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the brain injury association

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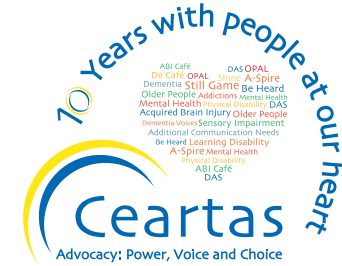
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# ABI CAFÉ STORIES -

## Living Life with an Acquired Brain Injury





# Introduction

This booklet is testament to the human spirit and the remarkable ability of people to re-build their lives in the most challenging circumstances. The openness and enthusiasm of ABI Café members in contributing has been overwhelming. By sharing their stories of how they've re-built their lives, our contributors hope to reassure others with acquired brain injuries that the road to recovery is not one they have to walk alone.

As well as being inspirational, we hope these stories will increase understanding of the incredibly complex nature of the difficulties faced by those with ABI (Acquired Brain Injury).

Ceartas and Headway Glasgow developed ABI Café in East Dunbartonshire both to raise awareness of the effects of brain injury and also to provide a safe place of mutual support and understanding. This booklet is the next chapter in the story of people working together to challenge a lack of awareness about acquired brain injury. Our collective hope is that it will provide a platform to educate and inform.

Acquired brain injury can display its effects in a variety of ways and may result from a range of traumatic experiences. The following stories illustrate this diversity, underlining that every person's injury is unique; accordingly, the response requires to be focused on the particular needs of each individual. We trust this booklet assists the reader's understanding of what people with ABI face day to day.

Everyone who contributed to this booklet has also been instrumental in making ABI Café a success. We're sure you'll agree their bravery in reaching out to others with acquired brain injuries makes for an inspiring and informative read.

# ABI Café

The ABI café is a monthly support and information group for people in East Dunbartonshire who have an acquired brain injury and for their carers. The group is run in partnership by Ceartas and Headway Glasgow:

it was started in 2011 and has continued to grow significantly since. The group currently meets in Kirkintilloch Baptist Church on the first Thursday of every month between 1.30pm – 3pm.

The group aims to reduce isolation for people with ABI by providing a supportive and relaxed atmosphere where they can meet other people and share experiences. The group also facilitates a variety of information regarding brain injury and its effects and also helps its users access practical help and support. Regular speakers and activities are also organised to stimulate discussion and provide important information.

Achievements of the group thus far include:

- Raising awareness of acquired brain injury within the local community and beyond, including hosting annual Brain Injury Seminars
- Meeting with Fiona MacLeod MSP who offered to raise a motion in Parliament recognising acquired brain injury
- Increasing members' confidence through comedy at Universal Comedy Workshops
- Arranging discussions and presentations on a range of topics including Welfare Reform
- Members have also gone through Headway's Self-Management Course





## Andy's Story

It was March 2005 when I had my stroke. I was in my flat with my girlfriend at the time it happened. The fact she was there probably saved my life. The stroke came completely out of the blue.

I just collapsed apparently and that's the last thing I remember.

Life changed dramatically after my stroke. I was a librarian before but I had to give up my job due to the effects of my brain injury. I was left with mobility weakness in my right hand side, as well as issues with my memory. The hardest part was learning to speak again.

As part of my rehabilitation I received 18 months intensive therapy at Murdostoun Castle. At first I struggled to come to terms with my situation and was reluctant to accept help. However, I've always been an optimistic person and the support I received at Murdostoun was massive in helping me regain my confidence. I had my own physiotherapist whom I really trusted and he played a big part in ensuring my rehabilitation was a success.

Through everything, I try to stay as positive as possible and look on the bright side. I've always really enjoyed going to watch live music: I get free tickets to concerts now which seems to keep my girlfriend happy as well! I'm going to see the Eagles and Eric Clapton this summer. I think it's important to have things to look forward to.

It has really helped meeting people in similar situations. The help of organisations like Ceartas and Headway have allowed me to be a lot more social and I have met some really good friends at ABI Café. It's good to know other people understand what you're going through.

If I could send a message to others who have recently acquired a brain injury it would be;

*Don't give up, you can get there and things will get easier.*





## Helen's Story

It was 10 years ago that I sleep walked and fell 30 foot from my flat, sustaining a serious injury to my brain. I don't remember anything of the accident but was told I was in an induced coma for a few weeks. I then spent five months in hospital.

After leaving hospital I felt very confused and found it difficult to concentrate when doing everyday, mundane tasks. I felt very nervous when I went outside and would become very disorientated, struggling to remember the route home. My memory was badly affected and I especially struggled with my short term memory. There were times I would forget I had put the dinner on and my two sons were served many a burnt meal. I felt like my life was a jigsaw puzzle and there were pieces missing.

One day I decided to get up and challenge the day, to try to live a life of quality, not just existence. I am so glad I made that decision. I've developed strategies for coping. Little things like using an egg timer and keeping a diary for appointments help a lot. Over time I have accepted my brain injury and now try to use my experience to help others with ABI..

When I first found out about Headway I was slightly anxious about going along. I phoned the organisation and staff convinced me straight away that attending would be a positive step. I haven't looked back since. The support of Ceartas has been great in helping to provide information and ensuring my voice is heard. Because everyone at ABI Café has shared a similar experience of having to re-build their lives, we have empathy for each other and can offer real support and advice.

Every brain injury is different, so giving one piece of advice is hard but in my case thinking of my two young boys helped me through as I knew I needed to get better for them. The public need to be aware not to generalise everyone with a brain injury. Every person with ABI is an individual and should be treated as such.





## John's Story

I was assaulted in November 2000 and the last thing I remember was being inside my girlfriend's front door. The next thing I knew I was waking up in hospital and being told that surgeons had removed a blood clot from my brain. After recovering and getting out of hospital I was really glad I couldn't remember the incident. I was even gladder to be alive and my life gradually regained some normality as I was still able to drive and get back to work.

However, in 2005 I had a stroke which greatly affected movement in both my leg and my arm. I was in hospital for about 7 weeks and I also had to wear a splint on my leg for 6 years. One of the biggest changes after the stroke was how it affected my memory. I found that my short-term memory had deteriorated and simple tasks like remembering what to buy at the shops became a struggle.

I have learned ways to cope with my memory loss. My sister is very good at reminding me about appointments and meetings. She recently showed me photographs of me and my dad at Celtic Park - so things like that help me have a memory of what I've done and things I have enjoyed in the past.

My long-term memory is not so bad. I lived and worked in Holland as a painter and decorator about 15 years ago and I can still remember some of the words I learned then.

The issues I've developed since my brain injury can sometimes get me down but meeting others in similar circumstances has helped a lot with re-building my confidence. In terms of coping with ABI, you need to try to come to terms with it as you'll never be the same person. However, there are lots of ways of coping with the loss of your memory and it's just a case of getting used to new ways of remembering things.





## Vivien's Story

In September 1986 I was admitted to hospital with what doctors initially thought was flu. It came as quite a shock when I was eventually diagnosed with viral encephalitis.

The virus left me with a brain injury and life became very different after my diagnosis. I was in a state of utter confusion for the first 3 to 4 months. I remember very little from this period when the viral encephalitis was at its worst.

I've changed a lot since that time. The brain injury has affected my life in many ways. After I came out of hospital, I began to struggle with my memory and concentration. I was constantly tired and could sleep for up to 24 hours at a time. The tiredness has never left me and I also have long periods when I become really frustrated and angry.

ABI Café has been a great help in my recovery. While everyone's brain injury is unique, I feel the people there get me and understand better than anyone else what I've been through. It really helps to see others with brain injuries overcome challenges and re-build positive lives for themselves.

I remember being so nervous coming along the first time but people were really welcoming and put me at ease straight away. It has been great to see the group grow and provide support to new members. Living with my brain injury is still incredibly difficult and I have lots of bad days, but through the help of groups like ABI Café and Headway - I've learned to adopt a positive attitude.

Because brain injuries are a hidden condition, I think they can be really misunderstood. I feel people just assume I'm fine and don't need any support because I can walk, talk and live independently. My brain injury has affected who I am in so many ways, from my anxiety to my memory and anger issues. I wish more people understood how complex brain injuries are. I hope that contributing to this booklet will help people learn more about brain injury and not be so quick to judge.



## Gillian's Story

In 2006 doctors found a tumour the size of a golf ball in a very dangerous position inside my brain. Following my operation, I was in hospital for six weeks and lost some vision in the left side of both my eyes and was also left with weakness in my left side. At the time I was told there was a chance I would lose all vision. I was so relieved to still have sight left that it inspired me to stay positive and I have managed to retain that outlook ever since.

Before my brain surgery I was a teacher and very passionate about my job. Having to re-learn basic tasks like using a knife and fork and simply putting a cup to my lips was a huge challenge after my operation. At the hospital the nurses and I would laugh at the mess I would get into trying to feed myself. They always reassured me that in time I would get there. They were right.

I also use a wheelchair to get around and this has been a big adjustment. My sense of balance was affected after my operation and I found walking extremely difficult. I try to be very organised as my short term memory is not good and I struggle to remember phone numbers and appointments whereas before I could remember these things quite easily.

Because of the partial loss of my sight I sometimes struggle with smaller print but I have wonderful friends who help with reading out menus and suchlike. As a backup I carry a magnifying glass for really small print and the kids at the groups I volunteer at have a great time playing with this, which is always really funny to watch.

I found out about ABI Café through a contact at Ceartas and it's been an absolute lifeline. The people are really friendly and we always have a laugh together as well as sharing and solving each other's problems. Everyone at ABI Café has been through a similar recovery process and can understand how difficult it can be.





## Clair's Story

In 2002 I was taken into hospital with flu which then developed into encephalitis. When the encephalitis subsided I was left with a brain injury as well as severe epilepsy. After my time in hospital, my injuries resulted in me being housebound. One of the biggest challenges was learning to walk again and my mobility is still an issue to this day.

Like a lot of people who acquire a brain injury, I've developed serious issues with my memory. I rely completely on my diary which is an absolute lifeline; I don't know what I would do if I were to lose it! Before my illness I was a welder and used to love being creative. Some of my creative skills have been lost but I still attend art classes.

A few years ago I heard about ABI Café and decided I would go along. At first I was very apprehensive as I didn't know what to expect, but from the first meeting I loved it and have made many friends. Everyone is very welcoming as we have all suffered from some kind of brain injury and that understanding is really important.

ABI Café gives everyone the chance to share our experiences and help each other to build full and meaningful lives. I have gained so much confidence from attending ABI Café that I gave a talk about my experiences at our Brain Injury Seminar. I feel very proud of myself that I have come this far.

People need to take time to learn about ABI and how it affects people and their families. You can feel alone out there in the world and it's hard for people to understand brain injuries but projects like ABI Café are so important at helping develop your confidence in a supportive environment.

If I could give one message to others with ABI, it's to never give up and get in touch with people in the same circumstances as yourself. It's important not to feel alone and the more people you speak to the less alone you feel.





## Volunteer's Perspective

*Karen Faull has been volunteering with Ceartas Advocacy for several years and carried out the interviews which provided the basis for this booklet.*

Like many people I was unsure as to what acquired brain injury actually meant and had no idea the challenges people with the condition face. I was really interested when Ceartas asked me to interview members of ABI Café for their booklet, and thought it would be the perfect opportunity to learn more about this often hidden condition.

During the interviews I have listened to life changing stories of courage and determination. Each person acquired their brain injury in a different way but all have approached their recovery with the same conviction. The people I interviewed have faced near death situations but have remained focused on the future through sheer determination and willpower.

As I learned more about acquired brain injury it quickly became apparent that it is a condition that doesn't discriminate. Acquired brain injury can strike at any time to any one of us, regardless of age or health. It can leave quite devastating injuries and more often than not changes a person's life beyond recognition.

I have heard tales of lost jobs and careers, of mood swings and anger issues, and of families put under huge strain. The common theme that struck me through all the stories I heard was the underlining determination to get better, to get on with living a productive and fulfilling existence. I have been inspired and moved by the stories I have heard and especially by people's enthusiasm for supporting others who share their experience of living with this life-changing condition.

Everyone I interviewed mentioned how important ABI Café has been in their recovery. It's a place where meaningful friendships are forged and problems solved. It's a vibrant, happy place, where people support each other to overcome the challenges ABI has thrown at them.



# Family Member's Perspective

I had been living down south when my brother sustained his brain injury. Seeing him for the first time after his stroke was truly awful. He could hear me and see me but was unable to speak. I thought he might not pull through and the doctors said they weren't sure if he would live or die. It could go one way or the other. They explained that after being in hospital - depending on the recovery process - my brother could end up needing round the clock care. By the grace of god, that didn't happen.

He was determined he was going to walk out of hospital and he's always been a fighter. He even refused to get into a wheelchair when doctors asked him. That determination is still there to this day. If my brother says he's going to do something, then he's going to do it.

The immediate effect the brain injury had on my family was massive. It was a lot for my parents to cope with as they were quite elderly: I decided to move home to assist with my brother's care. One of the biggest changes I observed in my brother was his mood swings. He can get really frustrated and angry at times. I can get frustrated with my brother as well as I sometimes feel he doesn't appreciate the help and support we give him.

I'm really proud of my brother and am so glad he lives independently, which is a huge achievement in itself. When I saw him in the hospital the first time I wouldn't have imagined the progress he has made. I try to remind my brother of everything he has achieved whenever he gets frustrated with his brain injury.

I would definitely say patience is the most important thing for family members of people with brain injuries. It will be frustrating at times, but having hope is important. There is light at the end of the tunnel.

# Possibilities, not Disabilities

Since ABI Café started it has become a place where people, carers and family members come to share experiences and support each other to re-build active lives. The following comments demonstrate what ABI Café means to those who come along:

“ It's a place where people with ABI can gain confidence to speak in a group. They feel included and get support, friendship, ideas and information from people with similar difficulties. ”



“ We have found out more info about access to support agencies for ABI in the last 30 minutes than we have been told in the last three years since the stroke happened. ”

“ ABI Café really gives me something to look forward to every month. ”



“ ABI Café gives me the vital opportunity to meet others in a similar position to myself. ”

“ I look forward to meeting my friends at ABI Café every month. We always have a laugh and the variety of activities keeps us busy! ”

“ I thoroughly enjoy being a volunteer with ABI Café and think its such a worthwhile venture. The group has given me a real insight in to the needs of people with acquired brain injury and I really look forward to coming every month. ”

“ ABI Café is a breath of fresh air, it is informative, encouraging and fun. ”





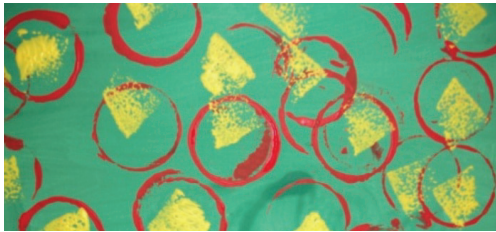
## John Clark

John is a freelance photographer who contributed many of the photographs to this booklet. John has a wide range of experience working with people in the community, including those with brain injuries. We hope you agree that his photographs capture the positivity and determination of those involved.



## Karen Mitchell

Karen has been coming along to ABI Café since it started in 2011. As well supporting her friends at ABI Café and keeping spirits up with her charm and humour, Karen has attended several art groups at Headway Glasgow. She has kindly contributed the following artwork.



**Anne Kirkwood** - Anne has been volunteering at ABI Cafe for several years and everyone involved would like to say a massive thank you for the enthusiasm and compassion she has brought to the project.

## Behind the Booklet



**Ceartas Advocacy** - Ceartas Advocacy provides an independent advocacy service for people over the age of 16 in East Dunbartonshire irrespective of their cultural background, gender, beliefs or sexuality. We treat those with the following as a priority:

Older people, dementia, mental health issues, learning disabilities, physical disabilities, sensory impairment, acquired brain injury, additional communication issues and addiction issues.

### What is Independent Advocacy?

Independent advocacy is a way to help you to make your voice stronger and to have as much control as possible over your own life. Advocacy Workers do not make decisions on your behalf and they will not put words in your mouth. Independent Advocacy will help you get the information you need to make good choices, and give you the help you need to express yourself clearly.

We are committed to providing a service based on the principles of equality, fairness and justice. We strive to ensure that the views and opinions of individuals are heard and respected, affecting in a positive way the lives of people using the service.

### Group Work

In addition to our advocacy service Ceartas also facilitate a number of support and information groups for people with autism, dementia and of course, acquired brain injuries.

These groups aim to reduce social isolation, raise awareness, provide practical support and also encourage their users involvement in the wider community.



# Behind the Booklet



## Headway Glasgow

Headway Glasgow work with people with acquired brain injury, their families and carers in the Glasgow area, offering relevant information about brain injury and its effects that will help in their rehabilitation. We try to ensure that people can find out about the services which will help them at the right time and have produced a Directory of Services for this purpose. We also make referrals to appropriate services when required.

We offer support to people in a few different ways. Our staff often help people to communicate with other agencies like housing, electricity or phone companies. This is usually on a short term basis but if people need longer term support, we try to access it for them. Benefits support is available through partnership with Digby Brown Solicitors.

Our main activity in this area, however, is facilitating Peer Support through the groups and activities that we run. These include social groups, art groups, self management courses, writing and discussion groups. The common theme is that people come together, meeting others who have been through similar experiences, enabling them to learn from and get support from one another. Headway works in partnership with Ceartas to run the ABI Cafe in Kirkintilloch.

Headway Glasgow is unique in brain injury services in Glasgow in offering long term peer support and in being a user-led service. We try to ensure that people who use the service are also involved in the running of the organisation, if they want to do so.

Headway Glasgow is a small, independent Scottish charity which is also affiliated to the wider Headway movement in the UK.

# Behind the Booklet



## Digby Brown

When we first heard about ABI Café's plans to produce a booklet detailing individuals' experiences of living with acquired brain injury, our first thought was - how brave! To have the courage to write down and share your personal experience of life before and after acquiring a brain injury, and use this as a source of inspiration to others, is not always easy, but certainly worthwhile.

At Digby Brown Solicitors, we see all too often the devastating effects a brain injury can have on the person affected, and their loved ones. We also see, time and time again, how the human spirit prevails and people pick up the pieces of their lives. It never ceases to amaze us how much it is possible to achieve, with the support of family, friends and organisations such as Headway and Ceartas.

Every day, Digby Brown's specialist serious injury team deals with cases where individuals have experienced an acquired brain injury. It is our job, not just to advise and support them through the legal process, and see that full and proper compensation is achieved, but also to ensure that we take a holistic approach, by promoting the use of rehabilitation and early intervention in the compensation process so that the injured person makes the best and quickest possible medical, social and psychological recovery.

At Digby Brown, it is our great pleasure to support the community of people we work with, and to this end we are proud to have played a part by assisting in the production of this wonderful testament to the power of the human spirit.