

Rebuilding

Reflections on the effects of acquired brain injuries,
from survivors, their families and those who work with them.

Introduction

Who are we?

We are a group of clients who use the National Learning Network's Quest Brain Injury Services in Galway. Although we are of different ages and backgrounds we have one thing in common - we have all suffered some sort of brain injury, be it a car accident, a fall, a stroke, a tumour etc.

Why this book?

We have gathered stories from past and present clients, their families and some people who work in the area, and put this book together to try to explain our experiences and to help people understand our journey.

Sometimes life after a brain injury can be difficult and confusing. Sometimes you can't always see the effects and sometimes people need a bit of help and direction to get back on track.

Our hope is that our stories will help others who find themselves in similar situations. We hope that by reading our stories you get a better understanding of acquired brain injury, and maybe some comfort knowing that you are not on your own, that you still have options, and most of all you still have a life to lead!



L-R: Deborah Noonan, Tara Haverty, Fleur Colohan, Daniel Dunne, Niamh Healy, Gemma O'Connell, Bill O'Brien, Brenda Winters
(Missing from photo: Katherine Keogh and Tina Hynes)



Réamhrá

Cé hiad muidne?

Is grúpa cliantaí muid atá ag freastal ar Sheirbhísí Gortú Inchinne Quest, i nGaillimh cuid den National Learning Network. Cé go bhfuil aoiseanna agus cúlraí éagsúla againn tá rud amháin comónta againn - d'fhulaing muid uile gortú inmchinne de chineál éigin, nó thimpistí tráchta, nó titim stróc, rith fola inchinne, srl.

Cén fáth an leabhar seo?

Bhailigh muid scéalta ó chliantaí reatha agus iarchliantaí, a dteaghlaigh agus roinnt daoine atá ag obair sa réimse, agus chuir muid an leabhar seo le chéile chun ár scéalta a léiriú agus chun cuidiú le daoine ár n-aistear a thuiscint.

Uaireanta tar éis gortú inchinne bíonn an saol deacair agus trí na chéile. Ní bhíonn sé i gcónaí le feiceáil mar a chuireann sé isteach ar dhuine agus uaireanta teastaíonn beagán cúnamh agus treorach ó dhaoine le dul ar ais ar an mbóthar. Tá muid ag súil go gcuideoidh ár scéalta le daoine eile a bhíonn i suíomhanna den chineál céanna. Tá súil againn nuair a léifidh tú ár scéalta go bhfaighidh tú tuiscint níos fearr ar ghortú inchinne faighte, agus b'fhéidir compord éigin mar nach bhfuil tú leat féin, go bhfuil roghanna fós agat agus thar aon rud eile go bhfuil saol le caitheamh go fóill agat!

Contents

Ábhar



How the book works:

Green - Experiences of those who work in the area

Blue - Experiences of people who have had a traumatic brain injury (TBI)

Red - People with other types of acquired brain injury (ABI) i.e. stroke etc.

Yellow - Experiences of family members

Pink - Acquired brain injury information

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Acquired Brain Injury

Sometimes you may hear the terms TBI or ABI being used about brain injury.

TBI stands for Traumatic Brain Injury, which is an injury as a result of a 'bang' or trauma to the brain, e.g. a car accident, a fall, an assault etc. ABI stands for Acquired Brain Injury and this covers all injuries to the brain including stroke, tumour, haemorrhage, infection, lack of oxygen etc.

Who does it affect?

An acquired brain injury can happen to anyone at any time during their lives.

How does a brain injury affect people?

Brain injuries affect people in different ways – physically, cognitively (thinking), emotionally and socially.

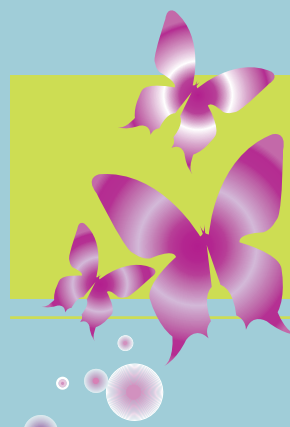
Often people with a brain injury make a good physical recovery but how they think and feel may change. Others may comment on how well someone looks and how they've made a great physical recovery but they don't see the more subtle effects. Sometimes these changes are only obvious to family and close friends.

These cognitive difficulties are far more difficult to see and explain. They include things like taking-in, processing and remembering information, filtering background noise, making decisions and planning tasks.

Níl aon staitisticí oifigiúla againn in Éirinn ach ceaptar go mbíonn thart ar 10,000 cás de ghortuithe inchinne gach bliain thar gach aois agus cúlra sóisialta.

D'fhéadfadh daoine a bheith fágtha le réimse mór deacrachtaí nach mbíonn le feiceáil.

Ní chuireann gortú inchinne isteach ar an duine a bhuaileann sé amháin ach freisin ar a dteaghlach agus daoine eile atá gar dóibh.



Eileen Joyce



In our culture, the medical system places a lot of emphasis on physical symptoms and so after a brain injury that is often the area best dealt with. Our medical therapies seem to be more often based

on the difficulties that can be seen such as physical difficulties. Therefore physiotherapy, occupational therapy, speech and language needs are often the areas addressed and prioritised.

Emotional and physical recoveries are two very different things: It is easy to see and measure the physical recovery and it is often assumed that emotional recovery will follow. Very often the emotional and social aspects of brain injury are not addressed until much later.

Having worked with survivors of brain injury and their families over the past ten years, I have come across many examples of how people struggle to come to terms with the traumatic emotional effects of the injury and the changes to themselves, their family and their whole life as they knew it.

Change in personality: Depending on what area of the brain has been damaged, an individual can go from being a positive outgoing confident person, to having to deal with fear, mood swings, depression, anxiety or panic attacks. Someone who was funny and outgoing may now be less confident, reserved and shy. Time and support are needed to help regain faith and trust in life again.

Change of role or relationships: A person's sense of themselves and the role and relationship they had with those around them can all change.

Someone can go from having a responsible job and being the main financial provider to a new role of being dependent and in need of care; from being a spouse or partner in an equal relationship to being the one cared for in an unequal relationship. Young independent adults may often have to return home for help and support, changing the dynamic of their relationship with their parents.

The difficulties in trying to explain the complexities and effects of a brain injury can often leave the person feeling misunderstood, making it difficult to get motivated and stay positive. This in turn can lead to frustration and depression. This is why it is vital that time and support is given for the emotional roller-coaster that these changes can bring.

Need for time: A lot of the clients and families in Quest look back on their recovery and speak about the need for time to learn to cope with the effects of injury. There is a need for time to grieve the loss of aspects of life as they lived it before, time to accept what is the present reality and time to test themselves again in what can or can not be achieved, time to regain confidence and find new ways of moving forward.

At Quest we offer people the time, space, support and understanding to come to terms with the effects of their injury. While some of that comes from the staff, a huge amount comes from the client's interaction with each other – people with the same experiences, fears, frustrations and hopes.



It was the 31st of December 1999, the dawn of a new century. As the celebrations at midnight began, my life began to go horribly wrong and was to change forever...

That was the night my headaches began and shortly afterwards, it was discovered that I had a brain abscess - cause still unknown. The operation went well and apart from my memory, everything else was fine.

In 2003 it came back, as a cyst this time. The cyst ruptured while I was in University Hospital Galway. I had to be flown by helicopter to Beaumont Hospital, Dublin. It's not many people who get to go in a helicopter but I was sedated at the time, so I don't remember a thing!

Physical Effects

After my brain injury I had to relearn a lot. Things seemed quite bad at the start. I worked on physical exercises to get me back to normal. They got me back close to normal, although I still have to work on my balance. The only real weakness I have now is that I can't run! This may sound funny and hard to imagine and it shouldn't really bother me but it does. I don't need to run but it's the fact I can't!

Also, a terrible effect was that I couldn't swallow for almost a year. Swallowing is something that we all take for granted and I had never before given it much thought. I stayed away from anniversaries and celebrations, where any eating would be done because I would feel very embarrassed. It wasn't until I was called to the

National Rehabilitation Hospital in Dun Laoghaire, that it was cured. I still have to do exercises to make it totally better. Having it come back made me so happy.

Cognitive and Emotional Effects

My memory was also affected which meant I could not get a job. Also, I used to cry a lot. My whole world had been turned upside down and I felt nobody understood. I did not stop to think about the effect it was having on my mother, who was with me the whole time and also my fiancé Paul, who worked during the week and then came to Dublin to see me. I was the centre of their world for a while and for that I am so thankful to them.

For a long time after, I had no job and emotionally life was just getting me down. It was like Rose said in the movie *Titanic*, "on the outside I was everything a young woman was supposed to be, inside I was screaming!"

Relationships

My mother has been with me through all my time in hospital. We are very close. Of course we always were but now I think she worries about me a lot. I guess any mother would. My dad also worried about me a lot. My mom gave up her job and only worked at weekends. My fiancé Paul would come up at the weekend. I thank God for Mum and Paul because I couldn't have made it without them.

Lifestyle

It changed my life totally. As I already said, I was sad for so long and like I said I could not get a job. I was at home or at Paul's home. It was depressing. Everyone wanted to mind me, they thought I couldn't and shouldn't do anything by myself. Someone had to be there all the time. They thought I couldn't be on my own. I know now they were just worried about me and wanted me safe and well, but that was making



me worse. My head was not in danger physically now, just mentally - my mind!

Rehabilitation

When I went to Dun Laoghaire in Dublin to the Rehabilitation Training Unit (RTU), it helped me deal with things. My memory was one thing that was worked on there, as well as the emotional side of things. I learned that all my symptoms after the brain injury were things that happen to others with the same problem. I was not insane like I thought. I realised that I was not alone and that was a great thing to know. Everything came into perspective then. I could talk to those people and they understood.

I finished in the RTU and started Quest in Galway that September, but as like the first time I started in Dun Laoghaire I didn't know what to expect. It was hard to change to someplace new - I hate change! But there were people with similar head traumas like myself. I got the help I needed there to work on skills I need for getting my life back on track.

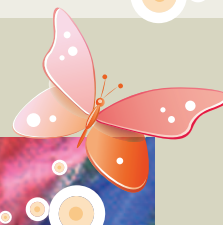
Now

Part of the purpose of writing my story is to prove to others that life after a brain injury is repairable! I hope my story gives courage to others who have had brain injuries.

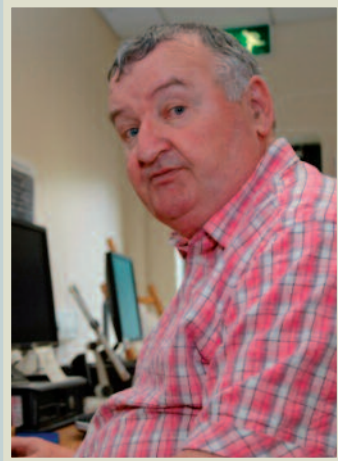
I have moved home to Achill now. I have gotten involved in the community here. A few of us from my area and I have set up a St. Vincent de Paul charity shop where I volunteer four days a week. I am also one of the leaders of a local youth club - No Name Club. In the evenings I do dancing, painting and go to music classes.

My thanks to Quest for the care and understanding I received when attending the service (and the follow-up phone calls to see how I was!).

*"Be not afraid of growing slowly;
be afraid only of standing still"* -
Chinese Proverb



Terry's Story



My life before my accident was very hectic. I worked as a supervisor for Bus Éireann and it was a very responsible and busy job. I was on call 24 hours a day. I loved driving, doing 10,000 miles per year and travelling the length and

breadth of Galway for 35 years.

I was very interested in wildlife and I saw a lot of it on my travels. I always carried my binoculars in the van so that I would get a closer look at anything of interest. My hobbies were keeping birds in an aviary and volunteering with the Order of Malta Ambulance Corps. I was with them for 30 years.

The night things changed was the 19th May 2007. After returning from a wedding and going to bed, my wife woke me at about 11pm and told me that I was not breathing properly. I told her to leave me alone and let me sleep but after another twenty minutes she woke me again and told me that I was gasping for breath. She said she was taking me down to the hospital. I got dressed and went with her and that is the last I can remember for the next eight weeks.

Hospitals

In all I was transferred a number of times between Merlin Park Hospital and University Hospital Galway. I went into respiratory and kidney failure and almost died. I spent seven weeks in a coma. When I came round and began to realise where I was, I was unable to move in the bed. I just kept looking at the ceiling and could not turn or move my hands or legs and I had to be fed, washed and shaved. I was looking

at doom and gloom, wondering what was happening but unable to ask questions. The first thing my wife told me was that my daughter had been married. I was very disappointed that I had missed my daughter's wedding but I was glad she went ahead as it was what I would have wanted for her.

At the time my granddaughter was five months old and I was determined to see her grow up, so I then tried to get out of the bed but landed on the ground! The physiotherapist then started to work with me and over the next month I had learned to walk and climb stairs.

Back at home

After a month in Merlin Park Hospital, when I went home I was confused by everything in the house. I could not remember where I had put things or what I had gone into the kitchen for. I also had a severe tremor in my hand, and it was through this that the consultant found that I had suffered some brain damage. This was a great shock.

I was put on medication for the tremor and it worked. Over the next couple of months my wife, after knocking on every door possible, met an occupational therapist from UHG who suggested that I contact a place called Quest. My wife started getting the ball rolling with Quest and the neurologist and in October 2008 I finally got into Quest Brain Injury Services, where I met other people who had suffered brain injuries.

For the next two years I went through cognitive and speech therapy lessons, as I found it hard to say some words and put sentences together. I also had lost all my computer skills and with the help of the IT instruction I soon got back into the use of the computer again. I learned to do some public speaking and started to give computer classes on a voluntary basis to a

charitable organisation. I also learned to do some photography on the computer. It had been the best two years of my life and I miss the place but I have to move on to let some other person

get some of the great therapy that Quest gives to brain injured people.

Terence Crowe



Marie's Story

Four years ago I was a very busy person - a wife, a mother of three and a full time teacher. One day after school I had a dental appointment and while walking to the dentist I collapsed on the street with a brain haemorrhage.

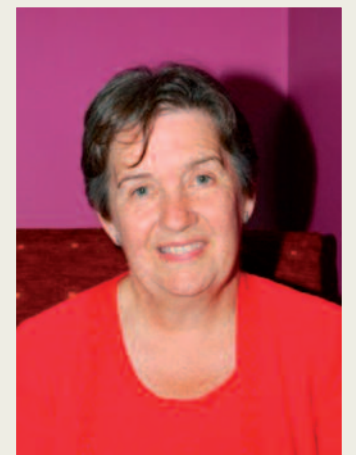
When I 'came to', I had no memory of the year, two holes in my skull, very little hair and was two stone lighter! Basically, I was a mess. I felt like I had been asleep for a year! I believe I was in hospital five times in Galway and Cork, conscious, but have no memory of it.

My recovery began after I got a shunt inserted. I then went to the National Rehabilitation Hospital in Dun Laoghaire. They then referred me to Quest Brain Injury Services in Galway where I spent two years as a client. Quest helped me put my life back together again. They gave me the confidence to get back driving and start teaching. I now work as a volunteer art instructor with Quest and I am back living a busy happy life again.

I still have side effects from my brain injury but I am able to cope with them. My short term memory was affected so I use a diary. I have difficulty multi-tasking so I have to plan a lot more. I have a poor sense of direction so I stick to the routes I know. Lots of good things have happened to me since my brain injury. I found out just how good my husband and family are. I also discovered that I have great taste in friends and have made some wonderful new ones.

For me, my brain injury gave me a new beginning and I would like to thank all the people who contributed to my recovery.

Marie Quinn Hogan



Rehabilitation Instructor, Quest Brain Injury Services

Fleur Colohan



Having worked in the area of brain injury over the past eight years, I've come across a variety of stories around people's different experiences of recovery. While there might be many similarities among the families and individuals I've

worked with, I can safely say that no two cases are the same. Each person has had a unique experience of their injury and of the effects they have been left with.

Many people and their families, who come to us at Quest, have little or no knowledge of the specifics of what actually happened to them. Often they leave hospital without the tools to adapt to the 'new them'. They have either been given little or no information, or sometimes given it when they were unable to take it in and were unaware of future possible day to day difficulties their injury might cause.

All too often, our system concentrates on the physical effects of a brain injury without checking or planning for the cognitive (thinking) and emotional effects that the injury may cause.

Many times people will arrive here at Quest and tell us that they thought they were 'going mad'. They had made a good physical recovery and 'looked fine' but they were now more irritable and cranky, got confused in conversation, found it hard to take in or remember information or to

do things that before would not have been a problem.

Hospitals will address medical issues, but what about everything else? After discharge some people manage to continue to access some services such as occupational and physical therapy when they return home and so have some support, however many others are discharged without any services or support in place.

For someone who has had a major life-changing event, adjusting to life without supports can be very difficult. Their whole role in life has changed in an instant.

Families too have to face massive changes. They have to get through the initial trauma of the injury and then may have to adjust their lives to cope with the impact of any disability that remains in the longer term.

Quest provides a range of supports and services covering things like brain injury education, cognitive rehabilitation (for memory and thinking skills), daily living skills, reading, writing, language supports, computer training, psychological and emotional support, community integration, job preparation and support.

The staff at Quest try to look at people as individuals. We try to work towards the person's goal and give them the tools they will need to take their life back. Often it's not the same as the life they had before, but by looking at all of the effects of brain injury: physical, cognitive, social and emotional – we hope that the people who come here leave us better equipped to deal with their challenges and build a healthy and productive life.

Gemma's Story



At the age of 32, stroke was something I had never thought about and fortunately I had never known anyone who had suffered one. I was an extremely busy working mum, travelling for three hours a day to and from work, studying for my Masters degree and planning my wedding. I had high blood pressure but was otherwise fairly healthy, a non-smoker with no family history of stroke, so it was such a shock.

The Stroke

I was extremely tired on the days before the stroke. While staying at a hotel in Dublin I awoke around six with a feeling like I had a bad hangover. I remembered grabbing for my bag and my left arm moving in slow motion and I felt dizzy and sick but by the time I got to reception I was fine, so I thought it was a trapped nerve!

I was back at work when I noticed the words I was typing were all wrong. I looked down at my hands and realised the left wasn't moving. I tried to stand but couldn't and when I tried to call for help my words sounded slurred as my face had slumped too. Thanks to the quick reactions of my manager and the first aider I was rushed off to the local doctor and then University Hospital Galway.

In Accident and Emergency, I went for a CAT scan which identified I had a bleed on the brain. My stroke consultant stayed with me when I went for an MRI and he talked through what was happening. We got good news that it seemed to be a small bleed and by the next day all movement had returned. I was released home.

At home I slept a lot, (which I now know is fatigue and is common.) I was getting panic attacks as I was convinced I was having more strokes, so I was rushed back to the hospital a few times.

About ten days later I awoke suddenly to cramp in my left leg. I couldn't sit up or move my left arm. As I was dragged downstairs all I remember thinking is "don't die on the stairs as my son might wake up and see me." I always was a bit dramatic! By the morning I couldn't even sit up or even wiggle my left toes. Now the diagnosis was that I had a clot that had caused a bleed on the brain.

On the stroke ward I was terrified. There was a lot of older people and their strokes seemed to be really severe. After a few days of being propped up in chairs and relying on someone to take me to the toilet, enough was enough. I was adamant I would walk again. So with thoughts of walking down the aisle, I focused on my physiotherapy. I was lucky it worked, though my left arm was a lot slower to recover. The hardest thing I have ever gone through (worse than giving birth!) was leaving the hospital, as panic attacks were taking over. I found travelling in a car overwhelming and even five minutes with my son exhausting.

At home I felt abandoned. I couldn't get my head around anything. Finally, my stroke consultant, who understood how debilitating depression and anxiety could be, requested a cognitive therapist to help me. At this point I was scared to leave the house and have anyone visit. But between the physiotherapy and cognitive therapy I had a focus, without which I am not sure I would have left the house.

When I got the all-clear to drive again it was like a cloud was lifted. It enabled me to attend Quest and there is light at the end of this dark, long tunnel. I have started to plan the wedding we had to cancel! Fatigue and panic attacks still affect me but I am learning to manage them.

Interview with Peter



What were you doing before your stroke?

Before my stroke I worked in Portumna as a chef in my own restaurant, working up to 100 hours a week. It was a very busy place, with tourists from boats and locals all

visiting the restaurant. I liked horse racing and went to the races but otherwise I didn't have time for much else except work.

How did you get your injury?

I had a stroke approximately 10 years ago while walking down the hall after watching TV and having a few whiskeys. I was in hospital in Ballinasloe for five months.

I went to the National Rehabilitation Hospital in Dun Laoghaire – dreadful food compared to Ballinasloe! I remember a French woman did physiotherapy. I spent one month in the NRH – didn't like it at all because I just wanted to be at home. I came home at Christmas time in a wheelchair.

What was the worst effect of your stroke?

Losing my speech was the worst part of the stroke and also losing power on the right side of my body.

What services did you use in your recovery?

After hospital in Ballinsloe I went to the NRH in Dun Laoghaire. I wanted to be at home. After a period at home I started in Quest and I lived in Galway city.

Quest was the best programme! I enjoyed the chats with the staff and the other clients. (I would go back again!) I enjoyed meeting people, the conversation, the atmosphere, and being with other people who had a brain injury. I put my "Life Book" together (pictures and stories) and because of my speech problems I can use it at home to tell people about myself. I enjoyed painting classes, and still do a bit at home.

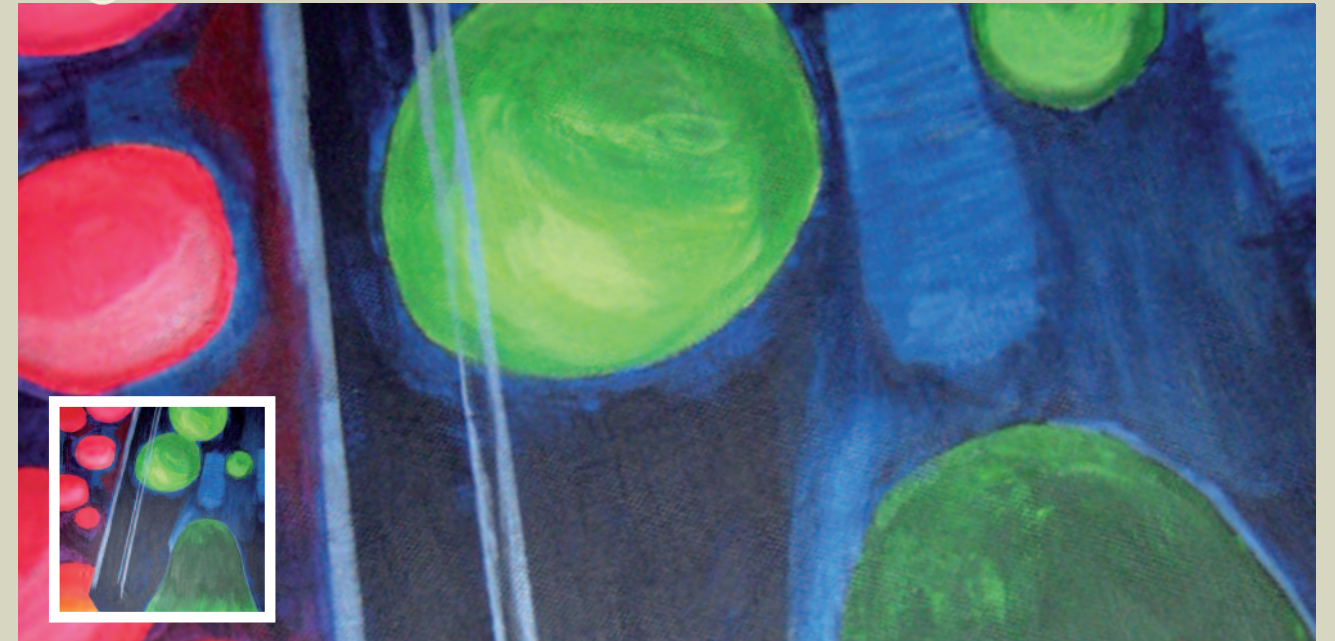
How are things now?

I stay in Galway Monday and Tuesday and don't attend any services at the moment. I just go for physiotherapy. When I'm in Portumna for the rest of the week I go down town to the shops, butchers, etc. I don't smoke since my stroke, just have an odd glass of wine... and I still enjoy sweets! I recently travelled by myself to Berlin to visit my son Mark.

Peter Treston



Niamh's experience of ABI in childhood



To be honest I have no memory of what I was like before my accident as I was only seven years old...but only from what my mum has told me and up to the present day. At the time they told mum there might not be much hope of any kind of recovery.

My mum left no stone unturned. She pushed and pushed me, as she was so afraid of what might be if she didn't.

There were times she told me we would fight so much. But now I see how right she was to do all the above.

It is 17 years since my brain injury and for the longest time I always felt different from all my friends in national school, many of whom I lost because of the accident.

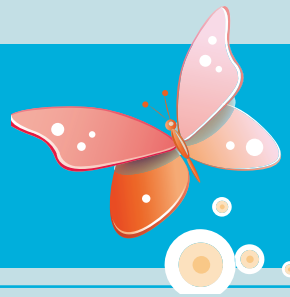
Since arriving at Quest now I know I belong...you guys are like me... an acquired brain injury is something we all have in common.

Niamh Healy



Me aged seven and Mum when I came home from hospital!

My Story



My accident happened in January 2005. Luckily I was a lone passenger in the car. I can't remember the entire story so what I am writing about is a mixture of what I remember or what I have been told.

I was a very successful, highly ambitious I.T. coordinator and facilitator. I generally worked in Galway but my work could be based anywhere around the country.

I am a married mother of two. At the time of my car accident only one of my children was school-going. Apart from my working life I was a fairly fit, very outgoing person. I played volleyball at a competitive level. I loved dancing, going out, socialising etc. I had a very full and active lifestyle.

The accident

My accident occurred when I attended a "wind down" dinner party, after the completion of a work project. I was leaving the party and heading home when the car that I was driving was hit. It seems I drove out in front of a van. I was brought to UHG and my brain was so badly swollen that I was placed in a coma to give my brain a rest. I remained in the coma for two weeks.

Effects

Initially when I came around I was wheelchair-bound. After a period of time I learned to walk again. To this day my speech is slurred at times (particularly when I am tired). I am slightly lame on the right side of my body. I remained in hospital until the end of April. My family had been contacted by the family of someone else who had suffered brain injury and they were advised not to allow me to be discharged from the hospital until I got further treatment.

I was not happy to remain in hospital but eventually, thanks to the advice we had been given to stay in UHG, they found me a bed in

Dun Laoighaire. I was removed from UHG and brought by ambulance to the National Rehabilitation Hospital in Dun Laoighaire, where I remained until the end of July 2005. While I was there I found it good but strange. I saw my family on a weekly basis, where I had been used to seeing them daily. Whilst there, I allowed my children to have a look around to show them that accidents can happen and the consequences they can have. It makes you appreciate being alive and how lucky we are. Before the accident I used to complain about trivial things.

When I was discharged from Dun Laoighaire from the NRH I had been in hospital for seven months. I was let home, where I am to this day! Unfortunately I am still unable to work but life has improved since those early days.

After hospital

After leaving hospital, I was advised to try and attend Quest in Galway. Looking back, it was probably the best thing that happened to me at that time. In hospital your life is run for you. You are told when to get up, when to wash, when to eat and nearly (not quite!) when to use the bathroom. It's very scary to suddenly be allowed home where you have to run your own life. It had been extremely worrying on my family, as I was 35 at the time and I had two children of my own. The youngest was just about to start school. To this day I joke with him that we learnt to write together.

Now

I am enjoying being at home, being with the kids and learning things together. Although, I admit sometimes it gets on top of me. My memory is still very bad but improving, my mobile phone has become my best friend as it constantly reminds me of things I have to do during the day or the foreseeable future. I often don't recognise people although they know me. My sleep pattern is terrible and at times I can

suffer from extreme tiredness during the day. I thought it was just me, but from talking to others who attend Quest I believe this is something that most of us who have had a brain injury suffer with afterwards.

One of the things that I learnt through my recovery is that the doctors were probably right! When I was in UHG, I was very impatient with all that was going on around me and very impatient with myself (my general lack of ability) and the doctors kept saying "it will take time". I learnt to hate this saying, but seven years on I have to agree. I am not there yet but I have improved with time.

Another thing that I learnt was the best way for

me to cope with my on-going recovery was to realise that you can never recover 100% and once I lowered my expectations of recovery I began to see it more. My main motto is "Learn to Cope, Learn to Recover and Learn to Live".

Life after the accident is good. I have gone from being a workaholic to being able to spend time with my kids. I have got a lot fitter and my patience level has nearly returned to normal. Although it's not quite there yet! I realise that I still have to "slow" things down a little bit more. I need to realise that unless things are urgent I don't have to do them right NOW, they can wait. So after all I have been through, life is different but good!

Anonymous



Kieran's Story

Since my injury...

Sometimes it's a battle and I feel like just throwing everything to one side and just saying 'f!*k it' but then I think of a Jewish saying "Into every life a little rain must fall" and I also realise that there are people an awful lot worse off than I am, and that I am very lucky to be where I am.

Kieran Barrett



Clinical Nurse Specialist (CNS) in Stroke Care, UHG



Trish Galvin



Stroke is a condition with a high incidence, and moderate mortality rates, leaving a large proportion of survivors with significant residual physical, cognitive and psychological impairments. Stroke is an illness with a huge personal and societal impact.

Historically stroke was viewed as a disease of the older person, an inevitable risk of aging, a forgotten illness. It was something that often fell between medical disciplines and therefore treatment often lacked a standardised approach. Stroke therapy and rehabilitation is now emerging from a period of relative neglect.

In 2008 the Irish Heart Foundation in association with the Department of Health carried out a national audit of stroke care in Ireland. From it, recommendations were made for the need to standardise stroke care across the country. The issue of stroke was moved more to the forefront and was now being viewed as a preventable and more treatable condition.

Today, there is a wealth of information available on the cause, prevention, risk, and treatment of stroke. Although there is no cure, most stroke victims now have a good chance for survival and recovery. Immediate treatment, supportive care, and rehabilitation can all improve the quality of life for stroke victims.

The move is on now to streamline a pathway of care from admission to hospital, to discharge and on into further rehabilitation.

One of the most important advances in stroke care is the realisation that organisation of stroke care into stroke units saves lives, reduces disability and institutionalisation.

In UHG – a five bed stroke unit, based in St. Rita's ward, provides acute care for those who have suffered a stroke. There is no set time that a patient stays with us; each case is individual, just as the effects of stroke are individual. Once a patient has made a reasonable recovery and is assessed as being appropriate we can refer them for further rehabilitation to Unit 4 in Merlin Park Hospital or to community rehabilitation. Where deemed necessary, we may refer onto the National Rehabilitation Hospital in Dun Laoghaire.

As a CNS, one of my roles is to provide patient and family support and advocacy, to be a point of contact, and provide education around a person's stroke, demystifying the condition and giving practical information.

In my time working in the area I have seen a shift in the age profile of those being admitted with stroke. It is no longer a 'disease of the elderly'. Because of changing lifestyle, diet and habits we are finding that an increasing number of younger people are coming through our doors. As stroke is a preventable disease another huge area is in making people aware of the risk factors of stroke, so that stroke will no longer be the biggest cause of acquired disability and third biggest cause of death in this country.

Mick's Story



I used to work in construction for a large company – good wages, good working conditions and I was very well looked after. I had company transport, food and accommodation. It was hard work but I really enjoyed it. I was also interested in Connemara ponies and so had bought six! I had hoped to train and breed some and I did some work on that as a hobby. My biggest hobby was shooting and fishing. I did river fishing and shore fishing. I also liked a bit of dancing – I'm a bit of a Mike Denver Fan!

On the 3rd Jan 2010 I got a stroke. I had been made redundant at Christmas, just a couple of weeks beforehand. I was helping my brother-in-law renovate his aunt's house when I got a bad pain in my head. It was a while later that it was discovered I had a stroke. I lost my talk and some memory. When I got out of hospital I tried to start work again straight away and did a bit. I felt so tired and could not understand why I could

not stay going like before. I felt not interested and unable to plan out and do work I had been doing so easily before. I was waiting to be told what to do. I was working with my son and I felt under pressure but didn't know what was causing it. I began to feel depressed and that I was always in the wrong place, doing the wrong thing.

I was introduced to Quest by Dr. Tom Walsh, a consultant in UHG and went there for an interview in October 2011.

At Quest I got a lot of information about my brain injury and can now understand more about it. I know now that although I can do a lot of physical work, if I get tired I find it impossible to process information and what is said to me. Only for the training and education I got from Quest I would be in a awful bad state of mental health and confusion.



Eolas Faoin Ghortú Inchinne



An acquired brain injury, or ABI, is damage to the brain that was not present at birth and is non-progressive.

The two categories of ABI are **Non-Traumatic** and **Traumatic** brain injuries:

Non-Traumatic Brain injuries include:

Smoke Inhalation
Brain haemorrhage
Tumours
Viral infections
Poisoning

Traumatic Brain injuries include:

Road traffic accidents
Assaults
Penetrating or open head injuries
Falls
Sports injuries
Concussions

*Stroke, traffic
accident, tumour,
assault, sports injury,
fall, oxygen
deprivation...*

Parietal Lobe:

Sense of touch, awareness of spatial relationships and academic functions such as reading

Occipital Lobe:

Vision

Cerebellum:

Balance, co-ordination, skilled motor activity

Frontal Lobe:

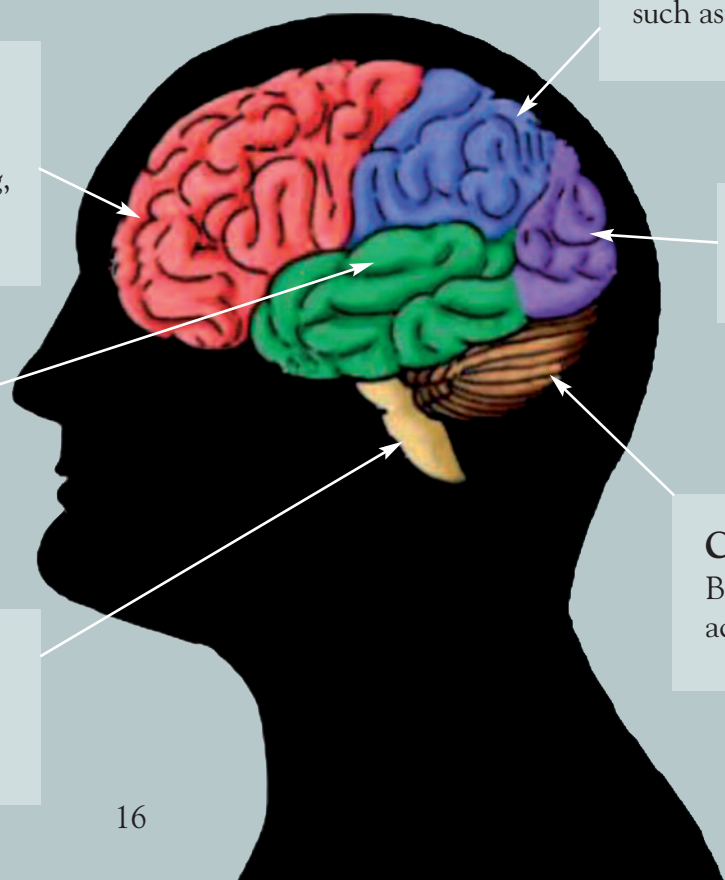
Emotional control, self-awareness, motivation, judgement, problem-solving, talking, movement and initiation

Temporal Lobe:

Memory, hearing, understanding, language and processing

Brainstem:

Breathing, heart rate, arousal and consciousness, sleep and wake cycles



General Effects of Acquired Brain Injury

Mar a chuireann gortú inchinne faighte isteach ar dhaoine ag brath ar nádúr agus méid an ghortaithe d'fhéadfadh gortú inchinne cur isteach i réimse bealaí ar dhuine ó dheacrachtaí beaga sealadacha go deacrachtaí níos mó agus athruithe pearsanachta. D'fhéadfadh na bealaí seo a bheith fisiciúil, cognaíoch, mothúchánach nó sóisialta.

Physical

- Weakness or paralysis
- Tiredness
- Headaches and / or pain
- Poor co-ordination and balance
- Seizures
- Vision and hearing problems
- Speech and swallowing difficulties

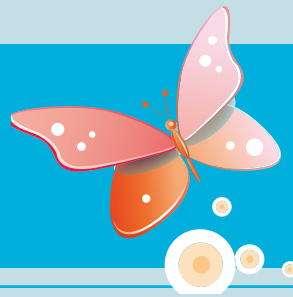


Cognitive

- Impaired memory, attention and concentration
- Sensitivity to noise
- Confusion and / or disorientation
- Lack of awareness and insight
- Reduced speed of processing information
- Problems with motivation and initiation (starting things)
- Difficulty with planning and organising
- Problems finding words

Emotional & Social

- Depression and anxiety
- Anger and frustration
- Mood swings
- Reduced tolerance
- Loss of role and identity in the family and / or workplace
- Loss of confidence
- Withdrawal
- Impulsive actions
- Relationship difficulties



Michel



My story is an unusual one, as it is about brain injuries that BOTH myself and my wife suffered.

Before our accident, both myself and my wife had a very active life. We did a lot of volunteer work, which involved visiting people and discussing questions of life and faith and traveling all over the country and constructing meeting places. We always looked forward to these projects and we made many friends.

My dream as a boy was always to be able to put my mind or hand to anything. That wish was kind of coming true!

I was the kind of person you would say that if I could fit in eight things in a day, I would try and fit in ten! If I wasn't working at a job I was working at my hobbies! One of my great interests was in making and flying stunt kites. Over the years I also had taken to canoeing and enjoyed taking pictures. Many years ago I decided to get involved in wedding photography. From there I was eventually tempted into digital photography.

The accident

Together, my wife and I took an interest in cycling holidays. We usually picked a warm country like Spain, France or Portugal. We would bring our bikes, cycling bags and tent. It was on our last holiday in Portugal in September 2010 that life changed.

We had landed in Porto and cycled south. We had a meal with friends. Two days later all we remember is we paid the fee for camping and cycled back to the main road. We cannot remember the rest of the day.

Around lunch time a car crashed into the back of us. The driver did not stop but drove on. Other traffic observed the mayhem and rang an ambulance. We were transported to Sines, a town on the coast nearby. Staff there realised the severity of the accident and the possibility of brain damage. They ordered a helicopter to bring us to a hospital better able to cope.



Prisca



Both my husband and I were involved in a cycling accident in Portugal in 2010 and both of us were left with brain injuries.

Before the accident I spent a lot of time visiting people, discussing the Bible and distributing our magazines with fellow members of the Jehovah Witnesses. I was happy being married, very busy with my life and several things.

I worked cleaning different places and loved knitting, sewing, cooking, embroidery, visiting friends all around the world, going on holidays and I loved cycling.

All this has changed since the accident.

We were on holiday in Portugal,

Michel cont...

Prisca and I were both in a coma. I had broken my neck in two places. I woke up three weeks later and realised something was wrong. I saw white walls around me, also my mother-in-law was in the room and Prisca was next to me in a bed. No bikes and no tent!

Hospital experience

When we got back to Ireland, to University Hospital Galway we were not put in the same room. I was on the ground-floor in a ward with 16 people and Prisca was on the 3rd floor. In my ward, life was not easy. I will spare you details, but I was looking forward to getting out of the "Circus" - my nickname for the ward. Also, while I was in hospital I had some very strange dreams, which I often thought were true and couldn't understand why the hospital staff and my parents-in-law would not take me seriously.

After hospital

One good day they decided I could go home. My parents-in-law were quite concerned since they had not been consulted. They worried about how would they cope with this brain damaged son-in-law. Although I was set free from hospital it was as if my wings were clipped. I still had a neck brace and was not allowed to drive my car. Jan, my father-in-law would have to do it.

Meanwhile, Prisca was still in hospital and there was talk of transferring her to the National Rehabilitation Hospital in Dun Laoghaire. When that happened we could pick her up at weekends. This was a long trek and not that easy for Jan. Some of our friends volunteered to help. They had been very good to us for months. One day a friend came up with her car to drop off a meal and crashed the car in snowy conditions, I felt so terrible that a kind person got into trouble for trying to assist us. Normally I would have gone to the scrap-yard and picked up second hand pieces to fix it up. But now I could do little. Life needed to be adjusted...

Then there was the welfare system. I applied for help with paying rent and met a community welfare officer but help was not easily forthcoming. It was decided that we would get help for six weeks and in that time we could look for a one-bed roomed flat. The fact that we needed carers to live with us was totally overlooked. Where would my parents-in-law who were looking after us live?

Then there was the application for disability allowance. In my case it was accepted but when I applied for Prisca she was refused

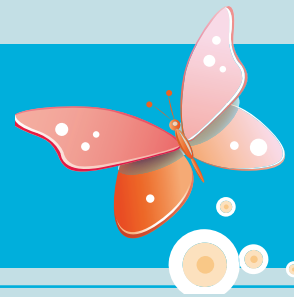


Prisca cont...

cycling and camping and meeting friends we had met before. One day, September 28th 2010 a lady drove into us, fast. I was in a coma and taken to hospital. The police kept all our belongings.

Because we are Jehovah Witnesses, we have family all around the world and so one of them came to the hospital and then rang my parents and Michel's sister. They then came to Portugal to help, and my parents are still looking after us now! The man who helped us in Portugal visited us in Ireland recently. He and his wife could not believe how far we had come.

After four weeks of not knowing anything we were flown to Ireland, then brought by ambulance to University Hospital Galway and I was there for two months. Several people came to help me, thinking about life and helping my damaged body to recover again. After Galway I also spent one month in the NRH in Dun Laoghaire and got a lot of help there. I came home and slowly came back to living and thinking with all the help from my parents and my friends in our congregation.



Michel cont...

on medical grounds! This is interesting – medical grounds? First of all there was no medical examination by the Department. I was told that since so many people are dishonest they would generally refuse people as a standard response.

Difficulties

I found it difficult to deal with things and often wondered what was happening to my mind? I could not sleep and was getting terrible nightmares. The doctor suggested going to a psychiatrist and taking medication. It started to become clear to me that I was going through a low valley. The doctor called it post traumatic stress syndrome and said it was quite common. Here I was, Michel, the man free from any trouble before, now on sleeping tablets, seeing a shrink and having violent ideas about people who I thought were treating me badly!

Some medication and advice from the psychiatrist seemed to balance things out a bit. But then there were still all those other questions. I would forget to take my medications, or I would put on the kettle but not make tea. I wondered was it just me getting older or was it the bang? Those questions still follow me through life.

Now

While in hospital, someone mentioned a helpful program that we would benefit from called Quest. Eventually we both enrolled and have found it extremely helpful. I would describe it as a group of whole-souled, dedicated instructors who think on their feet and adjust and suggest plans for our benefit. They have kindly suggested things like trying a photo training session to see if I still have my old skills or if we can rebuild them. My memory is also improving due to programs that stimulate it. A very nice additional aspect is the other clients. We were prepared for possible personality quirks as a result of brain-damage. Somehow thus far all the folks have a pleasant disposition and helpful attitude. Our circle of friends is growing. What more can we want! My parents-in-law keep saying we should have had all this experience at Quest a year ago. They have learned things about us through Quest that they used to think were a bit strange. Now they know it may be part of a well known pattern.

Michel Meijer



Prisca cont...

My recovery is very slow but positive. I've slowly been getting more strength. Swimming in the morning in Tuam helps us to move a lot better. Things have been a bit difficult recently because we have to move house. So we have to go through everything in every room and decide whether to keep it or not. Thinking and making decisions is not as easy as before and makes me sleep a lot. We hope it will get easier in our new house!

Life now is very different for me. I don't have the same strength and memory. I lost a lot of knowledge of normal things in life I always did.

Prisca Meijer



Abiola de Mojeed



Although trained as an Occupational Therapist, I currently work as a team leader in RehabCare's Acquired Brain Injury service based in Ballybane. I work with adults post-brain injury that are at community rehabilitation stage.

The service is provided through the Transitional Living Unit and Residential Services (an apartment and house which provide supported accommodation for people with an ABI), and also through community outreach support workers.

Despite the advances in early diagnosis and treatment of ABI, the fact remains that brain injury will be a life-changing experience for many people. Helping those people, their family members, and caregivers manage with these long-term consequences is an important role for our ABI service.

When a person is discharged from hospital into the community; it is imperative to have a smooth transition into a structured community support programme. In our service, the staff team are a vital part of this process. They work together with therapists and the individual to enhance their independence and to increase their participation in activities within their local community.

Staff within RehabCare's ABI service strive to assist each person with the challenges that have arisen as a result of their injury by listening to their individuals needs and ensuring that their

concerns are treated with dignity, respect and empathy.

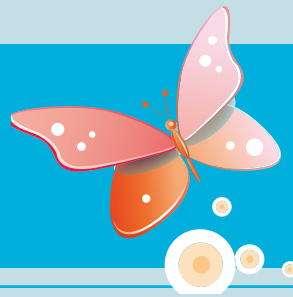
Through an average day working in the ABI service, I have found the continual consideration of five key factors is essential in order to allow for successful goal attainment and greater quality of life satisfaction for each individual. These are: assisting individuals to build and maintain motivation; engaging them in meaningful activities of interest; assisting each individual through the changes in role due to their injuries; assisting each individual with sustaining and developing their daily living skills and finally the consistency of staff support and expertise.

Motivating and engaging with individuals is imperative, for example in facilitating participation in assessments, identifying problem areas, identifying goals and the development of care/rehabilitation plans. Furthermore, it is important to develop a consistent person-focused support to each individual in maintaining their independent living skills needed to achieve long term positive health outcomes.

A smoother transition into an ABI service directly after their discharge from hospital can help the individuals in achieving their own independent goals.

There are many challenges currently facing such transition from hospital to rehabilitation services and some of these include physical needs, medical needs, family decisions, financial choices, nursing homes vs. rehabilitation services, and/or subtle psychosocial and functional challenges facing the individual. However, the longer the individuals are out of the rehabilitative pathway the greater the challenges of integrating back to the community will be.

Karen's road to recovery



Karen Walsh worked as a team leader with RehabCare's brain injury service in Galway. She loved her job and, was living life to the full. That all changed in October 2007 when she was involved in a road traffic accident.

I don't remember anything about that day, or any details about the accident, which happened just a few kilometres from my apartment. I have been told that I was the front seat passenger in the car, which was involved in a two-car collision. The left-hand side of the car received the main impact, leaving me with significant injuries, including a very serious head injury. I was brought by ambulance to University Hospital Galway, from there I was transferred, with a Garda escort, to Beaumont Hospital in Dublin, where I spent ten days in a coma. I was moved back to Galway, still critical. With help from my family, doctors and nurses, I slowly regained consciousness. But this was just the beginning of what was to be a slow road to recovery. For seven weeks I wasn't able to recognise anyone. I couldn't talk or walk. I had to be fed through a tube. I also had tracheotomy and was catheterised. It was a bad time for me because I was very frustrated and angry.

Gradually, I became more alert and began to recognise people. On Christmas Day 2007 I was able to go home for a short period. The trauma of the accident meant I had an absolute fear of getting into a vehicle again I felt safe in hospital, so I didn't want to leave, even for a few hours. When I refused to go home by a car, my aunt's husband who drives a mini-bus collected me. I had a wheelchair with me but I didn't use it. I

sat in the back with my mum and that made me feel safer. Of course once I got home, then my family couldn't get me to go back to the hospital!

From UHG I moved to the NRH, in Dun Laoighaire and I spent two intensive months in rehabilitation, where I had to relearn all the basic tasks like brushing my teeth, washing my hair, eating, cooking, etc. I wasn't the easiest person be around at that stage, because I used to get frustrated. I knew that I used to be able to do these things simple everyday things and it was really hard to have someone teaching me how to do them again. I just couldn't understand why I couldn't do them myself. The worst thing was that my sense of direction totally went. I would picture where I wanted to go, but I had no idea how to get there. My mother came to my rehabilitation sessions with me for these two months, simply to help me to get from A to B. I still have a few problems with direction but it's much better now.

In early May 2008 after leaving the NRH, I started Quest in Galway. Quest helped me in a number of ways. It helped me to regain my confidence which was a big thing for me. In practical terms, it helped me with my speech therapy, one-to-one counselling sessions, IT lessons. I also learned return-to-work skills.

Quest knew how eager I was to get back driving and so organised driving lessons for me through the Irish Wheelchair Association. After a number of lessons, I finally got the go-ahead to drive in December 2009. That was a massive step in my recovery.

Because I had worked for Rehab for a number of years, it was a case of role reversal as I now began using the service myself. To be honest, I wasn't very fond of Quest at the start. I looked on Quest as a place where I once had to bring service users through my work and now the tables had turned

and I myself was a service user. I was stubborn and I was looking at things the wrong way. I realise now that I would not have gotten to where I am today without wonderful love and support from my fabulous family and friends and the rehabilitation team at Quest.

I really missed Quest when I left. Everyone there has a mutual bond. People are there for different reasons, such as brain injuries, strokes, infection, and accidents like mine. The Quest gang really is a fantastic bunch and we meet up every few weeks for a catch-up. It's great to have other people who are in a similar situation around you as they understand what you are going through better than most.

Life is getting back on track for me now. I have found an apartment with a friend but still rely

on home at times. I am now back at work with RehabCare Galway. I wouldn't be where I am today without the help and support of my parents Paddy and Margret, my brothers Kevin, Noel and Shane, my friends and work colleagues in RehabCare and Debenhams. My life changed forever on that fateful day in October 2007, but my future looks good. As they say, "whatever is for you, won't pass you".



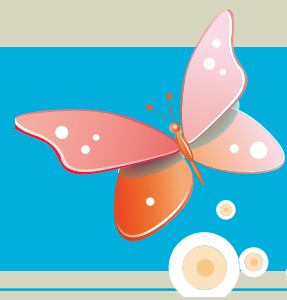
Brendan - returning home

After a few weeks at home I started observing more and more problems. I found it hard to concentrate for long periods at a time. Even watching a film, I found I would miss out on bits and when you are trying to figure out a story in your head, it is very difficult when you either cannot remember part of it or misunderstand it. Even in long conversations, I found them drawn out and I might miss out on crucial bits of information. But I learned that this can be improved on. It's very frustrating at the time but once I put the effort in to work on it I found the effort well worth it. ...

Now...

I have now learnt many important things since my brain injury. Until you are made aware of it you never stop to think how important our brain is – from first thing in the morning, having a shower, eating and then on into your interactions throughout the day, you are constantly using your brain.

Brendan Keane



I was a teacher in Dublin. I taught Maths and Business. I was a year into a part-time Masters. I loved to meet my friends, to go shopping and socialising.

It was May 1st, my boyfriend and I were travelling home to Galway to study for our exams. We were on the motorway home when he heard something and he felt the car wasn't driving right. We pulled into the hard shoulder and put the hazard lights on. I was out of the car checking the engine with Paraic. He was ringing the road side assist to get someone to come out and fix our car.

I sat back into the car to text. A big articulated truck crashed into the rear of the car. I sustained life threatening injuries. I was rendered unconscious and was brought immediately to Tullamore Midlands Regional Hospital where I was put on life support. I had swelling and haemorrhaging on the brain. I had a tracheotomy and was PEG fed for months because I could not swallow or chew. Gradually, with medical care I got stronger, learned to swallow and to take liquidised food. I can now take ordinary food. Anti-clotting injections were given to me daily for eight months. My body was bruised black and blue from these injections. There are marks on my neck and stomach from where the tracheotomy and PEG tubes were inserted.

In all, I was in a coma for ten weeks and spent time in the intensive care and high dependancy units in Beaumont Hospital and University Hospital Galway. Finally I went to the National

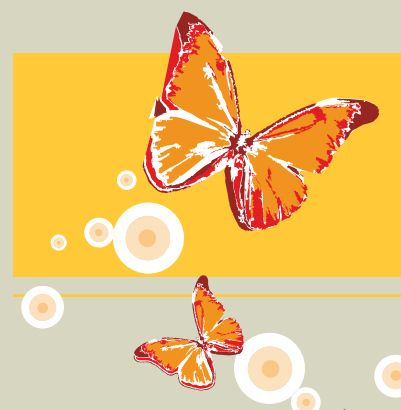
Rehabilitation Hospital. In total I was eight months in hospital.

I can't walk. Now I use a Rollater (a walking frame with wheels) but someone always has to be with me. I find this very difficult as I used to be so independent before and I loved to go walking with my boyfriend and friends in Howth, Wicklow and Connemara. Another thing that is very hard for me is my speech. As a teacher you have to have a clear speaking voice. Now I find talking clearly and loudly so difficult. Spontaneity is another difficulty. Even a simple trip to the shop proves daunting for me. I have paralysis in my right side. I cannot use my right hand properly (which was and is my dominant hand). For me functionality has gone out the window; even brushing my teeth or hair with my right hand is virtually impossible.

I loved my teaching career at the Dominican College, Dublin and I miss my friends and colleagues on the staff. Their ongoing support and friendship is so important to me at this difficult time. Also, I had been approved for a house loan and was looking forward to my life ahead in Dublin.

Thank God for my wonderful family and friends and amazing boyfriend. They make me laugh every day. I make sure to do something fun and sociable every week. It was recommended at Quest that I keep a diary and I now find it very useful. Going to Quest has been brilliant. The instructors are so nice and the clients are lovely!

Deborah Noonan



Beaumont Hospital

On the 1st of May 2010 our daughter, Deborah, sustained life threatening injuries due to a road accident after which she was a patient in hospitals for a total of eight months. She was rendered unconscious following the accident and she was brought immediately to Tullamore Midlands Regional Hospital. Later that day she was transferred to the intensive care unit in Beaumont Hospital where she remained for two weeks. We were confident that she was getting excellent medical attention and that she was in a centre of excellence if any emergency arose.

University Hospital Galway (UHG)

Deborah was transferred from Beaumont Hospital to UHG, where she spent nearly four months. While in UHG, Deborah made great progress. Communication with us was excellent and we appreciated the flexibility granted to us in being able to be at her side at all hours, day and night. The ward sister informed us of the disability services in Galway and of Primary Community and Continuing Care. These contacts were very important for later when Deborah was discharged from the NRH into our care.

During this time, I tried to live in the present and focus on every improvement in Deborah's condition. I didn't want to think of the future or about the long term consequences of her injury. I found reading literature regarding disability to be depressing.

National Rehabilitation Hospital (NRH)

Deborah was in the NRH for four months, from August to December 2010. I found the NRH a

difficult environment. There are restricted visiting hours. Most of the patients have severe injuries and long term disabilities. Prior to Deborah's discharge, the NRH organised a seminar for family and friends of patients which dealt with brain injury awareness, discharge planning and possible entitlements. This was helpful. However, it was sad listening to case studies of people who had acquired brain injuries.

Post hospital Care

Deborah now resides at home with us in Galway. Life hasn't changed very much for us. However, I ceased my involvement with some clubs and organisations because I lack energy and enthusiasm. Deborah's life has changed a lot. Prior to the accident, she was living in Dublin with her boyfriend and teaching in a secondary school. She was studying for a Masters degree in maths and had successfully completed one year of the course. Her life now revolves around a continuing rehabilitation programme e.g. home care, physiotherapy, occupational therapy, speech and language. She attends Quest. She loves going there. It gives focus and routine to her week. Her confidence and positive outlook have grown. The staff and other clients are brilliant.

Deborah is very pleasant, kind and appreciative of any help she gets. We think she is a very courageous and inspirational person. She radiates warmth and laughter. We are amazed at her strength of character and resilience. We are blessed to have her.

Marian Noonan (mother)

There is a lot of work you have to do to get back, or try and get back, to how you were before your accident, or as close to being 100% again.

At times I find it hard remembering things and it is very difficult not being to do things that should be simple to do, or get to places or events that I must go to.

G W



Micilín's story



My name is Micilín Feeney and I'm here to tell my story. A short story of my 31 years, seven of which have been spent with a disability. My disability is an acquired brain injury, which I sustained in a car crash, on Halloween night 2004.

The accident

I don't remember much about the accident itself. I don't remember the accident at all actually. The day was dry but cold. It was Sunday 31st October. I have been told that I was at a football match that day in Carraroe. I was playing cards for most of the evening in a pub. I was drinking cider while playing cards – I don't know how much I had to drink, but my cousin saw me and thought I looked sound. But I drank to excess most weekend nights. I got into my Mazda 323 about 11.30pm that night.

Luckily there was no one else in the car, and there was no other car involved in the accident. An undertaker found me at 12.05am. I had fallen asleep while driving and went off the road. I was unconscious when I was found and the ambulance workers thought I was taking my last breath from the sounds I was making. I remained unconscious for another four weeks.

Affects of accident

I, like most my age, was passionate about sport, in particular gaelic football. With a cruel twist of fate, I was named Lettermore Player of the Year in 2004 after my accident. My mother went to the awards ceremony and collected my trophy, as I was still in University Hospital Galway at the time.

I was a block-layer by trade, which I loved, but with the injury, my balance went AWOL. My social life too suffered and the relationship I was in broke up. Right or wrong I'll never know.

My dad had died of cancer three weeks before my accident, and that was a blow I thought I'd never recover from, and almost didn't. After the accident I had to be told about it all over again as I didn't remember. Also, while being in a coma my friend died in a car crash – three weeks after my car accident.

Life in hospital

Nurses in Galway kept my spirits up. Apart from nurses, there were the physiotherapists, occupational therapist and speech therapist – they were all great, I owe them all a great big thanks.

In total I spent eight months in hospital between, Galway, Beaumont, Galway again and finally three months in the NRH in Dublin.

After hospital

My balance has been affected for life. My speech is low and sometimes slurred. My confidence was gone but I slowly but surely worked on getting it back. My memory wouldn't be the sharpest tool in the box but it is improving. I attended Quest Brain Injury Services in Galway, studying brain injury education, daily living skills, social integration and computer and work skills. My sanity has slowly returned and more importantly my confidence.

Now

Since leaving Quest I started seeing my childhood sweetheart! We have recently moved in together and I'm very happy! I am looking forward, not backwards, with hope. I will leave you with this saying: "The glory's not in never failing, but in rising every time you fall!"

Micilín is pictured receiving a Leading Light Road Safety Award from Gay Byrne in 2008

Micilín Feeney

Our stories



Joan's Story

An attitude of gratitude

After my brain haemorrhage, I lost all sense of self and nearly all my confidence, but with the support and love of my family and nurturing environment and support of the staff of Quest I took steps on the road to recovery.

The new me

Now I am a more complete person; a person, who for the first time in my life has had time to look at me - the post brain injury me. I am not the person I was before the brain injury and it took a lot of time and adjustment for me to finally realise and accept that. I am now experiencing what it is to be the new present me; not the old me that worked to a schedule, that planned to eternity, that strove for control of situations, work, world, life. I am now beginning to let go of my anger at my situation, to let go of control and let God rule my life. I am beginning to engage with the present, and feel that I am finally developing an 'attitude of gratitude'

Joan Solan



Ita's Story

Over the years since my surgery things got better and better. At first I suffered from post-traumatic stress after the operation and decided that I needed to return to Galway, as I was from Galway, and family support was very important... I think that now I cope very well. I have my own apartment in Galway. I work at least three days a week with the elderly as a Home Care worker and am doing a course on Care for the Elderly. I also take part in tandem cycling every second week.

Ita Kilgariff



London in the 80's

I moved to London in the early 80's as there was no work here – it seems nothing has changed! I lived with my brothers in Harrow and we all worked together with roofing.

I had worked earlier in various jobs. One of them was in a hospital for nervous diseases – brain tumours being one of these. While working, I was getting headaches, so I went to the doctor and he told me to take an aspirin and lie down in a dark room. That didn't work so I went to my own doctor. He doubted something, and so he sent me for a scan. I could not believe when the guy in the hospital scanned me, as I used to be the one who brought people for scans and x-rays up to him. I never thought I would be the one having the scan.

The Tumour

The scan showed that I had a brain tumour. All I can remember was the neurosurgeon telling me that it was 'not malignant' – although I didn't have a clue what that meant! The family told me later it was 50/50 if I would pull through or not.

Later on I found out that a small percentage of the tumour was removed and the rest was treated with radiation. For a good period afterwards I would be having scans and sometimes having to wait over a month for results to see if the tumour grew back or not. They could not tell me on the spot. This was very distressing. For me the treatment was hard work but I still feel very lucky. The tumour affected my balance, co-ordination, hearing and memory.

Back at home

When I was over the treatment I felt I had to go back to work again. I called a social worker from the hospital and she referred me to a rehabilitation centre in Watford, where I was tested on various jobs. It was decided I should do a course on wiring assembly. I completed that and got a job in Wembley. I worked there for over five years. Then I was made redundant. I felt I was unfairly dismissed but lost my case.

After getting another job, I started getting headaches again. I felt I was finished. I honestly thought so, and felt it was best to go back home to my family in Mayo. I could have gone to my doctor but was afraid I would hear the worst. So after telling a friend of mine, I left for home.

Back to Ireland

Being at home a while, I realised I wasn't dying. I began to do the odd job and then remembered that my mother had given me the old cottage we were born in. I decided to do it up and with help from a friend of mine in England, Christopher, I eventually got the information I needed and then contacted local builders. Pake and Brendan, the Conroy brothers in Cong came in and did the job in three weeks. I also put on an extension.

Shortly before the job was finished my eyes were giving me problems. My brain swelled up and my eyes went out of focus. I ended up in University Hospital Galway for about a month then went onto Beaumont Hospital for about two weeks.

At Quest

It was then we heard of Quest. I was not sure what the place would be like, but after a few weeks I could not believe that such a place existed. First we all got diaries - a great way of keeping dates - and then we were given different timetables to follow so we all knew where we were. I could not believe that I was in such a place. I often hoped something would come up,

but never thought such a place existed. It was like the difference between day and night!

You can talk to people sometimes but they don't understand so it's great when you find a place that people do. We were shown how to use computers. I never used one in my life until I came to Quest and now I can use Skype, read my emails etc. I also got help using the washing machine - to other people this is easy, but when you get confused this can be very hard. The same applies to the dishwasher, microwave etc.

Getting around is also important - for instance from Quest to Galway station by bus is very complicated, but we are shown the buses and route. This is a great help as I can get very confused, and if you have not been out and about in Galway you are shown where the different landmarks, like post offices, library, different organisations etc., are.



Finally

I think that at the early stages of your injury, when things are being explained to you by your doctor, even if the person doesn't ask, they should be told about their injury. Also, it's important to be reassured that you are going to be okay by the doctor and also, a person should not be waiting long for scan results or any other type of results as it's distressing. Also it's important that people are notified immediately after their trauma about places like Quest, as in my case it was just by chance I found out.

Sin é an scéal!

Noel



Aisling



My life before

After studying for four years and getting a degree in marketing and languages, I went to work on cruise ships in the Caribbean. I worked through six or eight different contracts – each one for about eight months or so. I travelled to different islands in the Caribbean, down the west coast of the USA, and even had a trip from Europe, through the Mediterranean and across the Atlantic to New York, on a new ship.

When I came back to Ireland I wanted to work in television. I was just about to start out on a brand new career, about to change my life and do something I'd always wanted to do - a course working in television, camera work, editing, sound etc. What a dream come true and getting paid for it to boot! But alas, it was all too good to be true. One fateful night my life was changed alright, but not in the way I was expecting! Adios Amigos, life as I knew it was over. It was nice knowing you. Thanks for everything...

The accident

It was the one time I didn't have my seatbelt on (it's normally the first thing I do when getting into a car). Even now, every time I get in and go to put on my belt I think 'The one time I really needed it...' – Murphy's law.

Well my life changed then...but not in the way I was expecting.

I was first rushed to Letterkenny Hospital, then onto Beaumont Hospital and then to the National Rehabilitation Hospital (NRH) in Dun Laoghaire. I was lucky enough to have an uncle living close by so my mum could stay with him, which was great because she could visit and take me around to the different therapies and stuff. I could also go and stay with them at weekends. It was good to get out of the hospital. You could forget what you were doing there and what it was all about.

After I was discharged from Dun Laoghaire we came to Galway where mum lives, because I couldn't have lived independently.



Lily (Aisling's mother)

At the time of the car accident I was living in Galway and my daughter, Aisling was living in Donegal, just having started a media studies course. She had her crash in November 2005. After first being brought to Letterkenny Hospital, she was transferred to Beaumont Hospital, where I travelled up to see her. It was the 20th November. I got the shock of my life when I saw her first. I'd never seen anyone with a brain injury before.

In hospital

Aisling spent a month in Beaumont Hospital. The staff and caregivers there were excellent. They had a brilliant head injury nurse who met with the family and explained all that was happening.

Aisling was transferred to University Hospital Galway while she was still in a coma. At the beginning we were told Aisling would be sent back to Letterkenny but after a lot of discussion and persuasion we managed to get the hospital in Galway to take her.

When we first arrived in



Effects

As for memory, you don't realise how much you depend on it. You take it for granted until you don't have it anymore. You have to learn to do everything again, like writing, cooking, driving...everything!

Because it was the left side of my brain that was hit, it was the right side of my body that was most effected. Initially it was paralysed, but with lots of therapies and rehabilitation I got movement back – but not fully.

As part of my rehab I attended Quest Brain Injury Services in Galway for a couple of years. At the beginning, Mum had to drop me every day but I slowly got to learn the buses with Ciara (from Quest) and became more independent. I also worked on memory strategies, computers and other things like day-to-day life-skills with Lena the occupational therapist. All the while I was also working on my physio to build my physical strength.

After Quest I went back to Dun Laoighaire to the 'Next Stage' programme. I stayed in the centre from Sunday night to Friday morning, travelling independently from Galway. When I came back to Galway I completed a course with National Learning Network called 'Tús Nua'. From there I went to Belgium to a rehabilitation centre for three months. While there I did lots of physio and travelled around the country a bit and also to Paris!

Now

I'm not sure when exactly (that's memory!) but before leaving for Belgium I moved into a place of my own. With support of family and some hours with a Personal Assistant I now live independently in Galway. I walk a lot, go to the gym, visit with family and travel as much as I can! I also began a new course in Galway Technical Institute this September.



Galway we got a bit of a fright as there didn't seem to be the appropriate staff around to care for Aisling. But then we realised that it was Christmas week and many were off on holidays. As soon as the 2nd of January came round, all the therapies kicked in. The nurses, physiotherapists and occupational therapists were brilliant in Galway. They worked so hard with Aisling and many visited and helped her in their free time as well.

When Aisling first came round she wasn't the easiest person to deal with but they were very patient and kind with her. They worked with her until she was back walking and talking again. Once they saw the spark in Aisling they seemed to work extra hard with her to make sure she reached her potential.

Useful Websites

Suímh Ghréasáin Usáideach

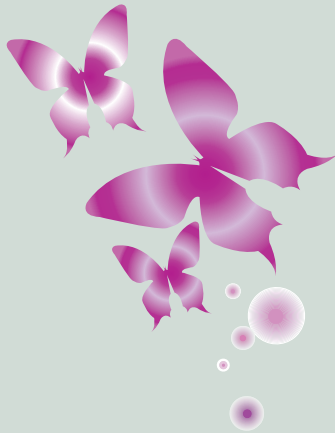


Here is a list of some groups and websites we found useful and may be of help or interest to you.

Brain Injury Specific Web Sites	
www.acquiredbraininjury.com	Useful ABI info, videos and work sheets. (Developed by Quest Brain Injury Services).
www.nln.ie	National Learning Network courses (and Quest).
www.rehabcare.ie	Provides support to people with disabilities including ABI.
www.headway.ie	Headway provides support and services to people affected by brain injury.
www.abiireland.ie	Residential, community and case management support nationwide.
www.galwayheadinjury.com	Support group for family members.
www.briireland.ie	Independent brain injury support and advocacy service.
www.beaumont.ie	Beaumont Hospital, national referral centre for neurosurgery and neurology.
www.nrh.ie	National Rehabilitation Hospital, Dun Laoghaire.
www.traumaticbraininjuryatoz.org	USA ABI site.

General Useful Websites	
www.citizensinformation.ie	Public service information. Information on disability and carers entitlements etc.
www.iwa.ie	Irish Wheelchair Association – Information on return to driving.
www.aware.ie	Support and information on depression and mental health.
www.epilepsy.ie	Brainwave-Irish Epilepsy Association.
www.flac.ie	Free legal advice clinic.
www.mabs.ie	Money advice and budgeting service.
www.welfare.ie	Gives you information about your social welfare benefits and forms to get started.
www.mentalhealthireland.ie	Information about how to deal with mental health issues.

Local Support Groups - Galway	
Galway Head Injury Support Group Tel: 091 768 168 Website: www.galwayheadinjury.com E-mail: galwayhisg@gmail.com	Provides support, information, referral and linkages to specialist services. They also provide counselling and co-ordinate monthly network meetings for carers.
Stroke Support Group Tel: 091 544310 Croi, Thomas Hynes Rd, Newcastle, Galway	Stroke support group provides information on issues important to people living with a stroke.
Caring for Carers West Tel: 093 25362 Website: www.caringforcarers.ie	Voluntary organisation: They provide training, respite, respite care breaks, information and advice to carers throughout Ireland.
Cancer Care West Tel: 091 545 000	Brain tumour support group.
ABI Ireland , Calbro House, Galway Tel: 091 700210 / 087 7840192	Information and resource service for people with ABI.



Acknowledgements

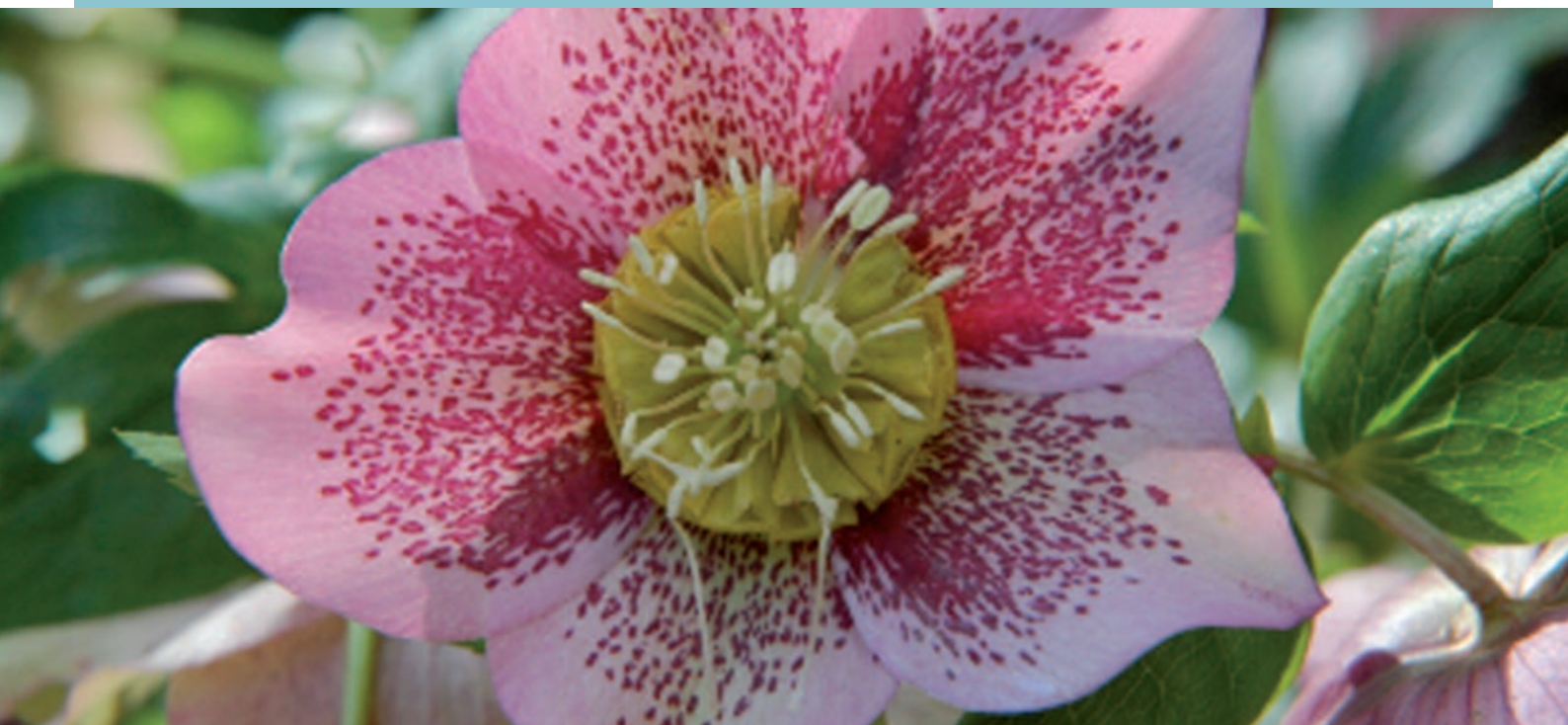
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Go raibh míle maith agaibh go léir!



Rebuilding

*Reflections on the effects of acquired brain injuries,
from survivors, their families and those who work with them*



Quest Brain Injury Services

A National Learning Network programme

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For information on brain injury visit: www.acquiredbraininjury.com