Heading in the Right Direction

A series of inspiring personal stories by survivors of an acquired brain injury
“I was coming around and beginning to realise the extent of things, thinking about my future. I felt so weak, couldn't eat, couldn't sleep, just felt lost and afraid of the unknown”

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“My sons were told that I would be in a wheelchair, unable to speak, have issues with memory, and live in a home. I think this was worse for them than me. My sons and brother had to imagine my life like this. But I was thinking; I’ll show you’... and I did!”

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“I finally found a place where I am safe and sound. I have never seen, but I believe in Positivity. I need to silence some voices that say no........it’s a start to a new day, a new life”

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The Headway Harbour Group

The Harbour group is a peer support group for people who have had an acquired brain injury. The aim of the group is to provide peer-led emotional support to group members, as well as acting as an information and social forum.

Over the course of eight weeks, the group members have explored issues important to their own rehabilitation process. They have reflected on their experience of fatigue, anxiety, and pain following a brain injury, and have learned ways of coping with these. They have also supported each other to think about what it means to have had a brain injury, and the impact it has had on their self-confidence, their personal identity and on close, personal relationships.

The group members have also dedicated their time to thinking about how they can help others better understand what it is like to live with an acquired brain injury. Together, they decided to write their own personal accounts of their experiences, their path through rehabilitation, and what has helped them along the way.

This booklet is a compilation of their journeys and a celebration of their honesty, bravery, and courage.

Claire McMoreland
Jenny Brazil
Deirdre Murphy

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November 2014:
1 month after waking from a coma, nearly 2 months from my accident.

I know there is someone out there feeling the same way as me,

The days have come and gone from hanging out with friends filled with joy to a bed brimmed with solitude

I have learned how to listen to the folk looking after me but they are passing a message that means nothing to me.

All has been lost and all has been forgotten but what to realise is that it’s not the end of the world

All has been scared all has been knocked the only answer is positivity.

Suddenly I can see everything that’s wrong with me

But opening my eyes reading my paper and talking to my friends I know that I can pull this together.

I finally found a place where I am safe and sound.

I have never seen but I believe in Positivity

I need to silence some voices that say no.......it’s a start to a new day a new life

I have the daylight at my command and I can shed positivity on my life.
March 2016:
1 year and 4 months from my accident & 1 year and 1 month back in work.

1 year and 4 months have passed and I realise who I really am now.

My past experience has shown me how to live.

With learning happening every day, I developed the strength to help myself and help my friends in need.

Some things have been lost & forgotten, but what’s important is that it is still possible for me to lead a regular 27 year old’s life.

Everything happens for a reason, and for me, this has been a constant echo since my accident.

I was told I could not do some staple activities that I used to do.

One door closed, queued up for another door to open to fill the void.

Sometimes hours turned to days and days turned to weeks without my reckoning.

The recovery goes on and I feel change is always good.

Niall Rooney, Age 27
My Difficulties

After an accident at work I have been left with a few difficulties, my speech, my eyesight, my levels of fatigue, and my memory.

My sight is the least of my worries, one of my eyes works fine, but I don't have two of everything.

One of the most annoying aspects of my speech difficulties is noticing how little time people give you in an interaction. People keep finishing my sentences, and guessing what I am trying to say. What some people don't realise is that this puts pressure on me and makes my speech worse, if people took a little more time and patience it would lessen this pressure.

Fatigue is another aspect that affects me daily, and mental activity takes a huge toll on my levels of energy. Yesterday I cycled 50k with some friends and felt great, I then tried to read the Sunday papers about the election, after just twenty minutes I had to have a rest, and don't remember anything I had read, it is hugely frustrating.

I want to get better, I have a family I should be looking after, not them looking out for me. I want to be normal.

William Montgomery, Age 46
Beginning Again

It has been a little under six years since my life changed forever. I had a near-death experience, which resulted in severely damaged sight and an acquired brain injury. I am still learning to cope with the circumstances on a daily basis. Despite the estimated time-frame given by doctors and professionals alike, it has become evident that these changes are not something that miraculously become completely healed after a certain amount of months or years. I am now fully aware that day to day experiences define the endless amounts of learning curves that will help me continue to learn and grow as the person I have become after my accident.

I will spare you the specifics of my accident, but I assure you that I am extremely lucky to still be alive after an experience that could have taken my life at the age of nineteen.

Continual support from my family and friends has helped in so many ways, but the circumstances can be quite a tough issue to understand for any blissfully-ignorant strangers I have met over the years since. It was very challenging to develop an understanding of the multitude of reactions and misinterpretations made by others, but I have matured to a point of not taking much notice as time passes by. Anxiety and depression have been extremely testing hurdles on my journey, but I have become aware of how truly beautiful life can be despite the drawbacks it may have at times. Learning to find my own mental space has opened up a whole new world for me. The aforementioned mental states can become total parasites at times, which is why I have developed a tendency to treat them
as enemies in a passive-aggressive manner.

The most beneficial method I have introduced as a daily routine is meditation. It helps to create a world of your own; a peaceful place, free of aggression and hatred, and fuelled by admiration for the hidden beauty that constantly surrounds us. Though I fully understand that it may not be for everybody, I can honestly say that the impact it has had on me has saved my life and helped to maintain my wellbeing. Life is extremely precious but fragile, and so is each and every one of us as humans. What matters is embracing the here and now and learning to live in each moment. The past and future are not ours, but right now, this moment, is ours for the taking.

That is how I believe we learn to blossom into a state of peace, to forgive our faults, and to appreciate every single gift we are given as each day passes. An open-minded perception and acceptance for the difference in others is one of the many outlooks we can either choose to embrace or ignore. Help to fuel a stranger’s happiness by simply giving a polite smile and by coming to terms with the fact that we are all so different in so many ways. This proves that karma truly exists as each kind gesture will be returned, time and time again.

James Coogan, Age 25
‘I get knocked down, but I get up again’

Before my aneurysm, I was working in Logistics in Cadburys for 25 years, as well as being a Senior Union Rep for Unite for 10 years. My average day involved getting my boys up, fed, and out of the house to school or work, and then being in work myself for 8.30am. I would attend meetings and juggle many tasks for both Cadbury’s and The Union. Always attached to my laptop, I would leave at 5pm and then continue my work from home. This busy lifestyle posed various challenges; fitting all of these things into a single day, juggling work, friends, family, and the normal duties of a busy Mam.

In July, 2013 I had my aneurysm and all of that changed. I was in hospital for 7 weeks with doctors expecting the worst. My sons were told that I would be in a wheelchair, unable to speak, have issues with memory, and living in a home. I think this was worse for them than me. My sons and brother had to imagine my life like this. But I was thinking; ‘I’ll show you’... and I did! I learnt to walk and talk again. Having been the ‘go-to’ person in work and at home, I found it very challenging having to depend on others and asking for help. I had to learn how to do this, and although it was very difficult, I knew I needed to take these steps in order to get back to being me.

Yvonne shortly after surgery
When things started to get back to normal, I realised that I had difficulties in areas where I hadn’t had them previously. I sometimes had trouble understanding what people were saying, and would feel lost in a conversation, as well as having trouble finding the right thing to say myself. Initially, I would pretend that everything was ok, I didn’t have the confidence to say that I was lost. This caused me a lot of anxiety. I didn’t want to look stupid. Although it was scary, I would force myself to stay in places that made me uncomfortable. I was afraid, but I fought through it. I started small, and then challenged myself to do more. Through my own growing confidence, and the support of my family—particularly my sons and my brother, as well as my friends, I can now ask people to slow things down for me, and tell me if I have said the wrong word. I struggle with fatigue, but I just have to work around it... That’s life!

Despite these challenges, I feel that I actually have a better life now. I was always a positive person, and although many things have changed, that has not. Different things are important to me now. I can spend more time with my family; we have chats and a laugh every day. I feel that I am still healing.

I believe that everything happens for a reason. I consider myself to be lucky that I can enjoy my life, and I would like to help others see that there is hope.

_Yvonne Kelly, Age 48_
Geraldine’s Story

In June 2014, I had headaches for 2 days. I don’t remember those days. I woke up in hospital. They said I had Encephalitis in my brain – I’d never heard of it. I had bad headaches for 6 months, now it’s only now and again. I still can’t get a lot of my words out. I get very tired after a bit of housework, so I sit down and then carry on again when I feel better. I’m only getting back to accepting my home. We moved to a new house 8 years ago and I loved it but now all I want to do is get out. I miss my grandchildren. I only see them once or twice a week. I was looking after them for 6 years. My husband Dave kept me going, he put up with my moods which were and can still be bad. Going to Headway has made all this a lot easier to take, and is helping me to accept things will never be the same again.

Geraldine Doyle, Age 64
Stephen’s Story

Unfortunately, I was not present for my injury. I have no memory of it or the time before. I have however heard many stories. I fell at approximately 23:30 on 31st December 2014, down a flight of stairs outside my apartment in Rathmines, Dublin. I was knocked unconscious by the concrete steps. My friends tell of how they found me in a pool of blood at the bottom and how they tried to wake me. They called the ambulance and waited with me, before accompanying me to James’s Hospital and then to Beaumont Hospital for the emergency brain surgery that followed. If one is to have a traumatic incident like this, New Year’s Eve on the point of midnight is not a good time.

I was kept in an induced coma, following my surgery, for six days. I had incredible swelling, so much so that my eye lids could not cover my eyes. My family were told that I may never speak, walk or even move again. Therefore, each limb that I managed to move brought celebration. Even when I scratched my nose it was noteworthy. I have been told that ‘howerya ma’ were my first words as I turned over and went back to sleep. I came back to speaking, but there was sometimes little sense. They would have the same conversation with me several times in the day, often more than once in the same hour.
My first memory is on the twelfth when the doctor took out the last of the staples in my head. I remember wanting to leave all the time. I could never remember or even understand why I was in hospital, why these people were keeping me here against my will. I was not allowed out of the ward for a few days more as a result. At least once, I packed a bag and tried to leave. I was told that if I could tell them where I was, then I could leave. Apparently ‘here’ is not a satisfactory answer. Eventually I was allowed to be brought to the café by my family. They were told to ask me questions about what I had done during the day, thereby helping my short term memory return. Once I could clearly walk and could clean and feed myself, I was discharged. Beaumont is an acute hospital and my bed was needed. They had done their job. I was sent to James’s for three days and then discharged home. If my mother had not been in a place to look after me at home, the hospital would have had no choice but to keep me.

This is when my rehabilitation began, though I was convinced that it was nearly complete. I planned on being back to work in a month, maybe two. I think the swelling on the side of my head did me good. It reminded me that I was not okay, that I should at least wait until it had gone. I would sleep ten hours or more every night, napping often twice a day, for two hours each. I missed being able to effectively read. While in hospital I asked for a favourite book of mine to be brought in, thinking I would use my time with it. While I knew the words, I could not hold the beginning of the sentence in memory long enough to reach the end. It was all meaningless, though I knew all the words. I set
this as my goal. I would read for an hour or two each day, Stephen Fry’s More Fool Me.

I remember meeting with my consultant. My brother came with me so that I would remember everything. The consultant was really friendly. He was surprised at my progress. He showed me
some brain scans taken from the night. I could see the swelling and the fractures in the skull. I had a list of questions and he answered every one. More than once he had to shrug. For instance, when asked if the headaches would go away, he said that they might, but they might not.

I was, with incredible luck, brought in to the National Rehabilitation Hospital for an assessment and asked to bring a bag to stay. I was not only lucky that I was given a bed in the NRH, but I was also lucky in being placed in St Patrick’s Ward, the ICU area of the brain injury section of the hospital. It offered more privacy and more space than was available in the other wards. They had many who were high dependency and I believe I fit in as requiring less attention. I would also be short term. The NRH changed everything in ways that I did not realise they needed to be changed. I met so many fellow patients in the NRH and we would talk at lunch times and around the quadrangle in between our appointments. There was little to do in the NRH but the WiFi was good and there were some great characters there. An art teacher who visited our ward showed me a liking for drawing and sculpting, hobbies that were very therapeutic. The art required little skill and did not strain memory. All of the therapies offered by the NRH showed me that any difficulties I was having were normal, not evidence of weakness.

I think and speak so often of the luck I was gifted. Some of that luck is simply that there exists knowledge in the area of neuro-rehabilitation and that it is available in Ireland. But I was also lucky in that I was one of the blessed few who would avail of
these services. Some never know that they exist. I am now self-sufficient again, independent and okay. My wonderful employer in no small way helped incredibly in the reestablishment of that independence. I do not exaggerate when I say that I might not be here if it was not for the people who helped me to recover. I skipped a few things, you see. I sidestepped the breaking down in tears in the early days at home, wondering if it was worth proceeding. I also left out the sleep deprivation in the NRH that led to me breaking down, the psychiatrist seeing me and sleeping tablets being prescribed.

There are few families that will not be touched by brain injuries, be they encephalitis, stroke, accident or cancer. As important as families are in the process of rehabilitation, as mine surely was, there are areas that they cannot cover. Many patients feel burdensome and will not complain in case it is seen as being ungrateful. As nurturing as a family member can be, it cannot be understated how beneficial a professional can be, as with a weight of experience they look you in the eye and tell you that something is okay. It is somehow more okay to express your natural frustrations and fear to a professional than to a loved one. Many will go without therapies that are not expensive and are cost-effective, in part because so many who experience a brain injury may not be able to speak up, often literally.

Stephen Shortall, Age 28
Therese’s Story

Saturday 1st March 2014:

Normal Saturday morning, after a week at work, doing housework, washing floors etc. Did the shopping, more catching up!! 7.00pm, made dinner, went to eat, watching television, rugby on, think it was Leinster! Then ... that was the start of the scariest thing in my life!

Tried to eat and had no power down my right arm... What was happening? Kept trying to hold my fork, but nothing, was trying not to let my husband see (as I thought) but of course he did! I didn't know where I was then and began to get confused and very scared. I made my way to bed, got in, clothes and all on! I kept saying I'd be alright. At that stage, I didn't even recognise my husband. Noel was insisting I had to go to hospital, eventually I knew something was badly wrong!

I don't remember the drive to Beaumont Hospital. I have only vague memories of the first few days, the look of worry and panic on my husband’s face will stay with me for ever, but he was by my side, I know he was holding my hand. I felt so bad for him because he had to phone our children, who were living away at the time. That was a difficult thing for him, breaking such news!

Saturday night in A&E Department, there were brain scans, tests, questions over and over for Noel about what happened. My memories were of what day is it? I didn’t know! Where are you? Wasn't sure! What year is it? Hadn't got a clue! Follow a pen...couldn't focus!
Sunday morning, I was brought up to the stroke ward, St Brigid’s ward. Of course I have no memory of this! More scans, MRI, bloods etc. and the dreaded lumber puncture, which I do remember! Doctors explained then they weren't sure if it was a stroke or not, but it could be an infection in my brain, Encephalitis, a word which turned out to change our lives!

I was so lucky, that I was started on a course of anti-viral, Acyclovir, as a precaution, while waiting for results to come in and confirm it was, in fact, Encephalitis...that was probably a life-saving decision made by that doctor!

Then, then were calls to family and close friends...just shock and concern.

I was coming around and beginning to realise the extent of things, thinking about my future. I felt so weak, couldn’t eat, couldn’t sleep, just felt lost and afraid of the unknown.

Eventually I got home, nurses coming three times a day. I was so tired and lost, the support of my husband, those important daily calls from my children and my family and friends, got us through those tough few weeks.

I knew I had changed that Saturday night, in a split second, I was a different person from who I used to be! ... Can't focus on people talking, can't take in what people are saying to me, can’t keep up with conversations. Asking the same question over and over! Words coming out wrong, I know what I want to say, but sometimes it doesn't happen. Hard to focus, easily distracted by noise or interruptions, can’t cope with bright lights and noise. Confidence rock bottom.
And the fatigue...

It takes time to readjust, trying to be strong for everyone, when you are inside falling apart at the seams! To learn and say I need HELP is very hard to do, to admit I can't do what I used to do, to lose some of my independence, to be cared for and not the care-giver! But I know with all my support and love I have around me, it will get easier. It's a big change for family and friends after an acquired brain injury too.

So, here I am two years on...

I am learning now to accept things and the changes in my and my family’s lives.

I have to be strong and dig deep in myself.

I take each day as it comes, good and bad, I just accept the odd bad one and move on, with help. It is difficult and very frustrating at times, but I am learning now to adapt to things and not spending my energy on trying to go back to the person I used to be, easier said than done!

But I’m getting there.

**Therese Gaskin, Age 58**

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**My mam, my inspiration**

by Therese’s daughter, Tara

My mam spent has most of her life caring for everyone else. She cared for my granny who suffered from MS until she passed away. She cared for my dad who suffered with a heart condition
in recent years. She cared for my accident/illness prone brother who seems to have nine lives and counting. She taught hundreds of children with special needs over the years and truly made a difference in their lives. I always thought her to be unbeatable, unstoppable, unbelievably strong.

I think this is why this illness and its effects on my mam have taken me and everyone totally off guard. I am used to her being ok.

Still even now, mam can read me like a book - a slight tone change, a look, and she knows there is something up. She's looked after us all.

I feel sad for her and my dad. I feel sad that these are the years that they should be doing all of the things that they always dreamed off. But now Mam gets tired so easily, she can't bear much noise or bright lights, or large crowds. So those dreams and plans will have to be altered.
I feel very protective of my mam now, when I see her struggling to say something, or walking towards me with her walking stick, or lost in a group of people chatting, I feel so sad. I just want her to be ok back to normal mam.

Sometimes I get annoyed when she's not ok because I'm used to her always being so strong and always having the right answers, I definitely don't have her patience and I find it very hard to see her like this.

The roles have reversed and I've somehow turned into the nagging daughter! I want her to eat better so that she gets every bit of extra energy possible. I want her to exercise a little more but I know she gets tired so easily. When she doesn't want to, I nag at her to go to the Harbour Group because I know that there are people that can empathise with her, help her to understand that she is not alone with the headaches and tiredness as they are going through similar things themselves.

I wish I could have somehow foreseen this illness and tried to prevent it, but c'est la vie.

We have all had to adapt and realise that we've lost a little of the old mam. But everyday I'm thankful that she is still here and as only mam could do she is learning and teaching us how to cope with this illness. My mam her humour, her patience, her kindness and selflessness get us all through this.
About Brain Injury and Headway

An acquired brain injury can happen suddenly to anyone at any time during their lives. It can arise as a result of a stroke, viral infection, brain tumour, brain surgery, lack of oxygen to the brain, or any impact to the head through a fall, assault or accident. Each person’s brain injury affects them, and their family, in ways that are often difficult, life-long and not always obvious to others. It can affect how someone thinks and feels, how they talk to and relate to others, and can impact on their work and social lives.

This collection of stories portrays inspirational first-hand accounts of the highs and lows on the journey through rehabilitation following brain injury.

Headway’s specialist support assists people to rebuild their skills and their confidence. This helps them, and their families, to get the most out of life after brain injury. To see more on what we do, visit www.headway.ie or call us on 1890 200 278

Headway is accredited by CARF International for Adult Home, Community and Vocational Brain Injury Services www.carf.org

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