

# Thank You



ACQUIRED  
BRAIN INJURY  
IRELAND

Sharing the life-changing difference made by supporters of Acquired Brain Injury Ireland

## “I WAS DROPPED INTO THE WORLD WITH NO SUPPORT.”

Emma's story is of a sensitive nature.

While none of the stories our Brain Injury Survivors share are easy reads, Emma's is particularly difficult.

Please be aware of that from the outset.

But I do hope you will read on because Emma is a brave and inspirational young person with an important story to share.

Emma has suffered with a chronic pain condition called Complex Regional Pain Syndrome (CRPS) since she was eleven years old. It causes severe and debilitating pain that never goes away.

Emma was a young girl dealing with relentless pain for years. When she was sixteen, she required crutches and a wheelchair at all times.

**A recent nerve block\* hadn't worked and she felt there was no support for her.**

*\*A procedure that can help prevent or manage pain*

**Emma couldn't cope and decided that she didn't want to live like that any longer. She attempted to take her own life.**

This was discovered by her sister who had gone to check on her and what occurred next were events that no family should ever live through.

CPR was administered by Emma's dad and sister through sheer desperation.



Emma before her brain injury celebrating her 16th birthday.

Emergency services were frantically called. Emma's lips were blue and she was barely breathing. Nobody knew if she would survive.

Emma was brought to an ICU bed in the Mater Hospital. She was in a coma for three weeks and had two strokes while unconscious. The situation was unthinkable.

**Emma was only sixteen. A sixteen-year-old girl should have been going to school, spending time with friends, shopping or going to the cinema. Not fighting for her life, having tried to end it.**

Doctors told Emma's parents that she might never wake up due to experiencing a brain injury which caused a complete lack of oxygen to her brain.

And if she did wake up, they were told to expect her to be paralysed, tube fed, unable to talk or even know that her family was around her. Whatever happened, a deeply heart-breaking picture of their family's future was being painted.

**Continued inside >>**

**But Emma's parents believed in their daughter and fought for her to be given a chance at life. And following a difficult journey, Emma woke up.**

She was attached to wires and tubes, confused, unable to talk and paralysed on one side. She remained in the Mater Hospital for months undergoing physio and occupational therapy. Following this she spent many more months in the National Rehabilitation Hospital.

Emma required a great deal of support. For at least a year, she couldn't put a sentence together or hold a conversation. She underwent various therapies to help her to return home to her family.

***"I was left for two years without anything."***

Emma was very frustrated following her discharge from hospital because there was nowhere to turn to for support for her brain injury. For children and young people living with a brain injury in Ireland, there is an extremely limited amount of support and Emma was too young to receive services for adults.

**This was challenging for Emma, especially because it was the complete lack of support for her pain condition that had first led her to the darkest of places. It was like history was repeating itself.**

Before Emma's brain injury, between pain flare-ups, she was in fourth year in secondary school. She loved to sing and was part of a glee club. She was living as normal a life as she could, until the pain and life became too much to manage.

***"It was horrible because I didn't understand what was going on in my head and my body."***

Her brain injury brought many additional layers of complexity to Emma's life. She had changed in so many ways. But in the early days, she would not even admit that she had a brain injury. She already felt so different to her peers.

Looking back, Emma shares that she can see that her personality had completely

changed. She suffered emotional lability, which meant she can experience all her emotions at once. This had an impact on all her relationships because she got frustrated easily due to being so overwhelmed.

Today, Emma experiences high levels of fatigue and can only be awake for a few hours at a time.

She suffers with epilepsy, meaning she will be unable to drive in the future which will have an impact on her independence.

***"I felt so let down. There is no support for kids."***

Emma has made such a critical point. Each year in Ireland, thousands of children experience traumatic brain injuries and have their futures stolen from them. To develop an appropriate service for children to the highest quality requires many resources. And sadly, Acquired Brain Injury Ireland has not had access to the resources needed to create a paediatric service.

We are constantly fighting and advocating for Brain Injury Survivors in Ireland but our calls to Government often fall on deaf ears.

But we will continue this fight. And while we persevere, we will do what we can without support from policy makers.

Living with and caring for a child or a young person with a brain injury is a life-changing event.

That's why we have grown our On with Life family support service to also support Parents/Carers of Children with an Acquired Brain Injury.



Emma and her loving family.

On With Life was founded on the generosity of supporters and has grown and developed due to fundraising efforts.

Thank you for helping to ensure that all families can access essential support.

Families are thrust into the role of carer without any experience. And while our On With Life service is an indirect support for young Brain Injury Survivors, we do endeavour to provide support, education and information to help the entire family.

***“It was like having a friend because when I met Ciara, I had no friends left. I had no one.”***

At eighteen, Emma joined the Acquired Brain Injury Ireland Family. She was welcomed with open arms by her key worker, Ciara.

Ciara was someone to talk to, someone who listened and importantly for a Brain Injury Survivor, someone who understood the impact a brain injury has on a person.

Ciara was there to support Emma as she transitioned from finishing school to working towards her future. She supported her with assignments and investigated college courses with her. Ciara supported Emma with her goals. What mattered to Emma was what mattered to Ciara.

***“Before coming here and meeting Ciara, life was very difficult”.***

As well as the dedicated one-to-one support from Ciara, Emma also participated in various rehabilitation groups at an Acquired Brain Injury Ireland Clubhouse. They included art therapy, information groups and crafting groups.

And even more importantly for someone like Emma who had become so isolated, she connected with other Brain Injury Survivors, some of whom she remains good friends with now.

Thank you for helping our team to ensure that Emma and others like her do not have to face the world alone.

**Emma is twenty-one now. She is no longer a young teen. She is a young woman trying to overcome a painful past and a challenging present while working towards a happy future.**

Building that future hasn't come easy to Emma. Following her lengthy hospital stays, she tried to go back to school. But it became impossible due to her fatigue and medication. She struggled to attend and understand what was happening around her.

She left school for a long time before deciding to try to return and do her leaving certificate. Despite only being physically able to attend once a week, she passed her exams and went on to further education – a remarkable achievement considering everything that had been thrown at her along the way.

***“Having support from Acquired Brain Injury Ireland helped me to prepare for and get through college”.***

Emma was very enthusiastic about animals. Looking after animals became the focus she needed and it helped her to build a routine. Seeing her passion and natural ability, Ciara supported Emma to do an animal welfare course and share her passion with her fellow Brain Injury Survivors in our Clubhouses.

***“I’m a magnet for kids and animals.”***

A determined Emma then went on to do an SNA (Special Needs Assistant) course before moving onto a Childcare course. She did a 150-hour work placement, despite her extreme fatigue. While on duty, Emma excelled and was offered a permanent role



Inspirational Emma at her graduation ceremony.

at reduced hours to manage her fatigue.

Emma credits support from Acquired Brain Injury Ireland with her return to college. And we credit the support from people like you.

Today, Emma's goal is to increase her independence. With support from our Rehabilitation Assistant Johnny and Social Worker, Ayla, she is working towards living in her own home. Nobody thought that sixteen-year-old

Emma would be in the position she is in today, given the severity of her brain injury: A college graduate and a childcare worker in employment, who plans to live independently. Emma truly demonstrates the difference that life-changing rehabilitation can have.

Thank you for helping people like Emma to rebuild their lives.

*"Being part of an event with multiple families; each family dynamic is different and each story/journey is different, but all linked by the shared experiences of one family member living with an ABI. There was no need for explanations."*

Parent of a child who attended an On With Life family event.

## On With Life Carers and Families Programme

A programme which supports Parents/Carers of Children with an Acquired Brain Injury.



A programme which provides supports for Parents/Carers of Children with an Acquired Brain Injury.



Our On With Life programme allows family members to share experiences and support each other in a safe non-judgemental environment.



### Who do we support?

- Parents/Carers
- Siblings
- Relatives
- Professionals working with children or young people with an acquired brain injury

### How do we provide support?



#### *Support Groups for Parents/Carers*

We provide a space to share the reality of living with a child/young person with an ABI.

#### *Education and Training for Parents/Carers*

We educate Parents/Carers as they cope with the challenges of brain injury through expert advice.

#### *Information for Parents/Carers*

We provide information about how to keep yourself well plus practical tips, strategies, and resources for dealing with concerns.

#### *Information and Training for Professionals*

We provide training to help educate staff in education, health and social care to support your child/young person.

## How do I find out more?

Contact programme coordinator Dolores Gallagher. E: [dgallagher@abiireland.ie](mailto:dgallagher@abiireland.ie) T: 086 010 2361

**TO GIVE A GIFT OR SPEAK TO OUR TEAM: PLEASE RING US ON 01 2804 164 (Option 2)**

Our Mission is to passionately serve and relentlessly advocate to empower and support people impacted by brain injury to rebuild their lives.

## Our promise to you

Your personal information will always be safe and secure. For further information on how we handle your personal information, please visit [www.abiireland.ie/privacystatement](http://www.abiireland.ie/privacystatement)

If you would prefer not to hear from us, please call us on 01 2804164 and we promise to respect your wishes.



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