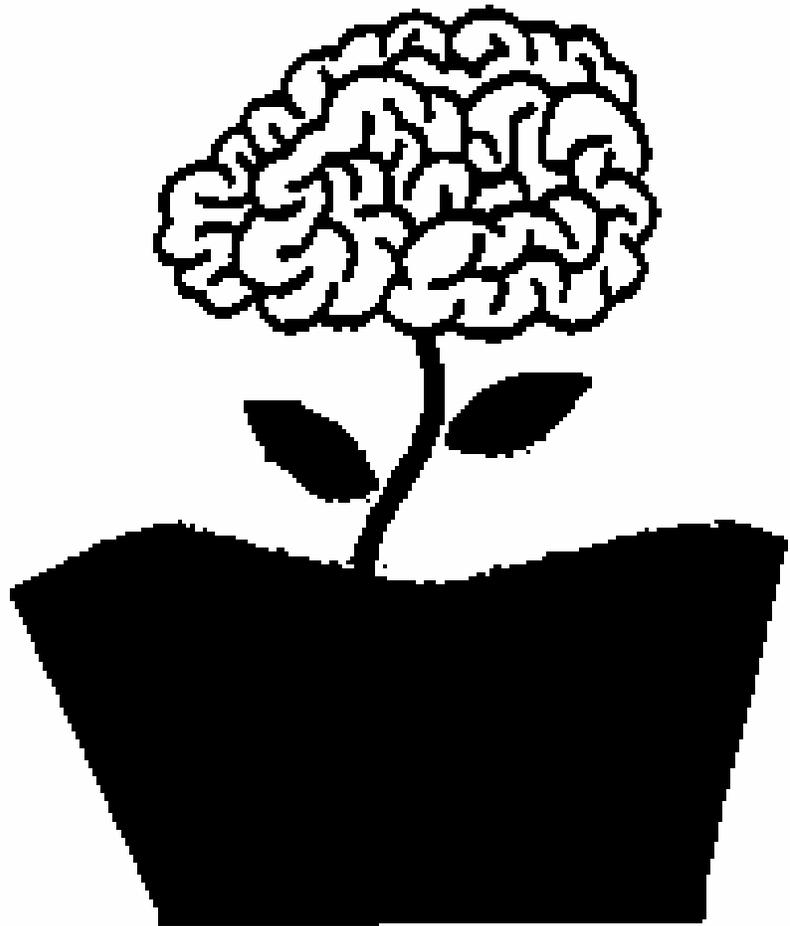


The Journey

Acquired brain injury



The experiences and advice of people in West Dunbartonshire who are affected by an acquired brain injury.

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“A sense of humour is very important – I've never lost that!”

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Section 1: Introduction

What is this pack?

This pack is a collection of experiences, advice and stories from people with experience of acquired brain injury (ABI). It has been written for people who have an ABI, and their families and friends.

The original idea and much of the material came from people who have an acquired brain injury and use the West Dunbartonshire ABI service. The Council responded by providing resources for a development worker from Outside the Box to facilitate the creation of this pack. Outside the Box is an independent organisation which helps people to develop their ideas.

The pack was developed with help from people who use West Dunbartonshire ABI services and the people who are members of the Brain Injuries Experience Network (BIEN). It has been compiled by Outside the Box Development Support with support from the West Dunbartonshire ABI Service.

The pack has four sections:

- An introduction
- The Journey – advice, guidance and stories about the different stages involved in having an ABI. There are hints and tips which people who have an ABI, and their families, have suggested
- Help for the Journey – useful information
- Our Journeys – a selection of stories from people in West Dunbartonshire.

How to use this pack

This pack can be used in lots of different ways.

- You can read it through from start to finish.
- You could look for sections you are interested in and read those.
- It might make you think of questions to ask people involved in your care.
- You could try out some of the hints and tips in the pack.
- You could give the pack to friends and family to read as well.
- You might just want to read the stories!



This pack has a limited amount of contact information about helpful organisations. This is because West Dunbartonshire Partnership has produced its own directory of services. You can get a copy by contacting the West Dunbartonshire ABI team.

What is an Acquired Brain Injury?

The definition of acquired brain injury (ABI) used by West Dunbartonshire Partnership is a condition which is caused by a non-progressive trauma to someone's brain which occurs when they are aged 5 years or older. Non-progressive means that the trauma happens once and does not go on causing more injury.

Typically, this could be due to damage to brain tissue after an accident – such as a road traffic accident, an assault, a fall, industrial or sporting accidents. It can also happen in other ways, such as poisoning, viral infections to the brain, neurosurgery or damage to the blood vessels in the brain.

An ABI commonly presents special problems as the result of the combination of different types of difficulties arising from the damage to the brain.

- Physical – such as difficulties in walking or speaking
- Cognitive – such as finding it hard to concentrate or remember things
- Behaviour – when someone behaves in a different way to before
- Emotional – such as when someone finds it hard to show affection or gets angry much more easily
- Social – such as when someone finds it hard to be with groups of people, or to make friends.

As a result, someone with an acquired brain injury will often need intensive health care in the short-term. Most people will also need help in the medium to long term from health services, social work services and voluntary organisations working together. This may be a lot of support, or just occasional support, as each person's injury and the impact it has for them is different.



Some causes of Acquired Brain Injury

People can get a brain injury for lots of different reasons.

“I was heading home and crossed the road but I was two steps from the pavement when OW! I went up in the air. I'd been hit by a car. The story of what happened I've been told because I never woke up until I was in the Southern General Hospital. I was in a coma for two weeks.”

- Andy

“My first memory of my brain injury is having a sore head, family were concerned and took me to hospital.”

- Roseanne

“Vincent had a brain tumor removed when he was ten years old. During the operation Vincent's pituitary gland was removed. This has left Vincent with an acquired brain injury.”

“16 years ago I was working on an oil rig platform. I fell and suffered brain damage.”

- Eddie

“7 years ago I was seriously assaulted by young guys for no apparent reason just that I was on my own in a bad area. I sustained bad head injury and I was in a coma and I sometimes feel like I've not woken up yet.”

- Phil

“I had a car accident in 2006 in which I suffered a horrendous brain injury.”

- Pamela

“My name is Douglas and I am 25 years old. When I was 18 months old, I cut my face on a shopping trolley and contracted cellulitis round about my left eye. The swelling caused some pressure on my brain, which left me with slight brain damage.

“When I was 16, I was diagnosed with Chronic Myeloid Leukemia and have been on chemotherapy of one sort or another ever since. These drugs seem to have made my brain damage worse.”

- Douglas

“Some years ago bad guys were threatening a neighbour. I had come on the scene after football. After giving threats I did not move and they left. Weeks later I met these people and they asked me to talk to apologise, I went to their house and had a drink which I thought was to make a wrong right. Little did I know these drinks I was given were laced with valium tablets. As I fell into a semi-sleep I was smashed in the head with a hammer and a pick axe handle. I remember the ambulance man saying I looked fatally injured. I had 13 skull fractures, broken cheekbone, right eye detached, loss of vision, bruising and bleeding of the brain. I was told by the doctors I would be in hospital for some time, but amazed them by being stable enough to go home after two weeks.”

- Stephen

“It all began for me in 2000. The left hand side of my body started to shake. It went on for months and eventually became quite violent. I went to see my GP who agreed it was abnormal, and so I was sent for an MRI scan. They found a Colloid Cyst in my cerebral canal. I had to have brain surgery to remove it.

“I was off work for quite a period of time, but I eventually returned although there were some conditions. I was quite happy to be back at work though and was doing well. I was looking forward to getting my driving license back. Then, one day as I was walking to work I fell whilst I was crossing the A82. At first people thought I'd been run over – there were cars swerving to avoid me! As a result of the fall I was bleeding in my brain – I had a large frontal lobe Haematoma which meant I needed another operation. Whilst I was recovering from surgery, I contracted Meningitis and Hydrocephalus. Both can be fatal. To stop the build up of fluid in my brain, caused by the Hydrocephalus, I had another operation in give me what is called a Vascular Shunt. This drains the fluid away from my brain.”

- Chris

"I woke up with a sore stomach, my partner at the time phoned the doctor and she came about 12.00. She booked an ambulance for me. I was admitted into hospital; seemingly I was talking to a cousin of mine and went into cardiac arrest. The time was about 5.00pm.

"I don't know how my family found out, talk about jungle drums, but they all got to the hospital. They were crying because the doctors said that I would not last the night. I had been declared clinically dead for 8 minutes and they said that it would take a miracle to survive. Normally they would work on you for 3 minutes then they would declare you dead but for some reason they worked on me for 8 minutes.

"For the next 8 days I have no recollection of where I was or what I was doing. It was like being in a deep, dark void, there was just nothing. My mum said I was like something out of a scary movie, when my eyes opened at random they were completely blood shot. They had wondered if someone had beaten me up, but I had no idea what had happened."

- Sandra

The impact of an Acquired Brain Injury

An ABI can have a huge impact, both on the person affected, and on their partner, family and friends.

Most people make an excellent physical recovery after a brain injury, which can mean there are few, or no, outwards signs that an injury has occurred. There can be physical problems present that are not always so apparent, but can have a real impact on daily life. Some of them are listed here.

- Movement, balance and co-ordination
- Dyspraxia (a loss of muscle control which can affect your balance and coordination)
- Loss of sensation
- Tiredness
- Headaches
- Speaking and swallowing disorders
- Bladder & bowel incontinence
- Epilepsy
- Eyesight problems

Someone who has had a head injury can be left with memory difficulties and some changes in emotional reaction and behaviour. These are more difficult to see than the more obvious problems such as those which affect movement and speech, but they can be the most difficult for the person and their family to deal with. Not everybody will experience all of these problems. There is a list here of some of the problems people experience.

- Memory difficulties
- Difficulty in finding words
- Agitation
- Explosive anger and irritability
- Lack of awareness and insight

- Inappropriate impulsive behaviour
- Slower thinking
- Visual distortions
- Getting lost
- Loss of inhibitions
- Fluctuations in mood
- Self-centredness
- Apathy and poor motivation
- Depression
- Anxiety
- Inflexible and obsessive behaviour
- Sexual problems

Headway is a voluntary organisation led by people who have had an ABI. It has produced publications to help and advise on many of these problems. www.headway.org.uk

Families

It has often been said that head injury affects whole families, not just one person. Some families cope better than others, but all have difficulties. There is no normal way of responding to a head injury.

Research has shown that there are three key coping strategies that lead to good progress in rehabilitation. These are:

- Acceptance
- Problem solving
- Personal growth.

The people in families and relationships who seem to cope best are those who have two particular qualities. Firstly, they have the ability to be flexible, not being rigidly tied to how things ought to be but being able to cope with change. Secondly, they have the ability to communicate openly and honestly, directly expressing positive and negative emotions and recognising the needs of themselves and others within the family.

“I think I always thought it would just go away and one morning she would wake up and be back to her old self, where nothing got to her or upset her. Having someone close to you lose their memory, and seeing how hard it is in everyday life is the most frustrating thing I have ever had to go through. It completely changes their personality, but if anything it has brought me and my mum closer.”

- Roseanne's Daughter

Everybody's experience is different

It is important to remember that an acquired brain injury and its impact is as unique as the person affected is.

“No two brain injuries are the same.”

- Chris

- Different people will have different symptoms and issues.
- Some will recover more quickly than others.
- Some people will have problems with things others don't.
- Equally, each family will have different experiences.

It is okay if you have a different experience from other people you might know or come into contact with. This pack uses examples which have common themes. Not everything you experience will be covered, but hopefully some of the stories and suggestions will help you on your journey through acquired brain injury.

Section 2: The Journey



Being in Hospital

"I didn't know what was happening to me. I was lost. I wanted somebody to explain it to me."

- Phil

"I wanted people to sit down and talk through what had happened to me. I wanted to know, 'Why me?'"

- Stephen

"I can't remember hospital at all."

- Member of the BIEN Group

When you have a brain injury, you may need to spend time in hospital. You will meet lots of staff. Sometimes it is hard to remember what they all do. Don't worry if you forget. You can ask them again.

Some people will only need a short time in hospital. Other people might need to be there for longer.

"In hospital, I'll always remember the look of shock on my relatives' faces. I wanted to be able to reassure them, to tell them I was ill but I was going to be okay."

- Chris

"One morning a Nurse said 'Hello Roseanne' - I looked at her and she asked if I remembered her but I didn't although she had been my nurse for four days."

- Roseanne

Hints and tips for hospital:



Don't be afraid to ask somebody to sit down and explain what has happened to you, what treatment you are getting and what effect that will have.

It is okay to:

- Ask somebody what their job is
- Make sure that they explain what their job means
- Keep asking until you are sure
- Ask them to write it down if that is easier for you.

It can help if your partner, family or friends keep a diary of what treatment you get and how you feel. You can re-read this later and it might help you remember.

Ask people to bring in photos of relatives, pets or the house to jog your memory.

Taking photos of you during your time in hospital can also help to remind you about what happened.

It can help to have something to look forward to regularly, like a trip out, or a family event.

Treatment and rehabilitation

Depending on your injury, you might need rehabilitative treatment like physiotherapy.

“I had to do lots of physio, pure agony, but then it got easier.”

- Andy

“I would be taken to the physio room. I was put on one of those big rubber balls. They held me by the ankles and rolled me around – apparently I loved it – being rolled back and forwards, but I can't really remember. One of the physios at the Southern told my wife that she knew I would walk again, she said she knew I had it in me.”

- Chris

Some people have a difficult time in hospital. This may be because they need several operations, or different types of treatment. It can also be because of additional illnesses that they pick up in hospital.

“Unfortunately my body rejected the first shunt, so I ended up back in surgery to get another one. This one worked well, but whilst I was recovering I again contracted a bad infection, this time it was MRSA. I got MRSA a second time after I was transferred back to my local hospital.”

- Chris

Sometimes, this treatment will carry on after you leave hospital.

“A few weeks ago I got my ‘saebostretch’ and it’s brilliant because it allows me to use my fingers independently. I’ll be able to use my arm independently within 6 months hopefully!! I have started using my ‘saebostretch’ and it is beginning to work!”

- Pamela

Hints and Tips for treatment and rehabilitation:



Don’t be afraid to ask questions about your treatment.

Remember that it might take a while before you see a difference in your physical health, so keep going!

Some people find it helpful to take a friend or family member with them when they go for treatment. This person can help by:

- Writing down any exercises you may be asked to do
- Taking notes of the conversation to remind you about what was said.

It can also be helpful to keep a diary of appointments, and after the appointment to make a note of what happened.

Leaving Hospital

This part of the journey can sometimes be the most difficult for carers and the person with the injury. Going home will involve adapting to daily life and coping with the changes having an ABI has made.

Lots of people also have to go back to hospital at times, for check-ups and occasionally more operations.

“I was in a wheelchair for ages. The first time I saw my head it looked really sore, but I got used to it. I’ve had lots of operations since then.”

- Andy

“When I got discharged from hospital I had lost my hearing and my balance was so bad I could not walk by myself. I had terrible mood-swings and was constantly tired.”

- Eddie

“Once we brought her home we all thought things would get slightly easier, but my mum found it really hard to cope with the fact that simple things she could do before were more difficult for her now.”

- Roseanne's Daughter

Some people will go to a rehabilitation centre before they go home.

“My wife was very concerned about me, and found a website for a Brain Rehabilitation Unit. She got in touch with them and the Manager agreed to come out and assess me. At that time I couldn't do anything for myself, I couldn't walk, and I couldn't talk. I just sat there. The thing people need to know is that although I wasn't speaking or moving, my brain was still working. I had a brain injury but I wasn't stupid.

The Rehabilitation Unit agreed to take me. I say that's where my real recovery started. 'A little bit of healing', that's what I call it. They gave me expert help. They were almost an all female team and they were fabulous. I had a key worker, and a nurse. There was a physio team and a hydro pool. It was like being at a holiday camp, just without the bar! “

- Chris

“After hospital I went to a rehab unit to prepare me for leaving and going home. I was angry a lot, but I liked some of the nurses.”

- Andy

Some people won't be able to go home. They might need care all the time, and the best place for that to happen might not be a house.

Leaving hospital can make people feel all sorts of different emotions.

“When I got home I felt very angry, just wanted to throw the towel in.”

- Roseanne

“When I was ready to go home, I had to wait a bit because they were doing a lot of work in the house to make it safe for me. People wanted us to move because there were stairs in the house but my wife refused. She had brought photos of the house for me when I was in hospital so that they would help remind me what it was like. She wanted me to go home to the house I remembered and loved. So the physio team started teaching me to climb stairs again!”

- Chris

Hints and tips for leaving hospital



Before you leave hospital, or a rehabilitation unit, talk to the staff about it. Think about, and ask for advice about, things like:

- Stairs
- Steps to the front door or into the garden
- How easy it is to get through the house
- Whether there is an accessible toilet.

For some people, it won't be hard to adjust to going home. For other people, there might be a lot of things to think about.

Getting a routine is important. Something like going for a paper each morning can be really helpful.

Family is very important. They can often help to support you. Friends can also be very important. Sometimes people lose touch with friends when they are in hospital. Going home is a chance to get in touch with them again.

You can also contact your local community services, such as The West Dunbartonshire ABI service. Community services can often help you to get access to assessments of what services will help you.

If you live in West Dunbartonshire, you can contact the ABI team by phoning:
01389 737020

You can get details of other useful services, and what the ABI team does, in the West Dunbartonshire ABI Resource Directory. (Contact the ABI team for details).

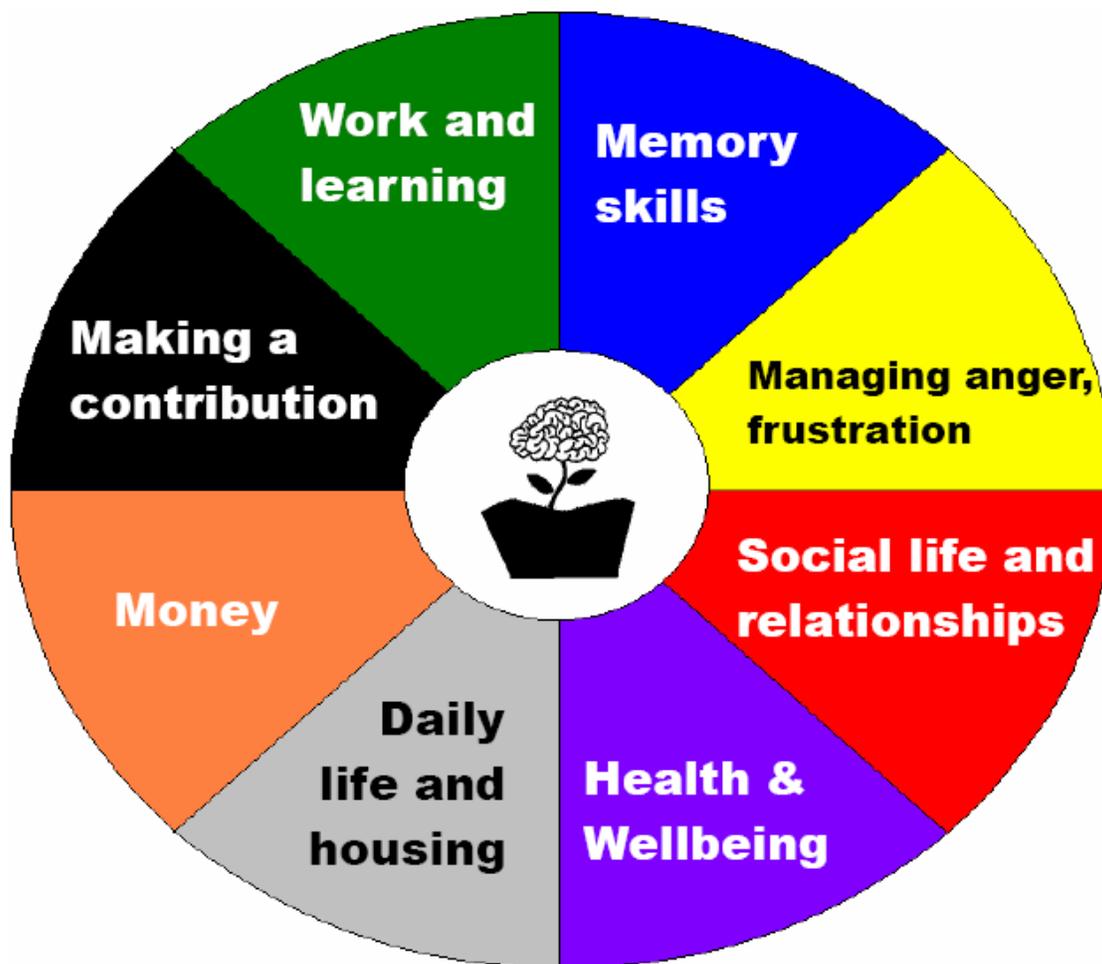
West Dunbartonshire Council's website is www.west-dunbarton.gov.uk, and has lots of useful contact details.

Common areas of concern

When we were talking to people about this pack, some common problems emerged. They centred on various parts of people's lives.

This wheel shows the main areas that are part of somebody's life.

The following sections look at each area and suggest ways to make dealing with some things more manageable.



Memory Skills

Lots of people find that they have problems with their memory as a result of having an ABI. Sometimes these will improve with time. Sometimes they don't.

Just like any other symptom, memory problems are unique to the individual.

"I hate people repeating themselves to me, I call them parrots! My Mum keeps telling me I've missed out loads of things, but I can't remember! Turns out I had to learn to walk, talk, eat, dress, wash – everything."

- Andy

"My short term memory is poor. I find it difficult to remember faces. When meeting someone for the first time I would focus on what the person is wearing for instance my support workers it was hat, earrings and scarf. One doctor had great big feet so I focused on his shoes. I had forgotten how to cook but now I can make mince and tatties and stewed sausages again."

- Roseanne

"I find that things come back to me. I wonder if they really did happen. I have to ask my wife."

- Chris

"I can speak to people I have known all my life, and forget their name and their family. This does get upsetting."

- Stephen

"I have lost some of my skills and lots of my memories. It is frustrating for me because I can't remember anything at all before the accident, I can't remember anything!"

- Pamela

"I knew at the time my mum's memory had been damaged but I don't think it had properly sunk in. As the weeks passed I found myself getting really frustrated and angry, not so much at my mum but at the situation. I tried my hardest to help out but there was only so much I could do. My mum had forgotten how to work the cooker, she even forgot to eat something herself. Our whole usual routine was gone. She would go shopping for the small things like papers, bread and milk but she would always buy too much of one thing, which changed every so often. First was toilet paper, she bought a pack of twelve every time she went to the shop. Then it was dog food – she bought tins upon tins of dog food, but she didn't realize she was doing it. Every so often she would take dizzy spells and lose her balance."

- Roseanne's Daughter

Hints and tips about memory problems:



Try using post-it notes in the house to remind yourself to do things.

Associating things with other things, like a dog in the street with your own dog, can help.

Write things down. Like a shopping list, or a list of things you need to do.

Some people keep a diary. They write down what they have done each day and it helps them if they need to remember something.

Ask people to send you text messages to remind you about things.

Set alarms on your phone, or ask somebody to set them for you.

Write down appointments on a calendar. Put the calendar somewhere where you will see it.

Ask support workers to give you a photo of themselves to help you remember what they look like.

Ask people to wear the same thing, or something distinctive when they visit. That might help you remember them as well.

When you are out, try remembering key landmarks to help you navigate.

Managing anger and frustration

Anger and frustration

After a brain injury, some people can find themselves feeling very angry and frustrated, both with themselves and with others. Anger and frustration are one of the things which can have a big impact on relationships. People told us about their experiences and gave some advice for others who are experiencing similar things.

“I get tired easily and I hate it when people can’t understand me just because I speak a bit faster than I used to. Sometimes I get angry and I don’t know why. I don’t like noise or small children making a noise. I can lose the plot easily!”

- Andy

“PS. I swear a lot now, more than I ever did. I keep getting told not to but sometimes it’s out before I know it!”

“I’ve had to learn to walk and talk all over again and it’s been frustrating for me especially the walking as it is taking a long time. I’m walking on my own in the house but outside someone is always with me and I can’t wait to be able to go on my own. I’m nearly there but it will take me a bit longer. My talking is coming along. It is frustrating for me because I know what I want to say and cannot always get the words out makes me want to scream.”

- Pamela

I remember the first time I met Andy over at the rehab unit, we had gone to say hello. I saw a young man, bored, angry and just fed up looking, but with a wicked smile, turns out he has a sense of humour to match. I was very wary of saying the ‘wrong thing’ to Andy, I didn’t know how to take him at first. I knew that he had had very negative experiences of carers in the past. I soon learned just to be me and Andy accepted this.”

- Wendy (one of Andy’s carers)

“I often used to get angry -I don’t now because I use a mood diary where I record my feelings this has helped me more than anything and it is private. When I start to get a headache I know I might lose my temper. I go to bed and lie down. Taking a break is really good.”

- Roseanne

“When I am angry I go to bed. It’s harder to cope when I’m tired. I can easily blow my lid.”

- Steven

“I have learnt only recently after years of bottling up my problems to breaking point, that I can talk to my workers and share how I feel. When I feel low, just a shake of hands or a pat on the back is great treatment.”

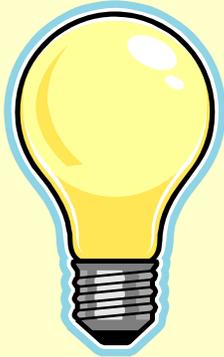
- Stephen

"I have a relaxation tape, it has breathing exercises. I also carry a prompt card. It says, 'stop, think, do not react'. Some people carry an explanation card, it tells people that they have an ABI and might need extra help or support."

- Anon

Hints and tips about anger and frustration

Some things that can help are:



- Taking a break
- Going for a walk
- Listening to music
- Writing a diary
- Keeping a mood diary
- Drawing
- Playing sport
- Talking to other people
- Going to a peer support group
- Learning to recognise warning signs.

If you find that you need more support, the ABI Service in West Dunbartonshire have a Psychologist who may be able to help. You could also speak to your GP about it.

Social life and relationships

- Relationships
- Social life
- Keeping friends
- Making new friends

Relationships

There are two significant types of relationship.

One is the relationship you have with your family. That family is not always 'family' in the traditional sense. You may not see much of people you are related to. Instead you may choose to have other people, such as close friends, playing a major role in your daily life.

Either way, it is important to acknowledge that an acquired brain injury can affect these relationships.

The other type of relationship is the relationship you have with your spouse, partner, boyfriend or girlfriend. These relationships can also be affected by an ABI.

"When my father died, my family asked the doctor if they could tell me. They were afraid I wasn't up to it. That upset me. The doctor told them I had to know. I felt like decisions were taken from me and made for me."

- Chris

Hints and tips about relationships



Talk to somebody you trust about how you're feeling.

Don't worry, often when someone has had an ABI they feel anxious and can get upset easier than they used to. Sometimes they find it harder to get on with the people they love. This is quite usual and it takes time for everyone to get used to changes. It's important not to keep these feelings to yourself, but try and talk to your family about it. They'll have feelings too and it may be that you all need to talk to someone who can help.

If it's getting hard to relate to family, then your GP can help to arrange to talk to a Psychologist about how you're feeling.

Psychologists can also talk to your family or partner and help them to understand how you feel and what's going on. In West Dunbartonshire the ABI Team have a psychologist who can work through some of these things with you, or there could be a group of other people who have had an ABI or their families and friends.

If you find it hard to talk about how you feel, you could try writing it down so that your family and friends can read it.

Social Life

What we mean by a social life is hobbies, leisure activities, going on holiday, having and enjoying interests such as music. These are some of the things that people do where they enjoy themselves. Most of them also involve mixing with other people – they are the kinds of things you do with your friends, and where you meet new friends.

Hints and tips about social life



- Start with people and places you already know and trust, and build from there.
- Don't forget to try new things, to see if you like it.
- Social activities should still be about what interests you – not 'what disabled people do'.
- Use Direct Payments and other flexible forms of support to help make social activities happen.
- Think about combinations of services and activities – such as using special transport to get to an ordinary place, if that is what you need.
- Think about what other sources of support and practical help there are around you – people in your community, ordinary clubs and activities – who might be willing to help.

Keeping friends

After spending a long time in hospital, people can find that they get out of touch with friends.

“In hospital I wanted to go home so badly, I was trying to get my mates to get me a wheelchair and push me through the Clyde Tunnel. I think it scared them.”

- Anon

Keeping in touch with people can be difficult when you are unwell. Sometimes people who have just experienced an ABI can't face being around more than one person at a time and feel so awful and anxious about themselves and their situation, that they can't bear to be with even their close friends.

Hints and tips about keeping friends



Try to find some way to keep in contact with your friends even though it may be the last thing you feel you need, because once you're isolated it's harder to come back to them.

Ask your family to try and keep contact with your friends until you feel up to it.

Making new friends

"I enjoy socialising and making new friends. I do this by going out and not being a shy guy."

- Phil

"Most important is knowing you are not alone. People do care and others have suffered too. Through my workers I have learnt how my illnesses affect my life. My group which meets Mondays and Thursdays for football have become really close friends. Just a day out together can do wonders for a brain injured person."

- Stephen

Hints and tips about making new friends



Come along to the BIEN informal meetings, or go to Headway.

Find someone you feel comfortable with and who can help get you along to new groups.

If there isn't an ABI group near you, find a small group doing something you're interested in e.g. relaxation groups.

Try a part-time college course.

Health and Wellbeing

Health and wellbeing can be affected by an ABI. Health and wellbeing includes:

- **Physical skills**
- **Sensory impairment**
- **Physical health**
- **Epilepsy**
- **Mental health**
- **Alcohol and non-prescription drugs**

Keeping well involves lots of things.

It starts with access to health services, including primary care. If you are staying at home, or nearby, then you will probably stay registered with the GP (family doctor) who knows you. But if you are moving into a new area, you may want to check out the local practices.

You may find you now need some extra help to keep well, so check out what is available to help you maintain good health and prevent or identify serious illnesses. This might be advice around diet, exercise and so on. It will also include care on women's health/men's health issues.

You may also need access to specialist services that support people with an ABI or particular disabilities.

The people we spoke to said that it was very important to get exercise – even if you can only manage a little bit.

They also highlighted the importance of drinking lots of water to keep hydrated, and eating well.

Sometimes people with an ABI might suddenly need a service that they haven't used before. This can happen if a symptom changes. Also, some people might find that an old problem comes back.

When this happens you might need to get back in touch with services or people you haven't used for a while.

It is important to be able to do this quickly if necessary.

Your GP is the central contact into Health Services.

In West Dunbartonshire, the ABI Service can refer you on to other services.

Physical skills

Physical skills can often be affected by an ABI. This might be balance, co-ordination, eyesight, walking, to name only a few.

Some of these skills will return. Sometimes skills may not return. Treatment like physio and rehabilitation can help work on some of these things.

“I used to read a lot but now writing goes into a long blur. I can read a magazine better.”

-Roseanne

“I hadn't spoken for months. My theory is that I was getting my words confused and didn't want to speak in case I made a fool of myself. One day my wife asked one of the male staff to give me a shave. He was talking to me, and I was just sitting there.

Then he said, 'I heard you're a Fireman Chris?'

The next thing I knew, I said, 'I'm a Firefighter.'

He had to check that it was really me that had spoken. It was. I told him, 'I'm not a fireman, I'm a firefighter – gender free.'

He stopped shaving me and rushed off to tell people I was talking!

The next thing was walking. They had got me a specially made wheelchair – brand new. People were behaving like it was Christmas for me. I might have looked out of it, but my brain was working, I was thinking. I thought, 'That's it. I'm going to spend the rest of my life in a wheelchair. Next thing, I'll be put in a home.' I really did think that. One day, when my father-in-law came to visit, I told him, 'I promise you, one day I'll walk out of this place.' And I did.”

- Chris

Sensory impairment

Following a brain injury, some people may experience a loss or partial loss of sight, hearing, taste, smell, touch and sensation. It is possible to have difficulties with these senses, even although the organs themselves have not been damaged.

Sometimes the damage is temporary and the sense returns. For many people this can take a long time, and there are people who are left with permanent sensory impairment.

Here are some of the problems people have spoken to us about:

- Eyesight: having double vision or blank spots in your vision
- Hearing: finding that you can't block off background noise so everything sounds like a clamour, or developing ringing in your ears
- Touch or heat sensitivity: finding that you can't feel the pain of standing next to a radiator, resulting in getting burnt, or finding that you always feel cold
- Smell or taste: finding that food doesn't taste the same as it did before, or putting on too much aftershave because you can't smell it.

Someone with a brain injury may not be aware of the problems they are having. For example, with sight, the eyes can be functioning normally but only processing bits of the information. So, someone could leave food on one side of their plate because they are not seeing it, but if you turn the plate round a bit then they'll see the food they missed before.

Family and friends can help by talking about their concerns and help the person to get advice from their GP or through the Sensory Impairment Teams available through Social Services.

There are specialist assessments that can consider a wide range of needs. Your GP or Specialist can then look at how to get you the most appropriate support.

“My eyesight was poor and I didn't think I was ever going to drive again but my eyesight is improving so I'll just have to wait and see if I can drive again.”

- Pamela

Physical health

Having an ABI can have a huge impact on your physical health. Common problems include eyesight problems, headaches and fatigue.

Some people will have had health issues prior to having an ABI.

It is important that these issues are not forgotten. An ABI can also have an impact on how somebody manages a prior condition. For example, somebody who has had diabetes for many years and then gets an ABI may not be able to remember whether they have taken their insulin. It can be hard for people to remember what a Doctor told them.

If you are experiencing difficulties with health issues, it is important that you contact your GP. It is especially important to get in touch with your GP if you notice a new health issue, or if an existing one starts getting worse.

“Headaches can be really bad. Watching television or reading – it's like a firework exploding in front of your face or a long nagging headache which sometimes causes you to slur your words – making people think you are drunk, or when walking down the road you stagger, unbalanced. This can lead to panic attacks where you just want to get home and hide away from the world.”

- Stephen

Medication prescribed at the time of his injury has lead to Vincent experiencing a significant weight gain. Vincent deals on a daily basis with a number of health and mobility issues. He needs a wheelchair for when he is out and about - he has his down days but generally doesn't dwell on things.

“Life now is not what I expected. My health is poor and I want it back, along with my fitness. I will eventually. I used to have a 6-pack, I want it back.”

- Andy

Hints and tips about keeping healthy



Try to do a little bit of exercise each day – just some chair exercises can be really good for you.

Eat a balanced diet.

Drink plenty of water.

If you notice a new symptom, don't wait too long before you go to the Doctor or tell someone about it.

Use mobile phone alarms or timers to make sure you remember when to take medication.

If you get the opportunity to get out of the house – take it!

Epilepsy

Epilepsy occurs in around 5% of people with brain injury, which is about ten times more common than in the population as a whole. Epileptic seizures, or 'fits', are most frequent in the first week after brain injury and tend to become less common after this.

What is an epileptic seizure?

An epileptic seizure is a sudden change in movement, behaviour or perception caused by uncontrolled electrical activity in the brain.

During a seizure, the nerve cells in the brain become over-active and fire off in a random and erratic fashion. This activity often disturbs neighbouring cells which can also become over-active and set up a kind of 'chain reaction', so that an area of the brain or the whole brain can become temporarily upset.

Sometimes this over-activity can occur with no obvious external evidence, but commonly the person shows signs and symptoms such as a change in or loss of consciousness, shaking or convulsing, tongue biting, etc.

Types of epileptic seizures

Generalised tonic-clonic seizures: Sometimes referred to as '**grand mal**' seizures. These are characterised by a sudden loss of consciousness and falling, followed by stiffening (**tonic phase**) and then rhythmic jerking of the whole body (**clonic phase**). The person may bite their tongue or lips, or be incontinent. Following this there may be a period of drowsiness, confusion or sleep. Generalised tonic-clonic seizures are sometimes preceded by a strange taste, smell or other sensation, known as an '**aura**', which tends to occur in the same way before each seizure.

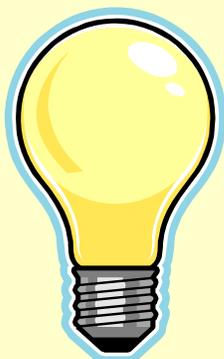
Partial seizures: Sometimes referred to as '**petit mal**' seizures (although this term is falling out of use). These affect only part of the brain. Changes in consciousness and behaviour occur, such as lip-smacking, picking at clothing, grimacing and

unresponsiveness. These seizures can also have symptoms of sudden anger, panic, depression and other states of mind.

If you are liable to epileptic seizures, you may be able to recognise the 'warning signs' that one is about to occur (e.g. an aura), and have time to sit down or tell someone what is about to happen. It may then be possible to prevent the seizure from becoming generalised by using a variety of techniques to reduce arousal levels. There is no single proven method of reducing the frequency of seizures or preventing the seizure from becoming generalised: different methods work for different people. It is important to look at individual patterns of seizures and, in particular, at any triggers such as tiredness, stress, caffeine and even relaxation.

Anti-convulsant medication may be prescribed to control seizures that develop after a brain injury. Some people are given drug treatment for epilepsy before they have even had a seizure following their brain injury, in order to prevent seizures from developing.

Hints and tips about epilepsy



(A lot of this information has come from Headway.
www.headway.org.uk)

Talk to your GP about any questions or worries you have about epilepsy.

There are voluntary organisations which can help with advice and support.

Your family or carers may have questions too, and it is helpful to share your concerns so that you can learn together.

It is helpful to keep a seizure diary so that you can learn to recognise any situations when you are particularly at risk, or likely to take a seizure.

This can also help you and others to understand what your seizure looks like, how long it lasts and what support you need - before, during and afterwards.

Some people like to carry emergency medical information around with them e.g. on a bracelet.

Hints and tips about meeting health professionals



These are the first steps that many people find helpful when they want to ask about their own situation at any time.

Take some time to think about what you want to know or if there is anything you would like changed around your own treatment or support.

- If you have questions about your condition or treatment, make a list. Examples might be what is the diagnosis, what are the choices around treatment, how to manage any effects of medication, how long symptoms will last?
- If you want something changed, make a list of what is good and what is not so good about things now. Try to be as specific as possible. Try to explain what your ideal would be.
- Leave the list for a day and come back to it, as you may remember other things you want to add.
- Talk it over with a friend, relative or support worker. They might have noticed things that you have forgotten.
- You do not have to wait until a clinic or GP appointment that is already arranged if you want to see someone sooner.
- It may be helpful to ask for a longer appointment if you are going to your GP.
- Take your list with you. If it is convenient, you could take a copy and give it to the doctor.

Get some help if you find it hard to remember what the doctor tells you.

- Ask the doctor to write down what he or she has said.
- Tell the doctor that you want to take notes to remind you later on, and then read them back and ask the doctor if you picked it all up right.
- Take a friend or relative with you into the appointment, if this will help you.
- Take a small tape recorder with you and ask the doctor if it is ok if you record the conversation.

Useful publications

It's okay to ask: leaflet produced by the Scottish Government and Scottish Consumer Council in February 2008:

Useful websites

www.hris.org.uk – for the 'It's okay to ask' leaflet and other useful information

Mental health and wellbeing

Mental wellbeing is important for all of us. It is how we think, feel and act and how we get on with other people.

- Good mental health and wellbeing helps us cope with life's problems and make the most of life's opportunities.
- It helps us flourish in each situation – our families, our work, home and so on.
- It is when we feel good and act well, both individually and together.

Mental health problems are when we have difficulties with our mental health which affect how we go about our everyday lives.

Mental illness refers to illnesses or conditions that a doctor can identify, which affect how we think, feel or act.

People can have previously had a mental health problem and then have an ABI. Sometimes the ABI will affect their mental health problem.

People can also develop a mental health problem due to having an ABI.

“As the days passed my mum started to get her strength back, but she still wasn't herself. She had developed a cleaning obsession. She cleaned 24/7, over and over again.”

- Roseanne's Daughter

When there is a big change in your life, such as learning to live with an ABI, it can often cause anger, frustration and make you feel down. Things like not being so physically active and having less contact with friends, can lead to someone becoming unwell.

Depression

Some people we talked to said that depression had been a problem for them. Some people say that depression feels like a black curtain of despair coming down over their lives. Many people feel like they have no energy and can't concentrate. Others feel irritable all the time for no apparent reason. The symptoms vary from person to person, but if you feel "down" for more than two weeks, and these feelings are interfering with your daily life, you may be depressed.

Treating depression is especially important because it affects you, your family, and your daily life. Depression is a treatable illness.

“I used to feel very depressed, didn't want to come out of my bedroom or eat. I was lucky that my family always made sure they were with me. I had many down days and nights in fact I didn't know day from night.”

- Roseanne

“Depression – a horrible word and a horrible sickness combined with a brain injury. I would shut myself away. I became dependent on alcohol and it was during these phases that I took two overdoses. Life meant nothing, but my body held out to be sent to a psychiatric ward twice.”

- Stephen

Alcohol and non-prescription drugs

Should people with brain injuries drink alcohol or use drugs? In making your decision, consider the following points:

- **People who begin or continue using alcohol or other drugs after a brain injury don't recover as quickly or as completely.**

If people who have had a brain injury begin using alcohol or other drugs, they may lose much of the progress they have made. Because they lost brain cells in the injury, the remaining cells must work harder for the person to do some of the same activities they did before the injury. If the remaining cells are affected by alcohol or drugs, they will not be able to take over the duties of the dead cells. That means skills a person could have regained are now lost.

- **Brain injuries can cause problems in balance, walking or talking that worsen when a person uses alcohol or drugs.**

For people whose brain injury has caused difficulties with balance, movements and speech, alcohol and other drugs further reduce ability in these areas.

People who have had a brain injury often say or do things without thinking first. This problem is worsened by using alcohol and other drugs. Acting before thinking can be a common problem for people with brain injury. It is also a problem for people who abuse alcohol and drugs. Not being able to control what they say or do can lead to increased risk-taking, arguments, or other socially inappropriate behaviour. People with brain injuries may learn ways to control their behaviour. However, they are unable to use these skills well when drinking or using drugs.

- **Brain injuries can cause problems with thinking, such as concentration and memory. Using alcohol and other drugs make these problems worse.** Many people have to learn new skills, or relearn old ones, after a brain injury. People may have trouble with concentration, memory, problem-solving and other thinking skills. Alcohol and other drugs can also interfere with learning new information.
- **After a brain injury, alcohol and other drugs have a more powerful effect.** Brain injury results in a loss of brain cells. Those cells that remain must do their own work plus the work of the dead cells. Because there are fewer cells after a brain injury, more alcohol or drugs go to fewer cells, increasing the impact of the alcohol or drugs on that person's ability to function. The person becomes intoxicated more quickly, and the effect of the alcohol or other drugs is much greater.

In addition, alcohol and other drugs interfere with the effectiveness of prescribed medications.

- **People with brain injury are more likely to feel low or depressed at times. Drinking alcohol (a depressant), or getting high on other drugs, makes this problem worse.** Depression is fairly common after a brain injury. Some people may try to cope by drinking alcohol or using other drugs. While people may "forget" their problems for a while, these problems are still there when they are sober. An endless cycle can be established at this point, with depression leading to substance use, which leads to increased depression. This behaviour decreases overall ability, increasing depression even more.
- **After a brain injury, drinking alcohol or using other drugs can cause a seizure.** Some people with a brain injury have an increased risk of seizures. Those who are at a very high risk are given medication to prevent them. Alcohol and other drugs increase the chance that even those at the lower levels of risk will have a seizure. Alcohol and non-prescription drugs prevent seizure medications from working, further increasing the risk of seizures.
- **People who drink alcohol or use other drugs after a brain injury are more likely to have another brain injury.** A person who has difficulty thinking clearly, walking smoothly, or reacting quickly due to brain injury is three times more likely to have another injury. People who further cloud their abilities with alcohol or drugs will have an even higher risk of another injury. Second and subsequent injuries will cause more harm than the first one. The destruction of more cells as the result of a second injury will leave even fewer cells to do the same jobs. Some abilities will be lost because of fewer cells to make these functions possible.

Don't forget that there are people and organisations who can help you if you are having a problem with alcohol or drugs.

Your GP or Social Worker can help you contact your local support groups, many of which offer one to one confidential help.

Daily life and housing

- **Dealing with services**
- **Where you live**
- **Personal Housing Planning**

Dealing with services

Support can mean different things.

- Support from a place or team of people like a day centre, community team or staff where you live.
- Support with personal things like having a bath, washing or getting dressed.
- Support to live in your own house like help with money, cooking or cleaning the house.
- Support to get out and about like driving you to see friends, help to join in things with other people, or someone to go on holiday with you.

Some support services that may be useful are:

- West Dunbartonshire ABI Services – who can also help you access other services
- Psychology
- Physiotherapy
- Housing Support Services
- Speech and Language Therapy
- Occupational Therapy
- Sensory Impairment Services
- Alcohol and Addiction services
- Housing
- Education
- Welfare rights
- Support groups
- Criminal Justice

Direct Payments are one way of giving people more control over the services they use. You can get more information about Direct Payments in the next section, and on the Update website, www.update.org.uk. They also have a telephone helpline: 0131 558 5200.

“My wife had thought about giving up work to look after me when I got out of hospital, but a social worker advised her not to, otherwise we might 'be divorced in about 6 months'! I had a care package put in place, using agency staff. I didn't like it much and wasn't happy. The social work department said the only alternative was for my wife and me to become employers. That way we could use Direct Payments to get the support we needed. So we became employers. We employ three Personal Assistants who help me when my wife is at work. It is a system that works fabulous! We have been working this way for three years now, it wouldn't work for everyone but it does for us – we even have staff lunches and days out at Christmas!”

- Chris

There are various ways you can try out choices, and be in control of what support you get.

One is to find services that provide the supports you want. If these aren't right at first, discuss with the staff whether there is scope to make changes, or involve other services.

Another is to get 'self-directed support' – where an organisation provides the flexible support someone wants, and the person and their family gets the opportunity to choose their own staff, but the staff are employed by the organisation and the funding is all managed by the Social Work Department. Some people have found that this is a good way of trying out what works for them. It may also be quicker to organise than support under Direct Payments, as you don't have to get the money side sorted first.

Where you live

Where you live is very important in helping you to live your life the way you want to.

Hints and tips about where you live

- It is easier to think about where you want to live, and then about the type of house and the type of support you might want, once it's clearer what type of life you want and what you want to do.
- Think about what type of support you want, and then look at which support services can provide this.
- Remember that it can take a while to get the right house in the right place, especially if you need a special type of house.
- Think of a house and support as a way of helping you have the type of life you want, rather than letting the house determine everything else.

Some people have asked, "I want to live on my own—will I be able to?"

Depending on how your brain injury has affected you, it may well be possible to live on your own. After assessment, adaptations to your home may be required to do this. You should always be supported to be as independent as possible.

"I got my own flat but I didn't like the carers that came with it (at first). My Mum had done my flat up along with my Aunts, Uncle and grandparents. I liked my flat apart from the 'red wall'. Got rid of that!"

- Andy

Personal Housing Planning

(taken from the Moving On Pack, extract written by Julia Fitzpatrick)

The starting point for a personal housing plan is just to think through a number of questions about who you want to live with or near, how and where you want to live, what your house needs to look like in order to meet your needs, and what you can afford. Because it is personal, each person or family may have extra information they want to add.

1. Where are you starting from?

Before you put lots of effort into thinking about or researching what options are available, it helps to think about where you live now, and about where you have lived in the past. This can help to build up a picture of what aspects you want to change and what you would like to continue. For example you might like the size of your living room but note that the bathroom is too small to be adapted for your needs, or the house is too far from amenities.

- What do you like about where you live now or where you have lived before?
- What do you not like? What isn't suitable for you? Why?
- What needs to change?

2. Who do you want to live with?

- How many people will live in the house as their main home?
- Will people from different age groups be living in the house e.g. children?
- Do you want to share with anyone?
- Will you need room or space for people to support you? Think about when and what kind of support you might need and if this will affect the size or type of house.

3. Where do you want to live?

- Think about what you do or would like to do (or have to do) on a daily, weekly or monthly basis.
- Think about your friends and family and how often you would like to see them.
- Think about what kind of area makes you feel at home and why.
- Think practically about how you or your friends or family will travel to and from where you live.

For example, you might like to walk to a local shop but be happy to get on a bus to work. Some people want to be able to see their family every day; others will want to meet up only occasionally. It might be very important to you to stay in a local area where you are familiar with the people or you might like the idea of getting to know somewhere new.

4. What will your home look and feel like?

Do you or your family have particular needs which will affect the type of house which will be suitable for you? For example, you might use a wheelchair which means you need to have level or ramped access to your home.

What sort of space or design or aids or adaptations might help you to do things in the house or be supported to do them? For example, if there was a kitchen surface that you could sit at, would this mean you could help with making meals, but if the kitchen is very small then you can't do this?

Do you need help with some things which might affect the size or type of house you need? For example, if you need help with bathing or going to the toilet, you may need a bigger bathroom so there is room for someone else to help.

Think through what elements of a property would be essential for you, and what would you like to have but could live without. For example, you might need at least 2 bedrooms - one would not be enough in your situation. However while you would like a garden, you could manage without one as long as you felt the house was quite private and no-one would disturb you.

5. What can you afford?

- Where does your money come from at the moment and how much do you have?
- Do you have to pay any money for care and support?
- What do you spend your money on now, would this change if you were to move?
- Think about what you would need money for to get a new home, and then to set it up and live in it. Try to estimate how much you might spend.
- If you moved, would you or could you get help with any of the costs? Where from and how much?

6. Any other points which might affect your plan?

- Are there local care or housing policies or initiatives which could help you, or which might stand in your way?
- Think about people who can help you work out your options or get more information?

Depending on your situation, you might want to get help with thinking about these questions. It could involve discussions and meetings with your family, the care manager, and support providers. It may also be useful to seek specialist or professional assistance to clarify certain areas e.g. welfare benefits entitlements; occupational therapy advice on aids and adaptations options.

7. Description of basic housing requirements

Once you have carried out this detailed planning, you are ready to be quite clear about what you are looking for and why, and have an idea about what you can compromise on. You don't need any technical or specialist knowledge to do this but your description will probably also include information on adaptations which you would need and any design features. This can provide a useful summary for you to refer to and for anybody working you when considering some preliminary housing options.

8. How would you use this information?

- Match against existing and potential housing options and work out preferred routes.
- Support funding submissions for capital and revenue grants.

- Provide the basis for applications to rented housing providers, or discussions with them.
- Provide a starting point for assessing house layout plans or housing offers.
- Provide an initial brief to an architect if you are getting your house built or adapted.
- Provide a summary of requirements to estate agents or new housing developers for property matching purposes.

It is worth spending time on the process of drawing up the preliminary information and on thinking through where a requirement is essential or desirable e.g. range of locations, and how much scope for negotiation there is around preferences. This will help others who are working with you to be clear about the parameters. However, bear in mind that personal housing planning is not a science, it is a process. In the course of thinking about and finding housing, people revisit and change their plan. This can be because a new opportunity is presented or because experience of searching helps people to become clearer about what is negotiable and what is not.

Disabled people or their families who have access to the internet can work through a detailed personal housing plan questionnaire and access information about options on:

www.housingoptions.info

Money

Planning for the future should include planning for the money that you will have. The sources of money for someone with a disability will usually be a combination of:

- welfare benefits
- Direct Payments or Independent Living Fund
- earned income
- income from trust funds, for example when someone inherits money, or from a settlement after an accident, and
- one-off grants or loans from schemes to help young people, or to help people do certain things.

The person needs to get information and advice on the benefits and other payments that they might be entitled to. The rules on benefits change, so it is worth updating this from time to time – for example, on how much earned income someone can have before particular benefits are affected.

“When a Social Worker from the Brain Injury Unit came to visit Douglas, he helped him to apply for benefits and was given the support he needed to attend Momentum and do some voluntary work. It is a great help knowing that there are people who will help Douglas and who understand what is wrong with him.”
- Douglas’ Mum

Welfare Rights Officers, Social Services, and the Department of Work and Pensions can help you to maximise your benefits and find out about your entitlements.

Families may also want to get advice on financial matters – for example, if someone wants to give money to this person or leave him money in their will. You can get advice from lawyers, accountants and other professionals.

Direct Payments

A Direct Payment is money paid by the local authority directly to a person who has been assessed as needing community care or housing support services. The local authority makes the payment instead of arranging services. The person uses the payment to purchase the relevant services (for example help in the house, to go out to work or with social activities).

In practice, recipients often employ their own personal assistants but this is not a requirement. Support can be purchased through agencies or in the form of services. The key benefit is that direct payments increase the amount of choice, control and flexibility people have over the way they live their lives.

Most people who use Social Services from the Council could get a Direct Payment. Your Social Worker or Care Manager should talk to you about Direct Payments when they look at what care you need.

Once someone is getting services, if these would cost more than £350 a week they may be able to get an allowance from the Independent Living Fund. After 6 months, you can ask to have this increased. The extra income can be used to get the additional supports which formal organisations don't usually provide.

A Direct Payment lets someone employ their own staff to give them the support they want. This is the arrangement that gives the person the most control and choice. Although you can start with care funded through Direct Payments, you could use one of the other arrangements (described above) to find out what works for you, and then switch to Direct Payments after a year or so. There is more information on Direct Payments in the section about dealing with services, and you can discuss with the Social Services Department what the current arrangements and options are in your area.

But the starting point for all of this is to be clear what kind of life you want, then work out what this looks like in practice, and what types of practical support will help this to happen.

As well as thinking about services, keep involving friends, family and other people in helping you make choices. Your ideas will probably change as you get to try out things and realise that one choice leads on to lots more.

Getting someone to help you manage money

Some people find that their injury has left them struggling to manage their money. For example, it can be hard to concentrate or to remember if you have paid bills.

These are some of the main ways people can get help to manage their affairs.

- You can have a joint bank account with someone if you are able to agree to this. You tell your bank that you want to do this, and they will help you with the paperwork. This is an arrangement that anyone can use.
- You can give someone power of attorney. Again, you need to be able to agree to this. This lets someone agree to things on your behalf. They are accountable to you for what they do. A solicitor will arrange this for you.
- One way to help someone who cannot manage their money is for their carer to apply for access to their funds. The Office of the Public Guardian will tell you how to do this. There is more information at the end of this pack.
- A friend or relative can take on the role of guardian to look after your welfare, your money or both. The Public Guardian will make sure your money is managed properly. The Local Authority and the Mental Welfare Commission will make sure your welfare is looked after.
- There is a law called the Adults with Incapacity Act, which helps anyone who finds it hard to manage their affairs – either for a short while or for a longer time. There is more information on this at the end of this pack.

Making a contribution

There are many ways in which we can make a contribution. One is through paid work. Others are the unpaid things we do – volunteering, being a member of an association or community group. We contribute as a citizen by voting, by asking questions and by contributing our views. We contribute by being someone's friend or neighbour. We contribute just by being part of a community and being with other people.

We benefit by gaining in confidence, and mixing with other people. The rest of the community benefits from our ideas and experience, and from the personal qualities we bring to our connections.

These are some of the practical things you can do when you are thinking about making a contribution.

- Make sure you are included on the electoral register, so that you can vote. Contact the Electoral Registration Officer at the local authority to make sure.
- Check out opportunities such as volunteering. These can be a way to try out new things and learn skills, which may lead to friends and new interests, and may even lead to a job.
- Join local community groups where people share their hobbies and interests. For example, if you like being outdoors, there are many organisations which are looking for people to help with environmental projects.
- Find out about the collective advocacy groups which bring together disabled people, or are tackling other issues which affect you.

People who use the BIEN group have found it helpful to meet other people who have had an ABI.

“I don't feel so isolated.”

“I thought I was the only person with an ABI.”

“I've always wanted to meet people with similar problems.”

“We're not alone. Simple as that.”

“I have become more confident in myself.”

- Members of the BIEN group

Remember that if you need help to go to places or join in groups, you may be able to get support from the ABI team or voluntary organisations.

Work and learning

Returning to your old job may not always be an option. It depends on the job you were doing prior to your brain injury, and the effects of your injury. However, it is worth speaking to your previous employer about alternative options.

In West Dunbartonshire, the ABI Service can also help through their links with a variety of education, non vocational and pre-employment initiatives. If you live elsewhere, you could contact your local council to find out more.

It is also worth thinking about doing something totally different from the work you did before.

“I have worked since I was 15 and was determined to get on with life.”

- Roseanne

Some people have used their hobby to get work by:

- Building on their interest and developing expertise
- Doing some volunteer work around it
- Getting part-time work, and moving on to full-time employment.

“I have attended a Momentum Pathways Course, to try and train me for work, either full time or voluntary. I have worked voluntarily at 'Home From Home' and at Knowetop Farm, two local charities. I have had various degrees of success with this, and I am now a voluntary helper with CLICSargent at their residential house at Prestwick, working on week long placements with children and young people who have or have had cancer. Just now I am on a 12 week Princes Trust Team Challenge Course, which helps to increase confidence and improves chances of getting into full time employment or further education. Through this I might be starting a college course this summer.”

- Douglas

“I would go back to my old job tomorrow if I could. But I am a very busy person these days. I train people who are going to work with people who have an acquired brain injury.”

- Chris

“Sometimes feel like I've not woken up yet because I don't seem to get taken seriously by anybody all because they think I'm incapable of making my own decisions but I shall succeed in all. I am determined and I make the best off what I've got left of this soft grey matter in my head. I study most days and work at my I.T skills “

- Phil

“I worked as an intensive care nurse in Stobhill hospital. Being a nurse was everything I wanted to be and I will be again. I'd like to thank my Mum and Dad for all the help that they have given me.”

- Pamela

“Vincent is a very motivated and capable student, always willing to help less able students with their work. He can retain information and sequences of operation. So far Vincent has made a Wheel-barrow Planter and has been involved with prototyping a table which we intend to manufacture”

- Stephen Softley, Woodwork Tutor (West End Project)



Hints and tips about work and learning

Talk to your support workers, friends or family about your plans.

Don't be afraid to try new things.

Focus on things that interest you.

Don't try to do too much at once. Give yourself time to get used to something new.

Think about supported employment projects.

Think about volunteering.

Talk to your local volunteer centre about opportunities which may be available.

Think about your own interests – is there something you could do around them? e.g. computers or art.

Make a plan.

Stop and think after about 6 months – you may want to review your plan.

The West Dunbartonshire ABI Team support people to access further education and local adult literacy individual or group sessions. People can also get information about this from local colleges or community centres. People who have had a brain injury can find that their reading or numeracy skills can be affected and it can help people's confidence as well as their abilities if they go along to local friendly literacy tutors.

Further education also offers a range of part-time courses which can help people build up confidence, top up their skills, or learn about new areas.

The Job Centre provides a Disability Employment Adviser. It might be worth going to speak to them.

Section 3: Help for the Journey

Future planning

- **Setting Goals**
- **Learning to live with risk**
- **Planning for change**
- **Change wheel**
- **My change plan**

Setting Goals

Day by day you will become more aware of things that you would like to change, or things you want to do.

Setting goals can be a good way to keep motivated. Goals don't have to be about big things, something like planning to go to see a friend, or getting the bus for the first time since coming out of hospital are just as important.

Hints and tips about setting goals

- Be open, flexible. Don't set a rigid plan too soon.
- Find ways to make choices in small things, and then making choices in big things will feel easier.
- You also need to keep revisiting the goal.
- It's ok to adapt it as you learn and get more ideas.
- Keep remembering the long-term aims as well as the day-to-day ones.
- Expect that some things won't work out

“After spending six months in hospital I was transferred to a rehabilitation unit. That didn't do anything for me, so I signed myself out after three months. I had my flat to sell and I couldn't do that in there, so I decided the best thing to do was leave and get on with my life.

I have never looked back, I sold my flat, got a wee council house, dumped my partner as he did nothing for me. I have achieved quite a lot. I attended an advocacy course and to my surprise I actually passed it.

I think the secret is, you can't let this destroy your life, you have to put on a brave face and be positive no matter what life throws at you. It could happen to anyone at any time.”

- Sandra

“Somehow, I think that Andy feels let down. I know that his life isn’t what he thought that it would be and until he came home didn’t realise just how much he had lost. It’s easy to forget that Andy has a brain injury. I sometimes say to him that it would be easier for him if he was in a wheelchair. People would accept your swearing and shouting because you would look disabled. Andy agrees.

I think that if Andy hears the phrase “you don’t realise how lucky you are” once more, he might scream. Andy may be lucky in that he is still here, but he would give anything to be the old Andy.

Trying to motivate Andy is probably the hardest part of my job. Andy is stuck between a rock and a hard place where education is concerned. He hasn’t got a Learning Difficulty, but he can’t attend a mainstream college. It so hard to try and resource facilities. We found Headway and although not keen at first Andy is now attending a cookery class there and is enjoying it.”

- Wendy (one of Andy’s carers)

Learning to live with risk

It is useful to think about real situations, and list out what our worries are. Then write down

- How likely is this to happen?
- What are the consequences or impacts if something does go wrong? You can then concentrate on putting safety nets in place for real risks.
- What makes the things that are likely to go wrong less likely to go wrong?
- If they would only be a bit embarrassing and no-one comes to any real harm, do they matter anyway?
- How can you prevent things happening if they would involve more harm?

These are a few things we have learned from our experience and other people’s.

It’s best to say what your worries are and then start looking at how to deal with them.

- There are risks of long-term harm to people in not taking any risks, or being so careful that you don’t have a life – no friends, no self-confidence, not being able to recognise or assess the risks in the unexpected situations that will come up.
- One of the best ways of protecting a person is to have a range of different types of people in their life who care about them - who will look out for you and do something if they think there is a risk.
- Another way is to get in regular contact with ordinary people who aren’t part of the family or formal services – such as friends, and the people who see you going about every day.
- Ask your family and friends to tell you if they are worried about you. Then you can work together to deal with it. For example, they may be worrying about something you have already discussed with the ABI team and have under control.

Planning for change

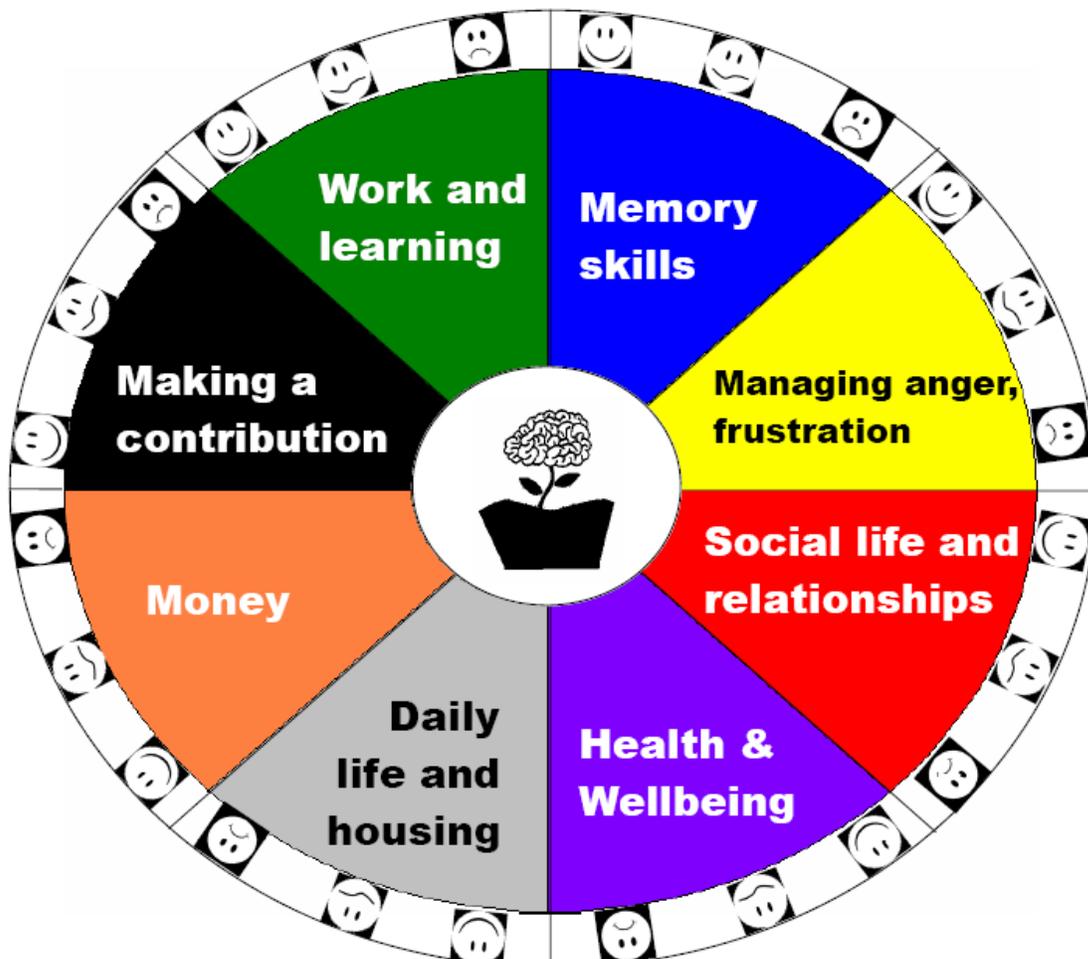
Just as symptoms are different for everyone, so is the way in which people recover. Some people are able to go back to their jobs and don't have to make many changes to their lives. Some people have to make bigger changes. The pace of recovery will be different for everybody.

You can use the wheel to think about the different areas of your life. If it would be helpful, you can use it to mark whether you are happy with the way things are, not sure about things, or unhappy. You could then talk to your friends, support workers and family about ways that you could change things in areas where you are not sure or unhappy.

The change plan on the next page gives you space to think about any changes in more details.

Change Wheel

I am happy with:	
I want to change:	



My change plan

Name: _____ **Date:** _____

	What I want to change	How can I try to change it?	Who can I ask to help me?
Memory Skills			
Housing and daily living			
Money			
Making a contribution			
Work and learning			
Relationships			
Social life			
Health and wellbeing			

Health and wellbeing for carers

It can be difficult for everybody to live in ways that help them to stay well, particularly for families of people who have additional support needs.

Research has shown that there are some things we all need to help keep us well.

- People around us – whether we have family, friends, social contacts, and a sense of community.
- Our own behaviour – what we eat, what we drink, taking exercise and so on.
- The environment – where we live, housing that is good or poor and whether it suits our needs.
- Income – for virtually every aspect of health and well-being, poorer people get unwell more often and take longer to recover than do people who are better off.
- Access to health services.

For many families, the practical consequences of disability affect all of these ways to stay well. Carers can also use the previous wheel and change plan to look at aspects of their own lives.

Hints and tips for carers

Let your GP know you are a carer and ask if this can be registered on your medical record.

Ask if the surgery has any carer's support services you could use. Your GP, Carer's Centre or Social Worker can help you to get in contact with your local services.

You have a right to a Carer's Assessment of needs. In West Dunbartonshire the local Carers' Centres provide a carers' support worker who can complete this assessment with you and who can give advice on a variety of supports that could help.

Carers' Centres may also provide:

- One to one support
- Support groups
- Alternative therapies
- Training courses
- Advocacy information
- Access to services
- Outreach
- A voice for carers
- Advice on benefits and carer's rights.

Remember:

- Don't be afraid to ask
- You too are on an ABI journey and are having to learn and cope with changes
- It's important to keep yourself well and supported, so that you can help your loved one through their brain injury journey.

Useful information

The West Dunbartonshire ABI Service

The Acquired Brain Injury Team is based in the West Dunbartonshire Council Offices at 6-14 Bridge Street, Dumbarton, G82 1NT. The ABI Team consists of the Service Co-ordinator, Clinical Neuropsychologist, Social Worker/Care Manager, Assistant Psychologist, Support Worker and Administration Worker.

Service Aim:

The aim of the service is to develop community based integrative assessment and social rehabilitation for brain injured individuals and their families. To facilitate individuals smooth transition between hospital and community where necessary by improving services and the knowledge and understanding of ABI among service users, carers and professionals.

Following referral a member of the Team will contact the individual for an initial assessment of support needs. The individual can expect to receive an acknowledgement of the referral within 10 days. When a Single Shared Assessment is undertaken we aim to complete this with the individual, within 28 days.

Support may include:

- Facilitating specialist assessments
- Maximisation of benefits
- Engagement with the individual in a wide range of activities from keeping daily diary/ mail folder to prompting with daily living tasks, shopping, using public transport and accessing social/education/employment activities.
- Referring individuals to appropriate resources e.g. The Momentum Project, Sensory Impairment Team, or Occupational Therapy supports.

This service provides:

- Assessment and Care Management – to individuals where Acquired Brain Injury or Traumatic Brain Injury is the primary issue in their life.
- A housing support service to individuals with Acquired or Traumatic Brain Injury - helping individuals to cope with day-to-day living.
- Information and support to service users, carers and workers.
- Joint working of cases with other teams where Acquired Brain Injury has been identified as an issue affecting the individual's quality of life.
- Specialist Assessments.
- Assessment and delivery of training – to identify needs and assist people with daily living e.g. memory aids, techniques to support people with challenges in day-to-day living.
- Relevant training is also available for other professionals involved in the support of individuals with Brain Injury.

How can you access this service?

To access West Dunbartonshire Acquired Brain Injury Team, you will need to be referred to the Social Work department. This is an open process, which means that anyone can make a referral to the service.

For more information, or to make a referral please contact:

West Dunbartonshire Acquired Brain Injury Service
Council Offices
6-14 Bridge Street
Dumbarton
G82 1NT

Tel: 01389 737020

Adults with Incapacity (Scotland) Act 2000

What the law does

The Act aims to help people who lack capacity to make some or all decisions for themselves. It enables carers or other people to have legal powers to make welfare, health care and financial decisions on their behalf.

What does incapacity mean?

In an everyday context, mental capacity means the ability to make decisions or take actions affecting daily life. Examples are when to get up, what to wear, what to eat, where you live, whether to go to the doctor when you are feeling ill, etc.

In a legal context, it refers to a person's ability to do something, including making a decision, which may have legal consequences for the person themselves or for other people.

Examples are:

- deciding about medical treatment
- buying and selling things
- managing money.

This law helps you if you have difficulties with any of these situations.

An adult lacks legal capacity to make a particular decision when there is evidence that he or she is unable to:

- understand the information they would need to make the decision; or
- make a decision based on the information given; or
- act on the decision; or
- tell other people what they have decided; or
- remember what decision they made.

This Act recognises that a person's capacity depends on the circumstances of each decision. Someone may be capable of making certain types of decisions but not others. This may depend on how complicated the decision is.

This Act also reminds everyone that a person's capacity may stay the same, or improve, or get worse.

The Act says that it is important that people get the right information to help them make as many decisions as possible. This could mean

- providing information in short, ordinary words
- writing things down, to help someone who has memory problems
- giving someone time to get to understand what is involved and think about what they want to do.

What does this law do?

The Act provides for a range of ways to allow other people to help you manage your own affairs or to act or make decisions for you when you are not capable of doing this yourself.

- One way to help someone who cannot manage their money is for their carer to apply for access to their funds. The Office of the Public Guardian will tell you how to do this.
- The Court can appoint a guardian to look after your welfare, your money or both. The Public Guardian will make sure your money is managed properly. The Local Authority and the Mental Welfare Commission will make sure your welfare is looked after

How does this take account of my wishes?

All decisions made on behalf of someone with impaired capacity must:

- Benefit you.
- Restrict your freedom as little as possible while still achieving the benefit that you need.
- Take account of your past and present wishes. You should have as much help as you need to understand what is involved and tell people what you want
- Take account (as far as reasonable and possible) of the views of other people who have an interest in your welfare. This includes your carers, relatives and friends. It can also include staff who know you and care for you.
- Encourage you to use existing skills and, where possible, develop new skills.

Welfare guardianship orders

These relate to your day-to-day welfare – where you live, who looks after you, going on holiday and so on. It lets one or 2 other people make decisions on your behalf whenever they are needed.

This order can be limited to 3 years, last for as you live, or until you are able to make decisions again.

An application is made to the sheriff. The application can be made by your relative or a friend, or by the local authority. Usually, the person making the application asks to be the guardian.

There is more information about how to make an application and what is involved at the Office of the Public Guardian and in a useful guide for carers which the Scottish Government published.

If the relative or friend is not sure about doing all the paperwork for the application, the local authority can make an application and name the relative or the friend as the guardian.

You can have one guardian, but it is a good idea to have 2 guardians. This way, they can both support each other. It also makes it easier if one person has to step down – there is still a guardian in place while an application is made to name another guardian.

Financial guardianship orders

These relate to your finances – spending money and buying things, including paying for care services if this is what you need. This order lasts for a long time, and lets one or 2 other people make decisions on your behalf whenever they are needed.

The arrangements are just the same as for welfare guardians.

For financial guardianship, a professional person such as a solicitor could be a guardian.

Intervention order

This is for a one-off decision or action. It can be a financial or a welfare matter.

The process is just the same as for the guardianship orders.

What happens if there are no relative or friends?

The Council can make an application for guardianship, if it has made an assessment, thinks you need a guardian, but there is no relative or friend to take this on.

The welfare guardian is the Chief Social Work Officer. But they will usually name a social worker to take on this role.

The council would appoint a solicitor to be the finance guardian.

Things that a guardian is not allowed to do

Guardians can make most of the decisions that help keep people safe and well. There are a few things that they cannot do.

- Consent to a marriage on behalf of the person
- Make a will on behalf of the person
- Consent to the person getting some forms of medical treatment. This includes the situations which are covered by the Mental Health (Care and Treatment) act.
- Place someone in hospital for the treatment of a mental disorder against their will. Again, the rules in the Mental Health Act apply here.
- Sell property, unless they get permission from the Office of the Public Guardian.

You can get more information about all of this from the Office of the Public Guardian.

Further information

Enable (a voluntary organisation) has produced a short guide to the Act.

[Easy Read Guide to Adults with Incapacity Act 2000 \(ENABLE\) >>>](#)

Another useful leaflet is It's Your Decision, which was written by Enable for the Scottish Executive (now the Scottish Government). It is written for people who may benefit from the Act. It is at:

<http://www.scotland.gov.uk/Resource/Doc/1097/009731.pdf>

There is a guide for carers, which describes the practical arrangements under the Act in a lot of detail.

Adults with Incapacity (Scotland) Act 2000: Guardianship and Intervention Orders – a guide for Carers.

<http://scotland.gov.uk/Publications/2007/08/29112925/0>

The Office of the Public Guardian has a general function to supervise those individuals who have been appointed to manage the financial or property affairs of an adult who lacks the capacity to do so for themselves.

www.publicguardian-scotland.gov.uk

“A sense of humour is very important – I've never lost that!”

- Chris

The BIEN group who contributed to this book stressed how valuable a sense of humour can be when living with an ABI.

Here are some experiences.

“I once went for the bus with one trainer and one sock on. I didn't notice until I got home. The result was a taxi home.”

“I have had to go for a paper to find out what day it is. Which is fine. The problems start when you go back an hour later for another one, because you've already forgotten you went earlier!”

“The rehab centre Manager came to see me. She asked my name but I just stared into space. She brought a blue ball out of her bag and asked if I could see it. She started to move it around. I followed it with my eyes. She told me to see if I could touch it, I went to move my arm. That showed I was reacting to things. She told me to try again, and just as I got my hand near the ball she moved it. I remember thinking 'You swine!'.”

The journey continues...

For the families and individuals affected by ABI, the journey continues.

We hope this booklet has been helpful.

It is a document which has been created for people affected by an ABI and their carers. The format can be added to or changed. It is very much a “Work in Progress”.

We would like to say a big thank you to everybody who contributed their time, stories, and expertise to this project.

Everyone has a unique and different experience of ABI and if people feel they would like to share strategies which have benefited them, we would be happy to add them to The Journey.

At the end of the day, you are the experts.

Section 4: Our Journeys

- **Eddie's Story**
- **Douglas' Story**
- **Phil's Story**
- **Chris' Story**
- **Stephen's story**
- **Roseanne's Story**
- **Vincent's Story**
- **Pamela's Story**
- **Andy's Story**
- **Sandra's Story**

Eddie's Story

16 years ago I was working on an oil rig platform. I fell and suffered brain damage. When I got discharged from hospital I had lost my hearing and my balance was so bad I could not walk by myself. I had terrible moodswings and was constantly tired.

If Kit (my wife) had not done so much for me I would have become a vegetable. Kit has helped me a lot - I would not speak as I could not hear myself, and had total double vision. So instead of feeling sorry for myself, with Kit's help, I have become more confident in myself. So people who are suffering brain damage must try and better themselves. If I can do it, so can you.

Douglas' Story

My name is Douglas and I am 25 years old. When I was 18 months old, I cut my face on a shopping trolley and contracted cellulitis round about my left eye. The swelling caused some pressure on my brain, which left me with slight brain damage.

When I was 16, I was diagnosed with Chronic Myeloid Leukaemia and have been on chemotherapy of one sort or another ever since. These drugs seem to have made my brain damage worse.

I mainly have problems with organising, time management and knowing when to start and finish tasks. I have trouble keeping my belongings tidy and organised, keeping appointments and planning my day. I find that I am very slow at doing things, often without me realising - the time just seems to fly past and I find that I have done nothing. Fifty minutes can seem like ten to me! I am also very tired because of my medication which does not help matters any, something that came to light fully when I was at College. I have attended a Momentum Pathways Course, to try and train me for work, either full time or voluntary. I have worked voluntarily at 'Home From Home' and at Knowetop Farm, two local charities. I have had various degrees of success with this, and I am now a voluntary helper with CLIC Sargent at their residential house at Prestwick, working on week long placements with children and young people who have or have had cancer.

Just now I am on a 12 week Princes Trust Team Challenge Course, which helps to increase confidence and improves chances of getting into full time employment or further education. Through this I might be starting a college course this summer.

Phil's Story

Hi my name is Phil. I am 28 years old and I live with my mum and my pussycat, the brown fool. I am totally addicted to music. I enjoy socialising and making new friends. I do this by going out and not being a shy guy.

I suffer from a head injury which I'm trying to overcome and I think I'm about three quarters up the ladder.

I seem to be quite good at typing thus showing how good I can be at typing small paragraphs and stories. I feel like I can do most things that people think I'm incapable of.

I don't get to do the stuff I want to, like chat up the birds which I'm very good at apparently, but that doesn't make any difference to me as I'm a show-off.

Seven years ago I was seriously assaulted by young guys for no apparent reason just that I was on my own in a bad area, I sustained bad head injury and I was in a coma.

I sometimes feel like I've not woken up yet because I don't seem to get taken seriously by anybody all because they think I'm incapable of making my own decisions but I shall succeed in all. I am determined and I make the best of what I've got left of this soft grey matter in my head. I study most days and work at my I.T skills.

Chris' Story

It all began for me in 2000. The left hand side of my body started to shake. It went on for months and eventually became quite violent. I went to see my GP who agreed it was abnormal, and so I was sent for an MRI scan. They found a Colloid Cyst in my cerebral canal. I had to have brain surgery to remove it.

I was off work for quite a period of time, but I eventually returned although there were some conditions. I was quite happy to be back at work though and was doing well. I was looking forward to getting my driving license back. Then, one day as I was walking to work I fell whilst I was crossing the A82. At first people thought I'd been run over – there were cars swerving to avoid me!

I was taken by ambulance to Vale of Leven hospital – there was an A&E there then. The A&E Consultant noticed the scar from my cyst and asked if I had had brain surgery. My wife said yes. He was worried I might be bleeding in my brain.

It turned out that I was bleeding in my brain – I had a large frontal lobe Haematoma which meant I needed another operation. Whilst I was recovering from surgery, I contracted Meningitis and Hydrocephalus. Both can be fatal. To stop the build up of fluid in my brain, caused by the Hydrocephalus, I had another operation in give me what is called a Vascular Shunt. This drains the fluid away from my brain. Unfortunately my body rejected the first shunt, so I ended up back in surgery to get another one. This one worked well, but whilst I was recovering I again contracted a bad infection, this time it was MRSA. I got MRSA a second time after I was transferred back to my local hospital.

My wife was very concerned about me, and found website for a Brain Rehabilitation Unit. She got in touch with them and the Manager agreed to come out and assess me. At that time I couldn't do anything for myself, I couldn't walk, and I couldn't talk. I just sat there. The thing people need to know is that although I wasn't speaking or moving, my brain was still working. I had a brain injury but I wasn't stupid.

The Rehabilitation Unit agreed to take me. I say that's where my real recovery started. 'A little bit of healing', that's what I call it.

They gave me expert help. They were almost all female team and they were fabulous. I had a key worker, and a nurse. There was a physio team and a hydro pool. It was like being at a holiday camp, just without the bar! I can't drink anymore. The first part of the body that alcohol affects is the brain. So if you have a brain injury alcohol is not a good idea! It annoys me though. Having a drink was a big part of my life. I miss the social bits of it.

When I was ready to go home, I had to wait a bit because they were doing a lot of work in the house to make it safe for me. People wanted us to move because there were stairs in the house but my wife refused. She had brought photos of the house for me when I was in hospital so that they would help remind me what it was like. She wanted me to go home to the house I remembered and loved. So the physio team started teaching me to climb stairs again!

My wife had thought about giving up work to look after me when I got out of hospital, but a social worker advised her not to, otherwise we might 'be divorced in about 6 months'! I had a care package put in place, using agency staff. I didn't like it much and wasn't happy. The social work department said the only alternative was for my wife and me to become employers. That way we could use Direct Payments to get the support we needed. So we became employers. We employ three Personal Assistants who help me when my wife is at work. It is a system that works fabulous! We have been working this way for three years now, it wouldn't work for everyone but it does for us – we even have staff lunches and days out at Christmas!

I am a very busy person these days. I train people who are going to work with people who have an acquired brain injury.

A sense of humour is very important – I've never lost that!

Stephen's story

Some years ago bad guys were threatening a neighbour, I had come on the scene after football. After giving threats I did not move and they left. Weeks later I met these people and they asked me to talk to apologise, I went to their house and had a drink which I thought was to make a wrong right. Little did I know these drinks I was given were laced with valium tablets. As I fell into a semi-sleep I was smashed in the head with a hammer and a pick axe handle. As I fought for my life I remember five people being there when there was only supposed to be two. A girl who was in the room who I met at court told me she was the one who phoned the ambulance, but ran away as she was afraid of these people. I don't know how I managed but I kept getting up. Then all I remember is the ambulance man saying I looked fatally injured. Remember being taken to Vale of Leven Hospital, then Canniesburn then onto the head injury unit at the Southern General. Result; 13 skull fractures, broken cheekbone, right eye detached, loss of vision, bruising and bleeding of the brain. I was told by the doctors I would be there for some time, but amazed them by being stable enough to go home after two weeks.

Headaches can be really bad. Watching television or reading – it's like a firework exploding in front of your face or a long nagging headache which sometimes causes you to slur your words – making people think you are drunk, or when walking down the road you stagger,

unbalanced. This can lead to panic attacks where you just want to get home and hide away from the world.

Most important is knowing you are not alone. People do care and others have suffered too. Through my workers I have learnt how my illnesses affect my life.

I once went for the bus with one trainer and one sock on. I didn't notice until I got home. The result was a taxi home.

I have had to go for a paper to find out what day it is. Which is fine. The problems start when you go back an hour later for another one, because you've already forgotten you went earlier!

I can speak to people I have known all my life, and forget their name and their family. This does get upsetting.

Roseanne's Story

My first memory of my brain injury is having a sore head, family were concerned and took me to hospital. I was given a fan to cool me down and apparently I threw it across the room. I don't remember being moved to another hospital in Glasgow where I was in a coma with my eyes open.

One morning a Nurse said "Hello Roseanne "- I looked at her and she asked if I remembered her but I didn't although she had been my nurse for four days.

When I got home I felt very angry just wanted to throw the towel in. When my daughter came into bedroom she was worried and sent for my son, I wouldn't get out of bed. GP wanted to see me right away. I was curled up in a chair in his surgery. I was sent to Southern General Hospital right away, I was kept in but I don't know how long for.

When I got home I used to Hoover six or seven times a day, if I saw a dog hair I would have to Hoover again. I burned out two or three Hoovers.

My short term memory is poor, I find it difficult to remember faces. When meeting someone for the first time I would focus on what the person is wearing for instance my support workers it was hat, earrings, scarf .One doctor had great big feet so I focussed on his shoes.

I used to feel very depressed, didn't want to come out of my bedroom or eat. I was lucky that my family always made sure they were with me. I had many down days and nights in fact I didn't know day from night.

I had forgotten how to cook but now I can make mince and tatties and stewed sausages again.

I used to read a lot but now writing goes into a long blur. I can read a magazine better.

I have worked since I was 15 and was determined to get on with life.

I often used to get angry - I don't now because I use a mood diary where I record my feelings this has helped me more than anything and it is private.

Vincent's Story

Vincent is 19 years old.

Vincent had a brain tumour removed when he was ten years old. During the operation Vincent's pituitary gland was removed - this has left Vincent with an Acquired Brain Injury.

Medication prescribed at the time has led to Vincent experiencing a significant weight gain. To address this issue Vincent attends a slimming club with his befriender, he works hard using a points system to eat a balanced diet if not to lose weight at least to maintain existing weight.

Vincent deals on a daily basis with a number of health and mobility issues he needs a wheelchair for when he is out and about - he has his down days but generally doesn't dwell on things. Since coming to the ABI Team in 2006 the team have never ceased to be amazed at Vincent's enthusiasm for anything new.

He has been attending Anniesland College on a part time basis where he is currently doing a HNC Multimedia Course. Vincent is a very good artist and has done some wonderful oil paintings. Vincent has also recently joined a woodwork class at The West End Project in Dumbarton where he has become a popular member of the group not only because of his sense of humour but because of the help he is always willing to give to other people -he has produced work of an exceptionally high standard which is further evidence of skills we were not aware of.

Vincent has "Tunnel Vision" so his contribution to this booklet in terms of advice has come from the perspective of an individual with a visual impairment which is something many people with an ABI have.

Pamela's Story

Hi everyone my name is Pamela. I had a car accident In Feb 2006 in which I suffered a horrendous brain injury and it's been awful.

I've had to learn to walk and talk all over again and it's been frustrating for me especially the walking as it is taking a long time, I'm walking on my own in the house but out side some one is always with me and I can't wait to be able to go on my own I'm nearly there but it will take me a bit longer. My talking is coming along but I still get frustrated when I know what I want to say but can't get the words out.

You will not believe this but I will tell you my biggest bug bare is my WEIGHT and I am struggling to shift it, but it is starting to come off now as I am on my exercise bike 4 nights a week for 1 hour a night. It is difficult but it is worth it because I want to get better.

My friends are great because they are here all the time they keep me updated on all the gossip.

My eyesight is poor and I didn't think I was ever going to drive again but my eyesight is improving so I'll just have to wait and see if I can drive again.

At first it was difficult for me to read and write but it was hard it was worth it because that's what I want to do. Typing is helping me to read and write and be able to email my friends and go on the internet because that's what I want to do. Reading and writing is helping me

with my talking it has helped me a lot because before I couldn't talk, now I can talk a little bit better.

I have lost some of my skills and lots of my memories. It is frustrating for me because I can't remember anything at all before the accident, I can't remember anything! I worked as an intensive care nurse in Stobhill hospital. Being a nurse was everything I wanted to be and I will be again. I'd like to thank my mum and dad for all the help that they have given me.

My recovery has been slow but it has been worth it. My mum and dad have been brilliant and so supportive, so that is part of why I am better. A few weeks ago I got my saebostretch and it's brilliant because it allows me to use my fingers independently. I'll be able to use my arm independently within 6 months hopefully!

I am going to keep working until I am better. I am so glad that I am walking and talking better because that is what I want to do. I am going to keep practising until I am better.

I am going to keep going and hopefully I will be better in 6 months. I am looking forward to dancing again with all my friends and going to work as an intensive care nurse. I would like to help other people understand my recovery because I know what I want to say but I can't say it (its driving me insane) hopefully this will help other people.

Andy's Story

These are Andy's words ("But I missed out the f***ing!" – Andy)

I was 17 when I had my accident. I had been out with my pals doing nothing much. I was drunk, but not p****d!

I was heading home and crossed the road but I was two steps from the pavement when OW! I went up in the air. I'd been hit by a car. The story of what happened I've been told because I never woke up until I was in the Southern General Hospital. I was in a coma for two weeks. Turns out I nearly died lots of times. Everybody kept saying I was lucky to be here! I had to do lots of physio, pure agony, but then it got easier.

I was in a wheelchair for ages. The first time I saw my head it looked really sore, but I got used to it. I've had lots of operations since then. After hospital I went to a rehab unit to prepare me for leaving and going home. I hated it. I was angry a lot, but I liked some of the nurses.

I got my own flat but I didn't like the carers that came with it (at first). My Mum had done all my flat up along with my Aunts, Uncle and grandparents. I liked my flat apart from the 'red wall'. Got rid of that!

Life now is not what I expected. My health is poor and I want it back, along with my fitness. I will eventually. A couple of my pals still visit, but not all. I hate people repeating themselves to me, I call them parrots! My Mum keeps telling me I've missed out loads of things, but I can't remember! Turns out I had to learn to walk, talk, eat, dress, wash – everything. I was very angry a lot of the time but I never cried once, no way!

I miss my old life, kind of. I miss having a drink sometimes cos I can't drink anymore. I miss having a girlfriend. I would like a girlfriend. I always had plenty. I get tired easily and I hate it when people can't understand me just because I speak a bit faster than I used to.

Sometimes I get angry and I don't know why. I don't like noise or small children making a noise. I can lose the plot easily!

I swear a lot now, more than I ever did. I keep getting told not to but sometimes it's out before I know it!

I know I'm 'lucky' but sometimes I don't feel it.

Sandra's Story

I don't remember anything about the 14th December other than what I have been told.

I woke up with a sore stomach, my partner at the time phoned the doctor and she came about 12.00. She booked an ambulance for me. I was admitted into hospital; seemingly I was talking to a cousin of mine and went into cardiac arrest. The time was about 5.00pm.

I don't know how my family found out, talk about jungle drums, but they all got to the hospital. They were crying because the doctors said that I would not last the night. I had been declared clinically dead for 8 minutes and they said that it would take a miracle to survive. Normally they would work on you for 3 minutes then they would declare you dead but for some reason they worked on me for 8 minutes.

For the next 8 days I have no recollection of where I was or what I was doing. It was like being in a deep, dark void, there was just nothing. My mum said I was like something out of a scary movie, when my eyes opened at random they were completely blood shot. They had wondered if someone had beaten me up, but I had no idea what had happened.

As the days passed I gradually got better, much to the doctors' surprise. While I was in my coma I felt no pain at all, but when I came round I found the pain I was in unbearable. I had never felt pain like that in my life and I don't want to ever again.

I gradually got better. I did know all the people around me to everyone's surprise; they had imagined that I would have been left like a Zombie. Thankfully my brain was not affected; I had not lost anything from my past at all. They were worried about my speech, but when the pipe was removed from my neck I could make noises. When my next visitor came I said 'Hi'. My younger sister nearly dropped dead. However I did need speech therapy during my recovery.

After six months in the hospital I was transferred to a rehabilitation unit in Wishaw. That didn't do anything for me so I signed myself out after three months. I felt that I was getting nowhere. I had my flat to sell and I couldn't do that in there. So I decided that the best thing to do was to leave and get on with the rest of my life.

I have never looked back. I sold my flat and got a wee council house, dumped my partner as he did nothing for me. I have achieved quite a lot. I attended an advocacy course and to my surprise I actually passed it.

I think the secret is you can't let this destroy your life; you have to put on a brave face and be positive no matter what life throws at you. It could happen to anyone at any time

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