workers Care support.

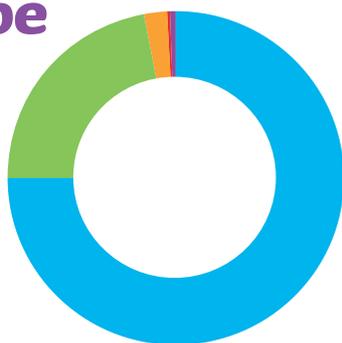
Lifetime Care

The Lifetime Care and Support Scheme supports people who've been severely injured in a motor accident in NSW. The Scheme is funded by a levy on Green Slips (compulsory third party insurance).



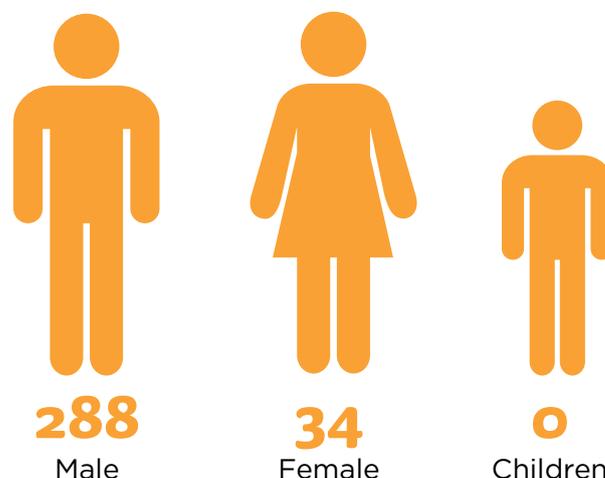
Injury type

- Brain Injury 75%
- Spinal Cord Injury 22%
- Amputation 2%
- Blindness < 1%
- Burns < 1%



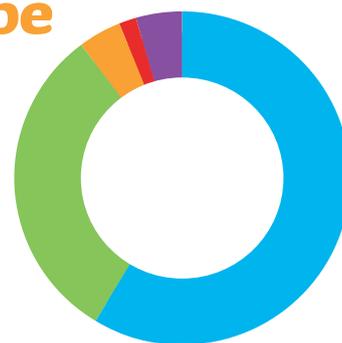
Workers Care

The Workers Care Program supports people who've been severely injured in a NSW workplace. The Program is funded by the NSW Workers Compensation Scheme.



Injury type

- Brain Injury 59%
- Spinal Cord Injury 31%
- Amputation 4%
- Blindness < 2%
- Burns 4%



We'd love to hear from you!

Do you have any feedback about *Shine*? Is there anything different you'd like to see in the magazine? Or maybe you'd like to share your story with other participants?

Email shine@icare.nsw.gov.au or call 1300 738 586.

General Enquiries: **1300 738 586**
Web: www.icare.nsw.gov.au

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