

Getting your head around brain injury

What we did next



Brain injury experience network
BIEN



We are survivors not victims



LOTTERY FUNDED



outside
the box

Background

Making the DVD

The Brain Injury Experience Network (BIEN) brings together people in West Dunbartonshire who have an acquired brain injury (ABI). The group first began meeting in 2006.

In 2008 we produced *The Journey*, which described the experiences of some members of BIEN and gave our tips and suggestions to other people who are living with an ABI and their families.

The response to that publication was very positive. We had written it for people living in West Dunbartonshire and maybe other parts of Scotland. But it was also read in other parts of the UK and in other countries.

A few years later we started working on a DVD. We did this for several reasons.

- We wanted to show that we were still progressing in our lives. Some of us have learned or regained more skills and we have all learned more about how to cope with life as it is now. The message we wanted to get over was how you can make your life as good as it can be.
- There were new members of the group who had not been part of writing *The Journey*. We had something to say too.
- We wanted to use a different way of showing what people with an ABI can achieve and reach more people.

The funding for the DVD came from West Dunbartonshire Community Health and Care Partnership (CHCP) and the Big Lottery Fund through a grant to Outside the Box. The West Dunbartonshire CHCP Acquired Brain Injury Team helped us to arrange this and supported us throughout the whole process. Outside the Box helped us plan and make the DVD a part of a bigger project to show what groups led by people with disabilities can achieve.

The dissemination project

We then asked the Big Lottery Fund for an Awards for All grant to let us do a good job on the dissemination of the DVD.

- We wanted to make sure the DVD reached people with an ABI and their families. We want them to feel there is hope and it is worth persevering with the early difficult stages because it pays off in the long-term.
- We wanted to reach staff who provide health care and other services to people with an ABI. Many staff in settings like intensive care and the specialist rehabilitation settings only see people soon after their injury, so it is good to help them remember that people can progress in their recovery and go on to have a good life.
- We wanted to also explain more about ABI to staff in local health care and social care services and other services who come into contact with people who have had an ABI, as they know less about what it can entail.
- We wanted to raise awareness with the public. Often someone with an ABI will not have an obvious injury and many people do not realise or understand about the disabilities and difficulties that people can have.
- We also wanted to gain more skills ourselves. Some of the areas we had thought about were planning what to do, communication skills when we are talking to people about the DVD and how they could distribute information about it, learning to give presentations and using different ways to get the message across. All of these activities can present difficulties for people who have had an ABI.

Throughout we worked closely with the Acquired Brain Injury Team at the CHCP. The staff there have supported and encouraged BIEN from the beginning.

Outside the Box held the grant for us and we worked together on some parts of the dissemination.

This report is the story of the dissemination project.

We hope that other people get ideas and encouragement from the report, just as they are getting from the DVD.

What we did

Launch of the DVD

The first stage of this project was the launch of the DVD. We had put a lot of work into making it and we wanted to give it a good start. We also wanted to celebrate what we had done.

We spent time thinking about what we wanted to achieve and planning it out. The people at Baby Grand who had worked with us on the DVD helped us prepare for the launch event and handled the technical side on the night.

We held a proper premier, showing it on the big screen and at Denny Civic Theatre. We had a red carpet and everybody got dressed up in good suits and even evening dress and we all looked fantastic. We invited people who had helped us and our friends and families and they were looking glamorous too. We wrote to the Queen and to celebrities who had been affected by brain injuries. The Queen sent us a really nice letter and we showed it on the big screen at the launch.

The response from the audience was great. People were moved by it – the sad and hard bits as well as laughing at the funny bits. We even had them singing along to the music that SHIMS played. SHIMS are the Scottish Head Injury Music Group and are all musicians who have had a brain injury. They played the sound track of the DVD and wrote a song for us.

You can see the trailer to the DVD and get links to some of SHIMS' songs through our page on the Outside the Box website: www.otbds.org/bien.

It is also on our YouTube page which you can find under BIENgroup.



Here are some of the kind things people have said about our DVD:

“It’s the stories of people who were brave enough to share their experiences as a way of helping people learn to cope after a brain injury.” John Russell, West Dunbartonshire Community Health and Care Partnership

“We hope the film gives hope to people affected by a brain injury and show them that there is life after brain injury – a good life.” BIEN member

After the DVD launch people told us what the film had meant to them, and that meant a lot to us.

“Moving, funny and really tells the story.”

“Brilliant. So proud of my brother and the rest of the group.”

“Moving. Inspiring, sorry lost for words. This will and has changed lives.”

“It’s also helpful to see how life works around others with a brain injury.”

“I am completely in awe of all BIEN has become and how amazing you all are.” Some of the comments people wrote at the launch

This is what we felt about the DVD and the launch

“Looking back on it, we gained a lot from planning the launch and being part of it as well as from planning and making the DVD.”

“There were parts of making the DVD and the launch night that were stressful. But we chose it. No-one else put us under any pressure.”

“It feels a bit weird seeing yourself on a telly and really weird at the launch when it was up on the big screen. But it gets easier after you’ve seen it a dozen times.”

“I thoroughly enjoyed the launch. I was very tired afterwards but it was worth it.”

“I enjoy the way we all encouraged each other.”

*“Making the DVD was brilliant. I thoroughly enjoyed doing it.”
“It was a great experience. I’m very glad I did it.”*

“I’m glad I did it. Making the DVD and doing the launch and now doing the presentations are big achievements.”

“My confidence keeps on growing: doing something this big, then seeing yourself doing it, then becoming more confident and comfortable with other people seeing it.”

Telling people in West Dunbartonshire

We did a lot to tell people in our area about the DVD and about the message we are trying to get across.

The main way of getting the word out to the public has been the publicity around the launch and then showing a short trailer on the public information screens you get in places like Health Centres, Council offices and other public places.

Each member of BIEN gave a copy to their own GP and Health Centre. This gave us a start to talking to staff in health teams, explaining what they can do to help us and other people with an ABI.

We have been doing training sessions for community health and social care staff. Each session includes showing them the DVD and answering questions.

We have now had 2 sets of training for Welfare Rights staff.

We sent the DVD to the Libraries and Sports Centres across West Dunbartonshire, and used it as part of staff training. That’s made it easier for staff there to be aware what people need. It feels more comfortable when one of the guys goes to a Sports Centre and asks the staff for some more support to help him do or learn something.

“We gave it to family and friends. Families say they are seeing things differently. They understand more.”

“You never know. Someone seeing that trailer could be the friend or relative of someone who has had a brain injury.”

“The feedback from staff at my Health Centre was good. People said it made them think differently about me and other people with a brain injury.”

“It still feels strange seeing the pictures of me just after I was injured. When we show it in training there is a gasp from the audience each time. That early section shows how badly we were hurt and what we each had to overcome. But you need to see that to understand how far we’ve all come.”

Telling other people

We invited people from other head injury groups to come along to the launch. We have also contacted other services supporting people with an ABI. That led to people asking us to come and give a presentation to the group or to staff at that service. That has taken us out and about to other parts of Scotland.

We got it on to YouTube – the 10 minute version and the interviews. We know it is being seen by people in lots of places because they get in touch. The DVD has been sent to people in Canada and Australia.

Staff at the ABI service in West Dunbartonshire took the DVD to the national Managed Clinical Network, which brings together staff from specialist ABI services across Scotland. It also has links with professionals specialising in caring for people with an ABI across the UK and with the international professional networks.

- They showed professionals how the experience of a sudden injury and the aftermath looks from a perspective of people with an ABI.
- They encouraged people there to focus on the impact of an ABI on people’s lives as well as on treatment and care.
- The MCN are now also going to make a patient-focused DVD.
- The MCN is in process of updating the website. It will include links to the BIEN DVD.

BIEN and the West Dunbartonshire ABI team are now sharing our experience on how we worked on the DVD and this is informing what the MCN will do – taking time, building people’s confidence and skills as you go, building relationships within the group and relationships between staff and the group.

We took the DVD to the Head Injury Information Day. Over 300 people came that day. We gave away 75 copies to people taking it back to their projects and teams.

We gave a presentation to the Care Inspectorate when they came to do an inspection in West Dunbartonshire. It showed what the CHCP was doing around service user involvement, including showing what the ABI team is achieving for the people it supports. It also let BIEN make our point about what people with a brain injury can achieve.

We took the DVD to a Scottish Head Injury Forum event and gave copies to people who work with people who have had an ABI in Scotland. People who received those copies have now told us how helpful it is to have a DVD to show to people who they work with. The biggest impact is for people who have been affected by a brain injury who can now watch a DVD made by people like themselves.

The ABI team also took the DVD trailer to the Brain Injury 2013 World Conference. They showed it to delegates who work in ABI all around the world and talked to them about what BIEN is achieving.

“Seeing the DVD does make staff see the people they support in a different way.” Member of ABI team

What we learned from doing the dissemination work

We have found that people still have to watch the pace and level of what they do. This means making sure we don't get too tired and having enough time to think about what we want to do.

“We all have to make sure we don't do too much.”

We've learned that it is really important to get contributions from group on ways to spread the word and tell people. Different people are good at different things. This way we get the benefit of everybody's ideas and strengths as well as sharing the work.

“We worked as a team when we made the DVD and now we're working as a team to spread the word.”

“Other people encourage the members of the group who take the lead in doing the presentations. But everyone is part of the preparation and in thinking about the feedback.”

We use our experience of living with a brain injury to make the training or presentation relevant to that particular group of staff.

When BIEN is asked to do a presentation to a staff team, the group think about our contact with staff in that type of role and about the issues people face in their lives. For example, before doing the training with the Welfare Rights workers we used one of the BIEN meetings to talk about people's experience of welfare rights issues. It makes the training more relevant for the staff and also helps BIEN members continue to have a voice and get across the issues that are important to us.

We've always appreciated the support we get from the ABI team. Our experience of the DVD and follow up to it has again showed the importance of links with the staff. The very positive support and feedback from the senior staff in the CHCP has also been good. It shows they think we matter and we are making a contribution.

"I hope people understand how much the West Dunbartonshire ABI team do. They have been so helpful to each of us and helpful to us as a group. The DVD does show what a difference their work makes."

The benefits so far

Difference it makes for us

We all think the biggest impact for individual people is in our confidence. That then opens up lots more opportunities. There have also been benefits for each of us.

We see the changes in each other. When we were getting people's feedback for this report we asked the staff team what they see. Their feedback is that they see the differences in all the members of BIEN and the main one is people being more confident. The realisation that we can make a difference and help other people and make real achievements in our lives. They see so many of us trying new things and taking on more challenges in life.

"It makes you feel liberated. Free of the stigma and people not understanding because they can't see the injury."

"I don't feel depressed the way I did before."

It's given me and other people the confidence to get going.

"I've got back to Aikido because I've got the confidence now. I used the DVD to help explain to the other people there what had happened and why I find some things difficult now."

"It feels good that we're continuing to learn new things, develop new skills."

"It has helped me come to terms with what happened to me. It's turned that into something positive, as that experience is now helping other people."

"The DVD and now telling other people have had impacts in people's lives – feeling more able to do things, try things."

"BIEN members have told the ABI team that this DVD has been a great thing for them as they have been able to record their feelings and experiences and feel that these are now being used as a support for other people who have had a brain injury, their families and for professionals to really see what it is like to live with a brain injury." ABI team

BIEN members often find it hard to go into social situations as we feel people don't understand their difficulties. However by promoting the DVD we are finding that more people around us are talking to them about seeing the DVD and understand our feelings better. For instance when we go to see a Welfare Rights Officer about their benefits the WROs who have seen the DVD are already communicating more effectively with us and are able to get our difficulties down on the forms more easily.

Impact for BIEN as a group

The impact for the group included more people joining it. It is now twice the size it was when making the DVD.

- It is easy for the ABI team to show new people referred to them what BIEN does.
- New people realise they are not alone in their experiences after a brain injury.
- People feel they know some of the people at BIEN, which makes it easier to come along the first time.

One person told the ABI team he would not have had confidence to come along if he hadn't seen DVD.

Someone else who had an ABI 20 years ago lost a lot of his social contacts. Seeing the DVD has helped him to get out of the house and come to the group.

“It feels good that we are helping other people and making a difference for them.”

“Making the DVD has been good for the group. We learned a lot about working together and being a team. Getting new members is good for the group. New people bring new experiences and ideas. It makes us stronger.”

“Making contact with other groups led by people with brain injuries has been good. It's good to feel part of something bigger.”

Since making the DVD and so many people seeing it locally, we have found that BIEN is now quite well known in our area, and we have had donations from several local businesses and groups. This

has also led to us being in the local newspapers a few times, which is helping more people find out about BIEN and what we do. Some of us get stopped in the street and recognised, which feels great!

Impact for SHIMS

Being part of the DVD and getting seen by so many people has also built SHIMS' reputation.

SHIMS are putting on concerts and playing at events and talking to people about the impacts of health injury. So that's another way we're all spreading the word.

It has led to members of SHIMS and of BIEN giving interviews. They then get onto You Tube and similar routes, so spread the word to more people.

"I'm glad the DVD has promoted them."

"SHIMS have fed back that they feel inspired by BIEN members to go out and work more on getting their music about living with brain injury out in the public domain!" ABI team

Difference for other people

Our families and friends tell us that seeing the DVD has helped them. It also reassures them as we continue to get more confidence and get out there and do more.

"Giving the DVD to my family has helped them understand."

"We have also had feedback from the BIEN guys' families about them now understanding more about what it had actually felt like for the ABI person and also about how much the person had appreciated their families support and how important it had been in their recovery!" ABI team

Telling more people about the DVD and our experiences has also made a difference for them. That includes the people in West Dunbartonshire who have started coming along to the group. It also reaches all the other people in groups who we've met and who are seeing the DVD.

“Feedback from other groups of people who have an ABI is important. They have all been positive. It is encouraging them to do it and tell their own stories. That has to be good.”

“Individuals with brain injuries have commented on feeling that they were very alone beforehand and now they can see that other people have had similar things happen to them and have survived.” ABI team

“We have had feedback that a carer from Australia who got the DVD and thought it was wonderful what BIEN had achieved and was inspired to keep going with her husband’s rehabilitation, even though we know this is hard work and a huge commitment for the ABI person AND the carer!” ABI team

“The feedback after presentations is that BIEN are giving other groups ideas about how they can have their voices heard, including making their DVDs.” ABI team

We are also having an impact for staff in the teams we train.

“The DVD has enabled us to get out there to talk to others about our experiences. Every time we have done this we have been amazed at people’s reactions and how many people have thanked us for teaching them about brain injury. “

“Feedback from the people getting the training is very positive – hearing people’s experiences, seeing people who have been badly injured now doing the training has a huge impact. We have had positive feedback from everyone who has seen the DVD.” ABI team

“Part of feedback is the requests from other people who have been told about the training and how great it is. Another 200 local workers have requested the training this year alone!” ABI team

Looking ahead – plans for the next year or so

Spending time telling people about the DVD and getting our message over has encouraged us to look ahead and think about the future for BIEN.

We are looking at BIEN getting our own website. At first we were cautious about this as some people were reluctant to share what they do with people they don't know. We've been learning more about what it involves and people are starting to come round to the idea now.

“It's important that we took our time and thought about what sort of web presence we want. It has to be right for everyone.”

It would be good to make another film showing the impact for families. A brain injury doesn't just affect the person who was injured. It changes the lives of the people around us too.

We want to keep spreading the word. We've learned a lot about making a DVD and this follow up project has helped us learn about how to reinforce the message. So our next DVD will be even better.

“Hollywood next!”

Our advice to any other groups

We're glad that the DVD and us meeting people is encouraging other people to think about doing something similar.

We asked members of the group what their advice would be to people in other user-led groups if they were considering making a DVD.

"Go for it. Definitely"

"You'll get so much out of it. You'll feel good about yourself."

"It's part of getting better."

"Have no fear. Just do it. Say what you have to say."

"It's all of us saying we're here. It is raising the profile of people who have a brain injury."

"It is saying that you're important. You matter."

"I'd like to do it all again."

"Do it. It lets you say: I succeeded at something. That includes the people whose families were told they would never do anything."

"It has been fantastic."

Contacts

BIEN and West Dunbartonshire ABI team

CHCP Offices
6-14 Bridge Street,
Dumbarton G82 1NT

T. 01389 737020

www.wdchcp.org.uk/our-services/acquired-brain-injury/

Outside the Box

Unit 23
150 Brand St
Glasgow G51 1DH

T. 0141 419 0451
admin@otbds.org

www.otbds.org