Spotlight report: The challenge of living with an acquired brain injury

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healthwatch
Rotherham

Contents

About us

Healthwatch Rotherham is the independent champion for people who use health and social care services in Rotherham. We are here to make sure that those running services put people at the heart of care.

Our sole purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf. We focus on ensuring that people's worries and concerns about current services are addressed and work to get services right for the future.

Introduction

Acquired Brain Injury (ABI) is an injury caused to the brain after birth. There are many possible causes of ABI including:

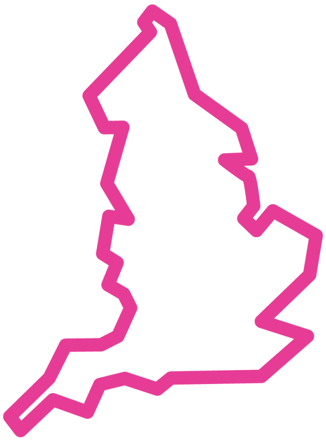
- **Trauma** (such as falls or road accidents)
- **Stroke**
- **Brain aneurysm** (a blister like swelling in the wall of a weakened blood vessel in the brain)
- Infections (such as **Meningitis** or **Encephalitis**)
- **Brain haemorrhage** (bleeding in, or around the brain)
- **Brain tumours**
- **Carbon monoxide poisoning**
- **Hydrocephalus** (a buildup of fluid inside the skull)

It is the **leading cause of death and disability** for people aged under 40 in the UK. The latest data provided by **Headway** shows that In the UK in 2023-2024:

- **335,409** people were admitted to hospital with an ABI, which equates to **1 admission every 90 seconds**.

In Rotherham in 2019-2020, the Headway data shows:

- **1,568** people were admitted to hospital with an ABI, of which
- **714** were women
- **855** were men



This is in line with UK wide statistics that show that **males are 1.5 times more likely** to be admitted for a head injury.

Whilst some individuals fully recover, many face challenges that can affect all areas of their life. These effects can be wide ranging, affecting individuals to a greater or lesser extent, and may be temporary or long term. They are often 'hidden' as they are not always obvious to others. They can be difficult to adjust to and some people feel as though they're a different person after their injury.

More than **1.3 million people** in the UK are thought to be living with the long term effects of ABI, which equates to around **1 family in every 300**.

Headway groups the **potential effects** into 3 groups:

Physical effects such as fatigue, impaired mobility, weakness/paralysis and speech problems.

Cognitive effects such as memory problems, impaired reasoning and reduced problem solving.

Emotional/behavioural effects such as personality changes, depression, anxiety and anger.

Unfortunately, access to specialist support remains limited, and many people with an ABI struggle to find the help they need after their initial medical treatment ends.

This report has been produced from insights provided through an engagement event with Headway Rotherham and an in-depth case study interview. It highlights the key issues we were told by individuals living with ABI faced in Rotherham, and details of support services available.

People don't understand

People told us that they felt that many people, including healthcare professionals, don't understand ABI. They told us that many professionals appeared to follow textbooks, rather than listening and using those with lived experience to better understand the condition.

> ***People and even doctors are not educated about brain injury and individuals' needs.***

Additionally, they felt there was an emphasis by healthcare staff on trying to fix what they see as problems, rather than listening to what the patient's needs actually are.

> ***You would think people studying brain injury would be more empathetic; they just want to fix us.***

People described how they are not listened to by those in healthcare services. Apart from the obvious frustrations this causes, listening is so important because the needs of those with ABI vary considerably. Treating everyone the same not only fails to meet the needs of the individual, but those affected also told us it feels discriminatory too.

> ***Not everyone's needs are the same.***

We heard how people felt that there is a general lack of understanding throughout society about ABI and the impact it has. Those we spoke to felt that education was the key to improving this, and suggested that young people could be taught about it in schools and awareness sessions could be run in the community.

A recent report commissioned by the All-Party Parliamentary Group on Acquired Brain Injury and charity The United Kingdom Acquired Brain Injury Forum (UKABIF), argues that brain injury should have the same focus on public health prevention, treatment and rehabilitation, as other major conditions such as cancer and coronary heart disease. If this recommendation was taken on board, awareness of ABI would be raised significantly.

Mental health problems are dismissed

Mental health often overlaps with ABI as both occur due to a disorder in the brain. This can cause problems with diagnosis and access to treatment, with some professionals confusing them as the same thing.

People told us that healthcare services are not addressing the mental health side effects of ABI. They feel:

- ignored
- misunderstood
- dismissed by services.

We heard how some were told they didn't have a mental health problem, they just have to come to terms with their ABI. Some felt they were denied access to mental health services because of their ABI.

> ***They shut us out like a door slammed in our face.***

Problems getting appointments and going back and forth, having to repeat the same information, also caused issues to those we spoke to.

> ***Each time it is as if I need to start all over again.***

People with ABI are far more likely to experience **mental health problems** such as:

✔**Depression** - coping with the potentially enormous changes to lifestyle or ability, along with changes in brain function, can trigger symptoms of depression

✔**Anxiety** - problems processing information, worries about recovery and adjusting to a new life are common and can all add to feelings of anxiousness

✔**Grief and loss** - for the life before ABI and abilities that have been lost

✔**Mood swings** - irritability and struggling to control emotions are due to the neurological changes caused by ABI

✔**Self esteem problems** - changes in abilities, independence and even physical appearance can all affect individuals self esteem and self worth

Without proper care, these mental health problems can worsen, making recovery even harder. There are many **coping strategies** that can support mental health after an ABI including:

- counselling and psychotherapy
- support groups
- mindfulness and relaxation techniques
- rehabilitation programmes

Communication needs to be better

We heard how communication from health services was often confusing and difficult to understand. We were told that important letters were too technical, inconsistent, or lacked key information, making it hard to understand their care.

> ***Letters from the GP are impossible to understand.***

The **Accessible Information Standard** (AIS) is a legal requirement to make sure that people who have a disability, impairment or sensory loss get information that they can access and understand, along with any communication support that they need from health and care services. However, we still hear how some healthcare services don't follow this. Without clear communication, patients struggle to understand their treatment and support options which can lead to missed care and unnecessary confusion.

Health passports and/or communication cards can also help individuals experiencing communication difficulties. These aids allow individuals to explain the effects of their brain injury and request the support that they need. This can help health care staff understand each individual's needs and ensure that they get the help that specifically works for them. They can also increase individuals' confidence when dealing with health care staff and give them a sense of control.

However, people told us that there was no specific Health passport for ABI, although the NHS was supposed to put one in place. We also heard health passports and/or communication cards are not always offered or explained, leaving people unaware that they can ask for one.

> ***If they do offer them, you have to know about it.***

Although there is not a specific health passport for ABI, NHS England has a **Health & Care passport** template that can be used by anyone with communication difficulties. The website also contains more information on what a health passport is for and how to complete it.

Headway also offers a free, personalised **brain injury identity card** which allows the card holder to explain the effects of their brain injury and request any support they may need.

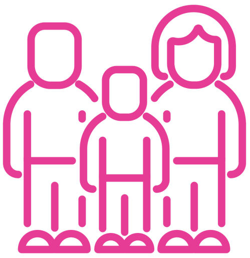
We were told that health care staff didn't always consider the effect of ABI on the individual during appointments, and these communication aids can help ensure that people get appropriate support.

The social impact can be huge

Social isolation after an ABI is common. It can be caused by many different factors including others being unable to accept the changes in the person, or due to difficulties being in certain environments or physical challenges. Emotional and behavioural changes can make keeping friendships difficult, especially as ABI can result in a lack of empathy and irritability.

Over 70% of ABI survivors feel that people in their lives don't understand the effects of their condition. The social impact of this means individuals may struggle to:

- build and maintain relationships
- return to work or get a new job
- take part in social events
- get out and about



Research shows that only around **40% of people** with moderate/severe ABI return to work after 2 years. Financial struggles make it even harder for individuals with ABI to fully engage in society and can make social isolation even greater.

Social isolation and exclusion can additionally make mental health issues worse. Those without strong support networks will struggle further to access practical help to overcome the problems they are facing.

The impact of social exclusion can be extreme. Research shows that **up to 60% of prisoners** have a history of traumatic brain injury, with some studies identifying even higher rates among female prisoners. Analytical evidence has also shown that **over 50% of those experiencing homelessness** have a history of traumatic brain injury.

We heard how people felt that they were discriminated against throughout society, both by organisations and individuals, as the result of their ABI.

> ***I'm fighting to be seen as 'normal'.***

> ***They need to change. They need to change their attitude.***

Breakdowns in relationships within families, friendship groups and employers can often be put down to a lack of understanding about ABI and challenges of managing the effect of brain injury. Without addressing these issues, individuals with an ABI will continue to face discrimination and social isolation.

Strain on families and carers

ABI doesn't just affect individuals - it reshapes the lives of their loved ones. Family members often become full-time carers but without the guidance or support they need.

Amongst other things, carers must manage:

- complex behavioural changes
- mood changes
- emotional needs at home

Most carers receive no training or emotional support to handle these challenges. When family members aren't given the right support, they can feel isolated and overwhelmed, which can make the situation even harder for both the carer and the person with ABI.

This was highlighted in a story we heard from one carer in Rotherham. She told us how she had to go to hospital by ambulance one day when she was really poorly. Because she cares for husband, she checked before they sent the ambulance that he could go with her. She was told that it would be fine and that they would give him a blanket and a book and put him in a corner. This made her feel uncomfortable, but when they arrived at the hospital, the situation got worse. Despite saying that he could be there, they then told her he couldn't. They both had to go home, even though she was extremely ill, as there was no one to look after him apart from her.

She told us:

> ***They were so rude and uneducated***

> ***They said to us there is nothing that they can do***

Case study: Geoff's story

*name changed

We spoke to Geoff* about how his brain injury changed his life and the struggles he has faced. This is his story.

> ***I was an engineer in a great job and a few years ago, my life changed forever.***

I've had several strokes, although some opinions differ on that. I saw a neurologist regularly after my first stroke. She was direct and straight talking and I understood her. She was in contact with me every 3 months which is now 6 months, but that's fine.

> ***She was great, she was the first person that said to me "I care" and that meant a lot to hear.***

One of my strokes was on New Years Eve and happened as I was in the shower. My partner at the time found me and called the ambulance which arrived after 2 hours. We were on holiday at the time and I was taken to a local hospital that I knew nothing about. I was left in A&E for around 19 hours. I asked someone if I could have a drink and they pointed to the vending machines, which just had tea and coffee in them [but] I have a milk allergy so the options were slim.

I eventually saw a doctor who said I looked fine and told me to go home with no thorough checks/assessments done. I told them I didn't want to go home as I wasn't well. At this point I'd gone 30 hours without food or a drink and no offer of anything. I was then offered a CT scan which showed I'd had a stroke but there appeared to be no damage to my brain. I was concerned as things had been missed in the past and questioned whether this was right...I asked the team to check my medical file for details of previous health issues and my strokes but they said that they couldn't access my notes due to being out of the area.

I thought the NHS system was one system where all healthcare professionals could see all my notes on my file. When I returned home, I had to get my notes from my practice portal and email them to the hospital to aid my treatment as they didn't know what previous damage I had suffered to my brain due to the different software operating systems.

I have a severe milk allergy which should be on my health records, however once after one of my strokes, I had to have a reflux/swallow test. The nurse attempted to give me yogurt to swallow. I tried hard to communicate with her to tell her I had a severe dairy allergy but she kept trying to get the yogurt down me and I couldn't speak to tell her. She gave up in the end.

> ***When I next saw her, I told her she could have killed me.***

The impact of having an anaphylactic shock is terrible on the rest of my health. My arthritis is hugely affected and for days I can't move my hands properly, my hands are almost turned inwards, the rest of my body hurts and I feel like a very old man.

The impact on my life:

The several strokes I've had have left me with a visual impairment - I now have Charles Bonnet Syndrome but also my vision is pixelated so I have to wear special glasses. I also have terrible headaches and at the end of the day I'm exhausted as my brain is working so hard to make sense of everything. I have to use a stick, people stare at me, I can bump into things and people "tut" at me. It's hard.

I also lost my partner through my illnesses. Because the only way I can cope nowadays is by joking about things, it changed our relationship; she couldn't cope with my way of handling things, and we eventually split up and that's been really hard. I did ask for some support for her and her mental health but this was declined, there's not enough support for partners and family members.

My mental health was really bad following the strokes and I did attempt to take my own life. I'm now left with scars on my chest from this.

> ***In 3 months, I lost my job, my sight, my partner, my home and I couldn't do the hobbies that I had always loved.***

I've learnt to cope with my life now and I laugh and make light of my situation, it's how I cope. This doesn't suit everyone I come into contact with and some healthcare professionals don't find it funny and some then don't believe what I'm telling them, but this is me now.

What needs to change?

- care should be patient centred - too many blanket approaches and policies that you can't move on!
- healthcare professionals need to take time and listen
- people's health notes should be read carefully and thoroughly
- everyone working in health care should have "allergy" training, not just doctors and nurses, but kitchen staff, cleaners etc.

What can be done to help?

1) Improved education and awareness

- More education is needed to improve awareness of ABI throughout society, particularly in schools and workplaces, to help people understand its effects and reduce stigma.

2) Training for all healthcare professionals

- Healthcare professionals must receive training to better understand the long-term impact of ABI. Training should also provide knowledge on where to signpost individuals to ensure continued support.

3) Clear and accessible information

- Information about treatment, appointments, and support services must be clear, provided in accessible formats such as easy-read or audio, and tailored to the needs of each individual.

4) Long-term mental health support

- Mental health support for ABI survivors should not be an afterthought - it is essential to long-term recovery.

5) Coordinated discharge planning

- Discharge from hospital must be accompanied by a realistic, personalised plan. This plan should cover rehabilitation, benefits, housing, employment, and emotional support to help individuals rejoin daily life.

6) Support for families and carers

- Providing practical training, help and emotional support is essential for carers to manage the challenges of looking after someone with ABI.

7) Individualised care approaches

- Services must provide care tailored to the individual needs of each person, taking into account not only their cognitive, physical and emotional needs, but also considering other aspects such as ethnicity, gender, financial position, and sexual orientation.

ABI support services

Local support services

- **Headway Rotherham**
  Telephone: 01709 524100
  Email: info@headwayrotherham.org.uk
  Address: Victoria Park Hall Rosehill, Rawmarsh, Rotherham, S62 7HJ

  Offers social events, carer/family support, telephone support, information and advocacy for individuals with ABI and their families.

- **Altered Brains**
  Email: info@alteredbrains.org

  A local charity based in Rotherham who provide community activities, social events and support for those with ABI. They also work with families and carers to help them better understand and cope with the impact of brain injury.

National support services

- **Brain Injury Group**
  Telephone: 03300 569 510
  Email: enquiries@braininjurygroup.co.uk

  Provides in house support and signposting around financial, legal, medical and emotional matters. They can also provide help around returning to education or employment and care and rehabilitation.

- **Headway**
  Telephone: 0808 8002244

  Provides vital support and information services including freephone helpline, useful information and links on their website, a brain injury identity card, a directory or approved residential homes/rehab units/respite facilities specialising in ABI and also an emergency fund to assist people dealing with financial implications after an ABI.

Local residential/at home/community services

- **Ariya neurocare**
  Telephone: 07891 429690
  Email: lucy@ariya.org.uk

  Provides residential and at home/community based services for individuals with an ABI.

- **Caremark Rotherham**
  Telephone: 01709 789340
  Email: rotherham@caremark.co.uk
  Address: Magna Business Centre, Magna Way, Templeborough, Rotherham, S60 1FE

  Supports with brain injury care in Rotherham, improving rehabilitation after discharge. Provides support at home with medication and rehabilitation programmes as well as out in the community with daily living tasks, emotional, recreational and social preferences.

Mental Health support

There are many mental health support services available, although they are not specific to ABI. A full list of services can be found in our **Mental health directory**.

Help returning to employment

Headway has lots of useful information on **returning to work after an ABI**.

- **Rotherham Council employment support service** – helps individuals who are unemployed to access training and employment opportunities.
- **Access to Work** – can help you get or stay in work if you have a physical or mental health condition or disability.

Driving and transport

- **Driving mobility** (William Merritt Centre Sheffield) - provides driving assessments after an ABI if you are seeking confirmation that you are still able to drive safely.
- **Travel South Yorkshire** - find out if you are entitled to free travel under the disabled travel pass.
- **Blue badge parking permits** - find out if you are entitled to a Blue badge to help with parking

Support for carers

Rotherham council have put together an extensive directory detailing support services available for carers in Rotherham. All information can be found in the **Carers directory**.

Other support

Citizens Advice Rotherham

Telephone: 0808 278 7911 (General advice), 01709 515 680 (Debt advice)
Address: 2 Upper Millgate, Rotherham, S60 1PF

Citizens Advice Rotherham can provide information, help and support to help you claim the benefits you may be entitled to, assist with employment issues or help with debt.

Absolute Advocacy

Telephone: 01709 794294
Email: cst.referrals@cloverleaf-advocacy.co.uk

The independent advocacy service for Rotherham. They can help you deal with any complaints you may have over your healthcare provision.

Acknowledgments

We would like to thank all those who took the time to speak to us and to Headway Rotherham for welcoming us to their sessions. Special thanks also goes to Geoff for sharing his experiences and talking about the challenges he faces. Lastly, thank you to our Sheffield University placement student, Will, for the research and initial report that he did on this topic that has helped in the writing of this report.

Committed to quality

We are committed to the quality of our information. Every three years we perform an in depth audit so that we can be certain of this.