

Action for Brain injury Week 2025

On a good day

An exploration into the fluctuating nature and impact of acquired brain injury.

This report contains the results of a survey launched for Headway – the brain injury association’s Action for Brain Injury Week 2025 campaign
On a good day.

A short-read version of this report is available on Headway’s website at
www.headway.org.uk/on-a-good-day.



On a good day

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BE PATIENT
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1. Introduction

An acquired brain injury (ABI) is a life-changing condition.

Every year in the UK, a person is admitted to hospital with a brain injury every 90 seconds. A brain injury can be caused by accidents, illnesses or medical complications, affecting independence, socialising, employment, relationships and mental health.

No two brain injury survivors have the exact same experience. And for many survivors, no two days are the same either.

An ABI is a fluctuating condition. This means that its effects can be more problematic on some days than on others. Many survivors describe having ‘good days’ and ‘bad days’.

Furthermore, the wide-reaching impact of brain injury means that families, partners and those closely involved in caring for the survivor are also often impacted by the fluctuating nature of this condition.

Our Action for Brain Injury Week 2025 campaign, *On a good day*, has explored the fluctuating nature of brain injury and aims to improve society’s understanding of how it can best support both survivors and carers with this.

As part of the campaign, we launched a set of surveys to explore the fluctuating nature of brain injury.

We have written this report to share the voices of those who contributed and are impacted by this often misunderstood, fluctuating and ultimately life-changing disability.

We would like to thank all of the brain injury survivors and carers who completed our surveys to help us better understand how brain injury can fluctuate. Thanks as well to all independent Headway charities and volunteer-led branches, and professionals who helped to circulate the survey to their service users, clients and patients. We would like to extend particular thanks to the survivors and carers who granted permission for us to use their quotes within this report.

For more information about *On a good day*, visit www.headway.org.uk/on-a-good-day.

For questions and enquiries about the survey and this report, please contact our Publications and Research Manager at publications@headway.org.uk.

For press enquiries, please contact media.office@headway.org.uk.

2. Key findings

- Fatigue, memory, anxiety and concentration are reported to be the most commonly fluctuating effects of brain injury.
- 80% of survivors and 84% of carers feel low in mood on a survivor’s bad day. Conversely, 80% of survivors and 91% of carers feel good on a survivor’s good day.



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- 64% of survivors and 53% of carers lose their tempers more easily on a survivor's bad day.
- 86% of survivors and 78% of carers find working or studying difficult on a survivor's bad day. Conversely, 62% of survivors and 78% of carers find work or studying easier on a survivor's good day.
- Around three quarters of survivors felt their relationships with a partner and others are negatively affected on a bad day. Conversely, two thirds felt that their relationship with a partner is good on a good day, although even on a good day, 27% still felt the relationship was neither good nor bad.
- Half of carers felt that their relationship with the survivor and others are negatively affected on a survivor's bad day. Conversely, 85% felt that their relationship was good on a survivor's good day.
- Around three quarters of survivors find it difficult to do things independently on a bad day. However, even on a good day, around a tenth of survivors struggle to do things independently.
- Two thirds of carers find it difficult to do things independently when the survivor has a bad day. Conversely, just over three quarters can do things independently when the survivor has a good day.
- Factors that contributed to a good day included improved effects of brain injury, having a healthy lifestyle, routine and having control, the occurrence of positive events and socialising.
- Conversely, factors that contributed to a bad day included struggling with the effects of brain injury (particularly fatigue), social pressures, changes in routine and lifestyle factors.
- For many survivors, a good day is not necessarily 'good' but simply not as bad as a bad day. Effects of brain injury can still be problematic on good days, with some survivors and carers worrying even on good days that things can change any moment for them. Furthermore, some survivors reported that good days were often directly followed by bad days, due to the 'boom-bust' cycle of attempting to do too much on good days and consequently struggling the next, causing a bad day.

3. What did we do?

We created and launched two surveys to be completed by brain injury survivors and carers.

We asked questions relating to the types of brain injury effects that fluctuate, the impact of good and bad days, factors that underlie good and bad days, and things that help on bad days.

Our surveys were promoted through our website and online communities. Our network of independent charities and volunteer-led branches helped with promoting the survey. Paper copies of the survey were made available for people who were unable to complete it online.

The survey was open between March – April 2025.

4. Who completed the survey?

The surveys were completed by a total of 1,203 people affected by brain injury. Of these, 957 were brain injury survivors and 246 were carers.

4.1. Brain injury survivors

Survivors of all ages completed our survey, with the majority being 55-64 years old (37.84%). 18.69% were above the age of 65. Only 1.24% of our respondents were under the age of 24.

42.76% of survivors were male, 56.56% were female, 0.11% were non-binary and 0.57% were other or preferred not to say.

Most survivors came from the UK, with the majority living in England (77.19%). 2.25% of survivors were from outside of the UK.

Just over a third of survivors had sustained their injury over 10 years ago (34.61%). Around a quarter had sustained their injury 5 – 10 years ago (24.49%) and 2 – 5 years ago (24.27%). Only 1.46% of survivors had sustained their injury fewer than 6 months ago.

4.2. Carers

Most carers were above the age of 45 years old (86.22%), with 36.89% of these being above the age of 65 years old. No carers were below the age of 18 years old, while 13.78% were between the ages of 18 and 45 years old.

Only 19.56% of carers were male, while the vast majority 80% were female. 0.44% preferred not to say.

Most carers came from the UK, with the majority living in England (84%). There were no carers from outside of the UK.

Carers were mostly supporting survivors who had sustained their injury over 10 years ago (36.89%). A quarter of carers were supporting survivors who had sustained their injury between 2 – 5 years ago (25.33%). In around a tenth of cases, the injury had been sustained less than a year ago (10.22%).

5. What did we find?

We asked questions relating to the types of brain injury effects that fluctuate, the impact of good and bad days, factors that underlie good and bad days, and things that help on bad days.

The remainder of this section discusses the key findings from our survey.

5.1. Fluctuating effects of brain injury

Of the effects of brain injury that we asked about, all were reported to be experienced 'sometimes' by at least 5% of survivors, suggesting that all effects of brain injury can fluctuate.

We asked survivors and carers to tell us which of the effects they feel fluctuate the most. Both survivors and carers ranked fatigue as being the most commonly fluctuating effect, followed by memory problems. Survivors then ranked anxiety as being the next most commonly fluctuating effect, while carers ranked problems with concentration in this place.

5.2. Impact of fluctuating effects

We asked survivors and carers about the impact of having good and bad days due to the fluctuating nature of brain injury, with a good day being when their effects are less problematic and a bad day being when they were more problematic.

We found that many different aspects of life are negatively affected by the survivor having a bad day, while these same aspects of life are positively affected on a good day. These aspects included mood, engaging in work or studies, socialising, relationships, independence and enjoyment of hobbies.

5.2.1. Mood

The majority of survivors reported that they felt good on a good day (80.35%) and low in mood on a bad day (80.31%). The majority of carers also reported this pattern, with 91.2% feeling good on a survivor's good day and 84.61% feeling low in mood on a survivor's bad day.

Some survivors and carers also reported losing their temper more easily on a day when the effects were more problematic, with 64.56% of survivors and 53.09% of carers agreeing with this statement. Around a quarter of carers (24.75%) and 17.53% disagreed with this.

5.2.2. Engaging in work or studies

Of the survivors who engaged in work or studies, the vast majority (86.93%) found this harder to do on bad days. 62.03% found this easier to do on good days, although just under a quarter neither agreed nor disagreed about finding this easier on good days (24.05%), suggesting that even on good days, work can still be challenging after brain injury.

Over three-quarters of carers (78.09%) also found it harder to engage in work or studies on the survivor's bad days. More carers found this easier to do on good days than survivors (78.13%), although 21.35% of carers neither agreed nor disagreed about finding this easier on a survivor's good days, suggesting that carers can still struggle at work or when studying even when the survivor is having a good day.

5.2.3. Socialising

The majority of survivors (81.68%) found socialising difficult on a bad day, while around two thirds (67.52%) found it easier on a good day. 15% disagreed that they found this easier even on good days, while 17.39% neither agreed nor disagreed, suggesting that even on good days, survivors can struggle with socialising after their injury.

Over three quarters of carers (79.38%) found socialising difficult on a bad day, but easier on a good day (78.12%). However, 17.19% of carers still neither agreed nor disagreed with finding socialising easier on the survivor's good days, suggesting that even on a survivor's good days, carers can struggle with socialising.

5.2.4. Relationships

Of the survivors who had a partner or spouse, around three quarters (72.63%) felt their relationship was negatively affected on a bad day. While two thirds (66.02%) felt the relationship is good on a good day, 27.35% still neither agreed nor disagreed that

it was better on a good day, suggesting that even on a good day, relationships can be impacted after injury.

Around three quarters of survivors (73.15%) felt that other personal relationships, such as those with other relatives, friends or colleagues, were also negatively affected on a bad day. 17.68% of survivors neither agreed nor disagreed with this. 70.71% of survivors agreed that their relationships with others was good on a good day, although 21.86% neither agreed nor disagreed with this.

Around half of the carers (51.58%) felt that their relationship with the survivor was bad when the survivor has a bad day. 20% neither agreed nor disagreed, while 28% disagreed that the survivor having a bad day had a negative impact on the relationship. The majority of carers (85.72%) felt that their relationship with the survivor was good on good days, although 11.46% neither agreed nor disagreed with this.

Half of the carers (50.3%) felt that their other personal relationships were bad on a survivor's bad day. 22.11% neither agreed nor disagreed with this. Just over a quarter of carers (27.89%) disagreed with this. 71.88% of carers felt that their relationship with others was good on a survivor's good day, although a quarter (25%) neither agreed nor disagreed with this.

5.2.5. Independence

Just under three quarters of survivors (71.67%) found it difficult to do things independently on a bad day. 23.11% neither agreed nor disagreed with this.

65.41% of survivors agreed that they can do things independently on a good day. However, 11.08% of survivors disagreed with this, suggesting that even on good days around a tenth of survivors struggle with doing things independently.

Two thirds of carers (66.66%) found it difficult to do things independently when the survivor has a bad day. 78.64% of carers found they can do things independently when the survivor has a good day.

5.2.6. Enjoyment of hobbies

The majority of survivors (80.34%) lost enjoyment of their hobbies on a bad day. 71.66% of survivors were able to enjoy their hobbies on a good day. Just under a quarter of survivors neither agreed or disagreed about being able to enjoy their hobbies on a good day, suggesting that even on good days survivors still sometimes are not able to enjoy hobbies.

Just under three quarters (73.06%) of carers also lost enjoyment of hobbies when the survivor had a bad day. 77.61% of carers agreed that they are able to enjoy hobbies when the survivor had a good day. 15.63% of carers neither agreed nor disagreed, suggesting that enjoyment of hobbies among carers is even impacted on a survivor's good days.

5.3. Feelings on good and bad days

We asked survivors and carers to use their own words to describe how they felt on good and bad days.

5.3.1. Feelings on a good day

For survivors, overarching themes for a good day included feeling happy, independent, positive, able, reassured, accomplished, hopeful for the future, social and like their pre-injury self.

"I feel mentally energized, I'm able to focus whilst working. I also feel more social and am more keen to reply to friends' messages for example."

"Very happy laughing and joking with the family talking."

"Feel as though some days I am the person I used to be."

"Clear headed, full of energy, vitality and optimism and can get more done on a good day than a month of bad days."

"I am energetic enough to perform all my household tasks and/or go for a long walk in the countryside. I feel almost like my "old" self."

"Lighter, freer and more in control. More chatty, too chatty. Accomplished for completing or even starting tasks like dishes, made the bed, change to day clothes. Nicer to myself and maybe more accepting of the brain injury."

However, some survivors explained that even on good days, they have to be cautious about overexerting themselves.

"More like the old me. I feel I can achieve something worthwhile but I tend to overdo things if I'm not careful to catch up on the things I have been unable to do on the bad days."

"On a very rare 'good day' I feel as if I can think more clearly and can achieve something. It's a fantastic feeling. 'Good days' come out of the blue. I always take advantage of them, even though I accept that there will be a price to pay,

and I'm going to have to hibernate for a day or few days after."

"A sense of relief that they still come around but concern for how long they will last."

"I have confidence in my career skills - writing and communicating. I can make people laugh. I want to get lots done to make the most of what I know will be a limited window of opportunity."

Others described the positivity of a good day giving a sense of euphoria.

"Invincible and brave with solid determination."

"Euphoria, blessed almost hyper, making the most of everything, it's like the fairy's waved a magic wand, those days are rare but feel it's my fault for down days."

"It feels magical. I feel invincible (for me). It feels wonderful to do basic things without feeling exhausted. But I know I have to be careful and limit what I do. But I prefer to do limited things rather than nothing. So I'm grateful for the reprieve."

"Elation at being alive and adoring the support given to me by my wife."

"Happy, bouncy, excited, can see things sharply. Take pleasure in small things. Enjoy my hobbies (gym, running, seeing friends). Feel happy like I don't want the day to end. Grateful to be here."

Carers were also asked about how they personally felt on a survivor's good day. Many carers echoed the feelings described by survivors above, such as feeling happy, positive, hopeful for the future, accomplished and like their pre-injury self.

"Happy to be normal again."

"Hopeful that things are 'going in the right direction'. Happy that we can be normal for a while."

"Happy, loving, blessed, confident about our future."

"Good, I can do the usual around the house, don't have to keep my mobile on hand in case they need me, can go for a coffee, then shop without worrying the brain injured soul is beside themselves because I'm not there."

"Proud; more at peace; more optimistic."

Additionally, many carers specifically described the joy and relief they felt on behalf of the survivor on their good days.

“I feel good, happy and enjoy seeing him smile and happy on his good days.”

“More positive that my brother can still enjoy some aspects of life.”

“I feel pleased that the survivor is still able to have some enjoyment from life and not everything is against them.”

“Even a good day is a long, long way from our previous life, but it makes me happier when I feel he is content.”

As with survivors, many carers explained that even on a good day they had anxieties around things changing for the survivor at any moment.

“It’s a little more relaxing on a good day, but that seed of doubt is always there waiting for the switch to flick and everything to change in an instant. So it doesn’t matter how good you think a good day is it can change in the blink of an eye!!”

“I feel like we have our old life back where we didn’t have to worry about all of this. I am happy, carefree and elated on the good days but also apprehensive as I wait for the inevitable... the bad days again.”

“Good but knowing that a bad day is coming so we have to do gentle things and not too much in a day. She says that she feels like a battery and the level drops dramatically if she gets over stimulated.”

“A bad day always follows a good day.”

5.3.2. Feelings on a bad day

For survivors, overarching themes for feelings on a bad day included feeling depressed, socially isolated and frustrated.

“Feeling cast adrift, as if I’m a ghost in society.”

“Overwhelmed, hiding and distressed/ embarrassed.”

“Short tempered, stressed, snappy, unable to prioritise tasks, overwhelmed.”

“I feel detached from the world and emotionless. I am not able to socialise even with my husband. So it’s very isolating. Everything is a struggle even thinking. Everything seems impossible even how to get dressed it’s easier to have a pyjama day. Yet I don’t like doing nothing so I try to keep going but achieve very little. So I suppose I feel agitated by the desire to want to do something.”

Some survivors described the specific effects of brain injury that contributed to making a day bad, with many survivors specifically mentioning fatigue as a key issue.

"Have no energy or inclination to do anything. Body feels heavy and head tight."

"Mentally and physically drained, like somebody pulled the plug out. No motivation, empty, nothing left to give."

"Exhausted! Overwhelmed. Like I want to sit in a room on my own. On edge."

"Shattered after doing simple tasks and overwhelmed by everything going on around me."

Some survivors specifically described how they would try to hide how they feel on bad days to protect their loved ones.

"I feel worthless and unwilling to burden my family/friends with how I am feeling."

"I feel everything, and seem unable to control it - anger, irritation, anxiety, which can then interact with the headaches. I think it makes me a very unpleasant person to be around, so on those days, I tend to "hide" in my office. For my sake and everyone else's!"

For carers, overarching themes for feelings on a survivor's bad day were similar to those of survivors. Carers also described experiencing depression, social isolation and frustration on the survivor's bad days.

"If I look after my mum so my dad can have a break I feel exhausted frustrated annoyed and just want to go sleep and start a fresh the next day I am short with anyone and everyone as my mum has driven me insane."

"It's really sad and difficult. The bad days impact negatively on me and our two children."

"Bad days are very trying, walking on egg shells is a common phrase used. But it can be a nightmare depending how bad the bad day is!!"

"Hopeless; frustrated; lonely and isolated as if I am in this bubble on my own."

Some carers specifically explained that being unable to help the survivor more than they wanted to on bad days contributed to their feelings of sadness.

"I feel guilty that I am only able to help the survivor to a certain degree due to my own family and work commitments."

"I feel broken because I want to help but the help is pushed away."

"Pulled in multiple directions. I feel like I am unable to juggle all the demands when he needs more support, I feel guilty that I'm not able to do anything fully, I can't give him everything he needs, I can't commit completely to work, I can't look after our animals as well as I should, I can't give attention to friends and family - you just feel you're failing whatever you do."

"Desperately sorry and frustrated that I cannot do anything to improve the survivor's condition."

Some carers described the emotional impact of having the survivor's challenging behaviour directed towards them on bad days.

"I find it difficult when I'm accused of being cranky, when in my opinion I'm being snapped at and it seems I can't say/do anything right, everything is my fault. So I then just stay quiet and then am accused of being moody."

"A bad day is very stressful. I walk on egg shells. Anything I say to try and pacify is met with sarcastic aggression and swearing. I have to walk away or leave the house as it's so traumatising."

5.4. Underlying factors to good days

We asked survivors and carers to tell us what causes a survivor to have good days. While some were unsure, others were able to describe a range of factors, with both survivors and carers reporting the same overarching themes.

5.4.1. Improved effects of brain injury

For many, a good day was when the various effects of brain injury were less problematic.

"When I find I am settled and moods stable."

"When I am able to communicate without it being too difficult."

"Lack of anxiety/panic attacks."

"I think things go better when my head feels clearer without the constant buzzing."

"Headache not so bad, they feel like they have achieved something."

Reduced fatigue was once again specifically described by many as being associated with a good day. Many survivors and carers further described the fatigue-combating strategies they implemented to facilitate a day good, such as pacing activities and resting.



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“If I have rested loads and managed to get my fatigue under a little bit of control.”

“Being well rested and using fatigue management techniques that I learned from the occupational therapist.”

“Pacing myself. Not just during the day, but in the days leading up a good day. Lots of rest.”

“When he is well rested and isn’t trying to do too much. Well hydrated and eating well.”

Many survivors and carers specifically mentioned the positive impact of having had a good night’s sleep in combating fatigue.

“When I have had a good night’s sleep, that contributes to having a good day and my head feels clearer.”

“If I am able to sleep well the night before and don’t feel tired when I wake, that makes it a good day, if I’m not in pain, that makes it a good day. Not having too much to do, so that my energy depletes before the days end, makes it a good day.”

“A good night’s sleep or when he’s enjoyed trip out or an activity with me.”

“When she has had a good sleep and also when she has talked with the children/grandchildren on WhatsApp.”

5.4.2. Healthy lifestyle

For many, practising a healthy lifestyle made a good day, such as having minimal stress, using relaxation techniques and practicing self-care.

“Looking after myself properly. Treating myself - hairdressers, massage. Sunshine. My voluntary work. Keeping busy.”

“Just feeling less tired and calmer helps with a good day.”

“As mentioned before, having a healthy life mentally and physically helps. Having a routine helps. I’ve recently cut out drinking in almost its entirety. This has had a significant impact. My good days are far more frequent.”

“Rest prior. Eating well and exercising. Quiet time prior to the good day. Less noise and commotion. Peace, nature.”

Survivors and carers also described the value of having a comfortable environment, with many specifically describing the contribution of good weather. For some, these comfortable environments were connected to improved effects of brain injury, leading to a good day.



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“Good weather and temperature, sun not overly bright so I can go outside and not over stimulated by the environment.”

“Rest, pacing, weather (cold weather impacts my spasticity, making it hard to move, warmer weather it's much easier so helps towards a good day).”

“Seeing my doggie friends and doggie people. Listening to the birds singing, Feeding the wild birds and squirrels. Telling myself it's okay, I survived.”

“Being and enjoying outdoors and the peace and quiet it brings. Enjoying the countryside, flowers, animals and the calm that brings.”

5.4.3. Routine and control

Many survivors emphasised how routine and things going according to plan contributed to a good day.

“When my plans and expectations go according to plan it gives me a good feeling.”

“Being careful to not to do too much, not being surprised by unexpected activities/demands on me, everything going to plan!”

“When things go exactly as he wants. No shocks, nothing unexpected happening.”

“Yes, when all tasks my wife undertakes go like clockwork...then all is very good.”

Some survivors and carers further described how having a sense of control over both the day and themselves contributed to a good day.

“Feel organised and in control. Got things planned. Things have gone to plan and no issues problems to try to deal with and problem solve. Not had to cancel things or let anyone down. Felt able to communicate and be understood.”

“When he feels in control of what is happening around him.”

“When nothing challenges him and he knows what is happening.”

5.4.4. Positive events

Survivors and carers felt that being able to personally achieve something, including where others benefitted, often contributed to positive feelings that made the day good.

“Being able to achieve a task or job I've set myself to do or help out neighbours.”



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"If I've achieved something on my own that I would probably avoid, like using a bank card or gardening. If I've actually remembered a day and date or what is happening on that day makes me a little bit more 'worthwhile'."

"I set daily targets - realistic ones - when I achieve these I feel very pleased."

"If he has achieved what he has set out to do and finishes a task/ tasks."

Being able to complete meaningful and enjoyable activities such as hobbies also contributed to a good day.

"New hobbies: knitting, painting, crocheting."

"I love it on days like today, when I have completed pre accident activities (like horse riding) and I love it that I have visited 'old memories' e.g. the stables where I used to ride and keep my pony years ago."

"Being able to do activities they enjoy such as playing pool or going to football matches."

"Taking part in hobbies he enjoys. Social time with old friends."

5.4.5. Socialising

Socialising with others who are empathetic and supportive, being appreciated by family or peers, or being involved in family activities were also contributors to a good day.

"Being around people who are close to me and know me well, make me feel safe."

"Being with like-minded people at Headway who understand and can relate to you."

"The love and support I get from my family and friends always make it a good day."

"Being able to join in activities with my family and friends. Don't feel so left out."

While many survivors felt that socialising with others made for a good day, others expressed that having quiet time to themselves offered relief from social pressures and expectations, and that sometimes being alone contributed to a good day.

"Less stress and a lower demand from others on my time and effort."

"Some quiet time on my own builds energy for socialising."

"A good day is when people leave me alone. I good day is when I can be me without people telling me what to do."

5.5. Underlying factors to bad days

We asked survivors and carers to tell us what causes a survivor to have bad days. While some were unsure, others were able to describe a range of factors, with both survivors and carers once again reporting the same overarching themes.

5.5.1. Effects of brain injury

Many survivors and carers described the range of brain injury effects such as headaches (or other pain), overstimulation and problems with information processing, that, when experienced, contributed to having a bad day.

“When I cannot process information, my brain gets stuck and I get frustrated and upset.”

“My low moods overwhelm me and at times I have communication problems and lack confidence.”

“When my muscles are tight or my movement isn’t going how I want to it to, and I get pain and things are more difficult to do.”

For many, fatigue was specifically reported as contributing to a bad day. Indeed, 27.05% of survivors and 28.66% of carers specifically mentioned ‘fatigue’ or ‘tiredness’ when describing the effects of brain injury that contributed to a bad day.

“If I get fatigued and do not have a rest, my day becomes bad, and I get headache and depression etc. I get more fatigued when doing lots of difficult things, like doing new things, going new places, trying to understand difficult documents/situations. Going to noisy & busy places also makes me very fatigued.”

“All of my bad stuff comes from my fatigue, usually I am okay in the mornings and had bad days in the afternoons. Emotional and cognitive situations, and general noise and overwhelm, leave me exhausted and then I have 'bad day' symptoms.”

“Fatigue has an affect on him, making other difficulties and things that he struggles with more prominent.”

With fatigue, many survivors and carers described the ‘boom-bust’ cycle of attempting to do too much on a good day, but subsequently struggling the next day with fatigue, ultimately leading to a bad day.

“If I have overdone it the day before. When I socialise with friends, I know the next day will be bad. If I have driven a lot, or just gone to the shops, it always impacts the following day.”

“Thinking I can do more than I am able to. Pushing myself cognitively on a good day quickly turns into a very bad day. A false sense of “I’m OK”.”

“If I have an extra busy day at work then the following day will most likely, be a bad day.”

“My bad days usually follow what should have been a good day, when I’ve done too much and so fatigue wipes me out causing me to have a bad day when I can hardly do anything and might just have to stay in bed.”

For some, feeling the general pressures of living with a brain injury and having a conscious realisation of the impact of the injury, such as one’s loss of independence, contributed to a bad day.

“A build-up of things that happen on a daily basis in life but as I find it difficult to process and understand, this leads to having a bad day. I just want to do what’s right but I can’t process quick enough so make bad choices and this has a devastating impact on my husband, daughter and will affect the days after.”

“Tasks that I can see need doing but I am unable to fulfil myself. I experience extreme frustration.”

“Inability to do what I used to do. Lack of independence and confidence.”

“His pain in his back causes frustrations and anger for him when he’s trying to help me with a task like cleaning emptying bins, he doesn’t like to see me doing everything as he was an active man before his injury.”

5.5.2. Social pressures

Social pressures and social situations that provoke anxiety, feelings of loneliness or frustration also contributed to many survivors’ bad days.

“Being let down, visitors, friends, ex colleagues not contacting me, almost zero visits from ‘friends’.”

“Worrying about what might happen. Or if I have to meet new people. Extremely nervous in crowded places.”

“Other people are a big factor - its other people’s behaviours that trigger my intolerance and moods.”

“Too much noise, too many expectations. Other people not doing things how he thinks they should be done.”

For some, the specific frustration of experiencing society's lack of understanding of brain injury contributed to a bad day.

"People not understanding the implications of brain injury."

"The lack of support, others cannot see the difficulties I have inside."

"Being in busy places with people who don't understand my situation. Having to try to justify why I can't / don't want to participate in certain activities."

"When he feels he isn't understood or isn't being listened to. If you don't answer him straight away."

5.5.3. Change in routine

Just as following routines helped to make a good day for many survivors, unexpected changes in plans or a shift in routine were a cause of anxiety for many that contributed to a bad day.

"Last minute change of plans, things that come about unexpectedly especially on a bad day I struggle to adapt and overcome the change even if it is something small."

"When I'm not clear what lies ahead of me. I prefer to plan ahead so that I prepare for the day/week/month. Impromptu extreme situations lead to a bad day."

"Having too busy schedule outside of routine, if things are not planned. Doing anything outside of a planned day just causes absolute chaos."

"Change in plans, a suggestion she does not like, being told what to do!"

5.5.4. Lifestyle factors

Several survivors described lifestyle factors that contributed to bad days, with many survivors specifically mentioning that not getting a good night's sleep or drinking enough water contributed.

"Not enough sleep. Not eating properly. Not listening to my body."

"Stress, poor sleep, poor nutrition."

"Lack of sleep - if I have not had a good night I am more short-tempered the following day with less patience and an inability to maintain concentration."

"Not eating properly. Not drinking enough fluids. Bad news. Bad weather. Noise."

5.6. Factors that improve a bad day

Having first identified what contributes to a day being bad, we subsequently asked survivors and carers to tell us about what improves a bad day. Many of the responses offered covered the themes already described above.

5.6.1. Resting

Resting was suggested by many, once again highlighting the impact of fatigue and the need to combat this on bad days to feel better.

“Resting more often than I would normally do.”

“I always have an hour in bed after lunch - lights out, curtains closed. Sometimes I sleep so it’s more than an hour. I always feel better when I get up.”

“Sleep. It feels like my brain shuts down and like an old computer, I have to completely switch it off, so it can reboot!”

5.6.2. Engaging in activities

Physical exercise and being out in nature were also used as ways to feel calm and improve mood on a bad day.

“Getting out into my garden, weather permitting.”

“Get outside in the countryside if possible or garden with the dog and listen to nature.”

“Mindfulness gardening outdoor walk - park, gardens or beach.”

Others discussed completing activities they enjoyed on ‘bad days’ to feel better or to distract themselves from negative feelings.

“Intentionally listen to comedians. Intentionally curate my musical listening. Podcasts that lift me. Check in with friends. Send a card, email, text, WhatsApp to someone. Generally choose to be proactive, even though I really, really don’t want to.”

“I listen to audiobooks, cuddle my dog, watch comfort TV, rest.”

“Distracting myself in whatever way possible but mainly through reading.”

“Do something I enjoy doing even if it’s just having a bath. Eat something I like as a treat. Give them (survivor) a hug / cuddle. Talk to someone else who understands - ring the Headway helpline.”

Some aimed to complete a task to feel a sense of achievement on a bad day.

"List 3 things to do at a time. It helps me focus on things to do, no matter how little. Once doing these 3 things, I'll list the next 3 things."

"Focus on doing at least one thing that makes that day better than the day before."

"Accepting, resting and resetting small goals to achieve that day."

"I spend a lot of time making things to raise funds for Devon Air Ambulance who saved his life and this helps me feel purposeful and positive."

5.6.3. Mental exercises

Mental exercises such as self-reflection, relaxation techniques, positive affirmations and practicing meditation or mindfulness were also helpful to many on a bad day.

"Watch a movie. Take a walk and do a voice memo, talking about how I feel. I then end it off with advice for myself and use it next time to listen instead of talking."

"Breathing exercises, music, writing in my journal."

"Remind myself that I am a lucky one. Remind myself how amazing the people around me are. Take myself away on a dog walk and spend time 'thinking' and rationalising. Continually planning and wondering of ways that I can gain the right balance."

"Read positive quotes and focus on them when wake up."

Some described how making a conscious effort to keep things in perspective would help on bad days.

"I usually just think tomorrow will be a better day. I think the best thing is to be kind to yourself and remember happier days will come."

"I have a piece of card in my pocket with 'This too will Pass' on it."

"Think of the things in my life that are good. Think of how far I've come and that I will continue to persevere."

"I try to tell myself it's not my fault and it's not personal. It's not their fault either. It's just the way it is."

5.6.4. Communicating with others

Some described how connecting with others (including pets) on bad days would help, especially others who understand brain injury.

“Go for a coffee with friends or my dad.”

“Meeting with a friend for lunch or talking to family who live in Scotland.”

“I read or paint. I talk to my Headway friends because they know what I am talking about.”

“Text a fellow carer, try and get out the way for a walk.”

Conversely, others felt that on bad days, they wanted to be left alone, as the pressures, expectations or lack of understanding from others contributed to the day being bad. Indeed, we have already reported that 84% of survivors found it difficult to socialise on a bad day.

“Take time out to relax by sitting in a quiet room, reading a book, doing a word search, being on my own, going for a walk by myself.”

“I close myself off from other people and avoid socialising, I find that time to myself is really important. I also have a nap in the middle of the day to allow me to focus again.”

“I try to be alone. It’s easier because I am less affected if I don’t have to interact much.”

“Knowing I don’t have to meet other people’s expectations/demands. I can heal in my own time and space.”

Some survivors described how effectively communicating their needs to others on bad days would help, as misunderstandings could be avoided.

“Just stating that I am not feeling great. Making others aware. I have used my brain injury card when in a shop and finding it hard to get my words out or anxious. It definitely helps occasionally.”

“One step at a time, do what I can and scale back on what I had hoped to achieve. Let people know as early as possible if I cannot meet up or whatever I have committed to.”

A number of carers described arrangements whereby the survivor would take time to themselves on a bad day, allowing the carer to access support from others.

“I’m still figuring this out. Sometimes I ring a taxi and he visits his nan. This is helpful (being away from the family home and being with someone non-judgmental).”

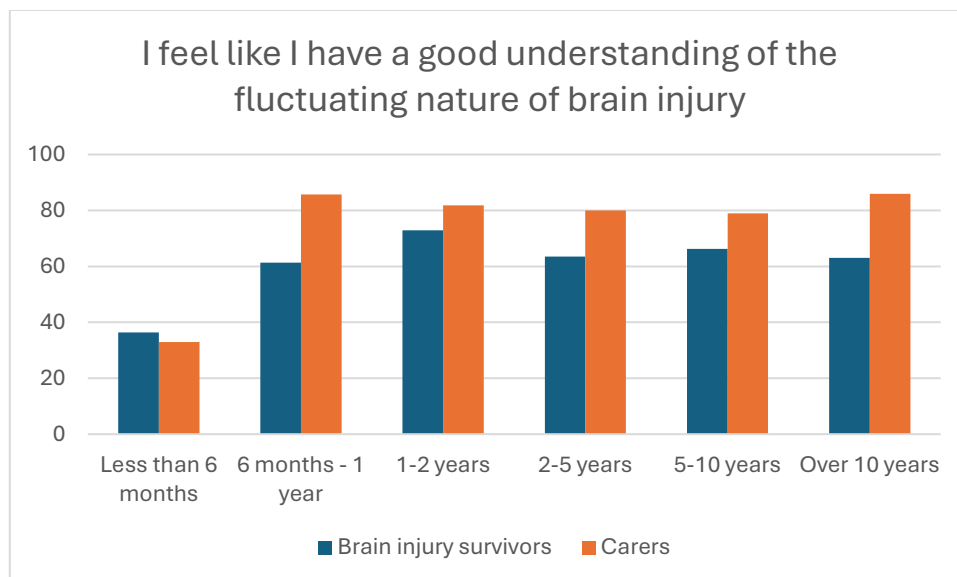
“I make sure she goes upstairs and rests during the day and then spend time with my friends, making sure she messages me when she wakes up.”

“We have both developed clear understanding and communication that sometimes we need quiet time apart from each other to centre ourselves, do our own thing and re-join in a better state.”

5.7. Personal and societal understanding of the fluctuating nature of brain injury

We asked survivors about both their own and others’ perceived understanding of the fluctuating nature of brain injury.

63% of survivors and 81% of carers felt that they had a good understanding of the fluctuating nature of brain injury. We found that the majority of survivors and carers developed this understanding after 6 months.



While around a third of survivors (36%) and carers (36%) agreed that those close to them had a good understanding of the fluctuating nature of brain injury, just under half of the survivors (47%) and carers (49%) disagreed that those close to them had a good understanding.

Only 1% of survivors and carers agreed that society in general had a good understanding of brain injury. 88% of survivors and carers disagreed with this, with just over half of survivors (55%) and carers (52%) strongly disagreeing with this.

5.8. Professionals’ understanding of the fluctuating nature of brain injury

We asked survivors and carers about professionals’ perceived understanding of the fluctuating nature of brain injury. We selected professionals that are likely to be

encountered after brain injury, namely welfare benefits assessors, employers and GPs.

5.8.1. Welfare benefits assessors

60% of brain injury survivors reported that they had either applied for or were in the process of applying for welfare benefits. Of these, only 17% felt that the assessment process considered the fluctuating nature of brain injury, while 68% felt that the assessment process did not consider this. 15% were unsure of this.

"I spoke positively as was on a good day and forgot all the bad stuff, as I do, they stopped my benefits until daughter wrote a long letter explaining how I am."

"The application process was hard as it asks about frequency in a black and white way, not recognising that each week could be different."

"I feel that the system is full of people who have little or no understanding of TBI. A typical example would be if you communicate with them on a 'good day' and they will draw the conclusion that there is nothing wrong with you. On the contrary, they do not witness you confined to your home and totally isolated and in very low mood on your 'bad days' because they are not there."

"I wore a clean shirt to the assessment and was judged fit to work because I was clean and had turned up. They ignored that I was so tired from mental effort of finding the location that I fell asleep while in the waiting room. Also that it was my 1st shower in days and made me tired."

"I went for a PIP assessment several years ago and the assessor clearly had no idea about my fluctuating symptoms after my stroke. Needless to say I didn't get awarded PIP. In fact, I have been turned down for every benefit I have tried to claim. Thank goodness I can now do a few hours of work a week to help keep us afloat."

73% of carers reported that the survivor they were supporting had either applied for or were in the process of applying for welfare benefits. Of these, around a third (32%) felt that the assessment considered the fluctuating nature of brain injury, while over half (56%) felt the assessment process did not consider this. 12% were unsure.

"It's very complicated and the questions asked don't fit brain injury fluctuations."

"We made it very clear on the application information what he was capable of on a good day but what he wasn't able to do on a bad day - we did this ourselves after being given great advice from our local Headway branch, but without their help we wouldn't have been able to do this."

“The person who did the interview took the brain injury survivor at face value, how they were on the day. They didn't seem to realise that it meant the survivor was putting all of their effort into the interview, and that they were totally wiped out afterwards.”

“They did a face-to-face appointment and went on what they saw on the day but I did feel they listened.”

5.8.2. Employers

52% of brain injury survivors were employed at the time of completing the survey, or had previously been employed and working with a brain injury.

Of those who were employed or previously employed, 42% of survivors agreed that their employer had a good understanding of the fluctuating nature of brain injury and had made reasonable adjustments accordingly. A further 45% of survivors felt that their employer did not have a good understanding of this, while 13% were unsure. We therefore found mixed responses among survivors regarding employers understanding the fluctuating nature of brain injury.

35% of carers reported that the survivor they were supporting were employed at the time of completing the survey or had previously been employed and working with a brain injury.

Of these carers, just under half (47%) felt that the survivor's employer had a good understanding of the fluctuating nature of brain injury and had made reasonable adjustments accordingly, while a third (33%) felt the survivor's employer did not have this understanding. 20% were unsure. We therefore found that most carers felt that the survivor's employer did understand the fluctuating nature of brain injury and had made reasonable adjustments accordingly.

The more favourable responses given regarding employers' understanding of the fluctuating nature of brain injury may be due to the existence of legislation that protects the rights of employees with a disability within the workplace, such as the need to consider reasonable adjustments under the Equality Act.

5.8.3. GPs

59% of brain injury survivors and carers reported that the survivor had previously sought support from their GP for coping with the fluctuating nature of brain injury.

Of those who had sought this support, 52% of survivors felt their GP had a good understanding of the fluctuating nature of brain injury, while 45% felt they did not. 3%

were unsure. 53% of carers felt that the survivor's GP had a good understanding, while 43% felt they did not. 4% were unsure.

We therefore found mixed responses among survivors and carers regarding GPs' understanding the fluctuating nature of brain injury, with both survivors and carers having similar attitudes.

6. Key messages

6.1. Key campaign messages

A number of themes emerged from the survey findings that we can summarise into key campaign messages as follows:

- The varied effects of brain injury can fluctuate. Fatigue is a commonly experienced effect of brain injury that regularly fluctuates, often underpinning the bad days of brain injury and being associated with feeling negative moods such as depression, frustration, isolation, guilt and feeling useless. Other commonly fluctuating effects include memory problems, anxiety and problems with concentration.
- Living with a fluctuating condition such as brain injury can affect both survivors' and carers' moods, engagement in work or studies, ability to socialise, relationships, and independence.
- Good days were reported to cause survivors and carers to feel a range of positive emotions such as happiness, independence, positivity, ability, reassurance and accomplishment, among others. However, even on good days, there remains a sense of anxiety about circumstances changing at any moment and a consciousness of avoiding over-exertion to prevent a bad day from following.
- Bad days were reported to cause survivors and carers to feel a range of negative emotions such as depression, social isolation, frustration and helplessness.
- Good days were caused by the effects of brain injury being less severe (specifically being able to manage fatigue), having a healthy lifestyle, following a routine and feeling under control, experiencing positive events and socialising.

- Bad days were caused by the effects of brain injury being more severe (specifically coping with fatigue), societal pressures, changes in routine, having an unhealthy lifestyle.
- Bad days can be improved by resting, engaging in enjoyable and meaningful activities, completing mental exercises and communicating with others about one's needs.
- Survivors and carers generally feel they have a good understanding of the fluctuating nature of brain injury, with many developing this understanding after 6 months.
- Survivors and carers have mixed experiences of welfare benefits assessors and GPs' understanding of the fluctuating nature of brain injury. Employers' understanding of fluctuating nature of brain injury is rated more favourably, possibly due to existing legislation in this area.

6.2. Survivor messages for others

Brain injury survivors and carers had described a variety of activities and strategies they personally employed to cope on bad days. We further asked them what others can do to help them feel better on a bad day.

The themes that emerged from the responses echo messages shared by survivors through previous Headway campaign work, such as [See the hidden me](#) and [A life re-written](#).

6.2.1. Offering a safe space to communicate

For many survivors and carers, being offered a safe space to communicate their feelings and needs without pressure and judgement helps on a bad day. Good quality communication was also mentioned by many, consisting of allowing the survivor to take their time with processing information, and simply listening without needing to provide solutions.

"Just being understanding about my symptoms and that it's as a result of a brain injury, not a choice. Also, avoiding overwhelming me with questions or their problems."

"Listen. Take time to let you talk without assuming they know what you're about to say, quite often I am trying to say something different. Realise I am now a bit different in lots of ways but to appreciate I am still here!"

“Listen without judgement, gaslighting or being dismissive.”

“Check in, be able to listen without trying to fix it.”

6.2.2. Compassionate treatment

Some described how being treated with compassion and respect makes a difference.

“Be compassionate and considerate, ask how you are doing give you space and time to recover, offer understanding support and accept that their energy ability fluctuates its just that your may be more extreme.”

“Listen to me & give me a hug.”

“Sympathise rather than boss me about.”

“Have more empathy, people don’t see problems unless they can see something visually wrong with you no one can understand Brian injury unless they have suffered one.”

“Some respite would be brilliant. I don’t get a day off and just having someone to talk to about what’s happening would be an enormous help.”

6.2.3. Improved understanding of brain injury

Many requested that others improve their understanding of brain injury, the impact of it and the fluctuating nature of it.

“Just understanding what can fluctuate and understanding what can happen in terms of a brain injury.”

“Understand more, educate yourselves about brain injury symptoms, still believe in me, don’t treat me differently if that makes sense...I still have parts of me that was the person I was/you remember. Let’s re-learn together and hopefully adapt.”

“Speak slowly, be understanding. Read Headway information on the internet.”

“Awareness, try and understand that whilst he may look normal a lot has changed. Equally whilst a lot has changed, he is still the man he was before the accident. You try and explain to others how he is, but few understand, even those you think do, say inappropriate comments. Don’t moan about your life as there is always someone worse.”

“There is a real misconception, because he functions so well on a good day that somehow the bad days aren't real or we're making it up. I think better general understanding of how much things fluctuate and how bad the bad days can be would help. I also think better understanding of how much pressure it puts on the partner when things are fluctuating so much, and how much of a mental load partners/carers take... when we say we're tired we mean we're completely exhausted on having to do the thinking for two people!”

6.2.4. Offering practical assistance

Living with the effects of brain injury, especially fatigue, was reported to be a common underlying experience to bad days, affecting independence and the ability to engage in activities. Therefore, for many, offers of practical assistance on days when effects are particularly problematic was valued.

“Help with cooking, cleaning etc, helping me rest, being understanding.”

“Perhaps ask if I need any help to complete things I need to do that day.”

“Help with day-to-day chores, understand that I am not faking it and I need to rest.”

“Offer support especially with practical tasks problem solving, and organisation. This is really important because although we might be ok at this on a good day sometimes in a bad day it all goes out the window!! A hug reassurance and understanding is good too.”

“Give me space, help by doing tasks like preparing food and drinks, don't give me anything to cope with like info etc, take me to places like appointments if I need to go because I can't get there myself on a bad day.”

6.2.4. Understanding survivor's contact needs

Some requested that others recognise and respect their need for space and being left alone on their bad days without judgement or reproach.

“Give me space and quiet or not want me to talk with them. Let me just be or go for a walk with me in nature but let me have peace and quiet.”

“Fortunately, my husband is very helpful and gives me space. I think friends and other relatives are sometimes frustrated as they have no understanding of the 'hidden' difficulties a brain injury can cause.”

“Give me the space I need to recoup my energy.”

“Just let me gather my thoughts and breath, I just need a little bit of time to understand what I am supposed to be doing.”

Meanwhile, others value being contacted on their bad days, particularly appreciating when others would initiate contact, and valuing contact from others with an understanding of brain injury.

“Listen to me or make contact and show they care and that I'm not a burden.”

“Contact me to see how I am doing, rather than always wait for me to contact them - making me feel over self-reliant.”

“Reach out. Ask if I'm ok. Talk to me about something other than brains. Make me laugh.”

“Some of my friends are aware of my brain injury and if they don't see me or hear from me for a few days they know I am struggling. I get the occasional text message checking to see if I am OK and that helps.”

“Coming to see me and taking me out. I hate being cooped up in the house.”

“Sometimes just offering a cup of coffee makes a difference and a reassurance that I am still of value.”

6.3. Key messages for survivors and carers

We have identified several themes that underpin the experiences of good and bad days for brain injury survivors and carers after brain injury. Based upon these findings, we are concluding this report with tips for survivors and carers to consider, to hopefully improve the experience of life after brain injury by minimising bad days and offering tools to cope when these do occur.

- **Reach out to others** on a bad day. Talk about how you are feeling, ask for practical support, and do not feel that you have to get through the day on your own. You can speak to friends, family, or others who you have a good relationship with and who understand the impact of your brain injury.

Our Headway support groups, helpline and online communities are available to you as well; more information on accessing these is available on our website at www.headway.org.uk/supporting-you.

If you are struggling with your emotions, you may wish to contact [Samaritans](#) for emotional support, or seek advice from your GP about getting professional

support for ongoing issues such as depression or anxiety.

- **Learn ways to cope with fatigue** and other effects of brain injury. Our free-to-download publications cover information on many different effects of brain injury and can offer expert guidance on how to cope. You can download these from our Information Library at www.headway.org.uk/about-brain-injury/individuals/information-library.
- **Try to get a good night's sleep** by learning about sleep hygiene and relaxation. Our publications on [fatigue](#) and [sleep problems](#) after brain injury both contain guidance on this, as well as our [webinar on sleep after brain injury](#) available on YouTube.
- **Communicate with others** if you are wanting to be left alone and have time to yourself. Doing this in a respectful way means that people will better understand why you may be minimising contact, helping to avoid social misunderstandings. You can consider using your [Headway Brain Injury Identity Card](#) to help with having this conversation.
- **Find activities** that are important and meaningful for you to do and complete these on your bad days if you are feeling able to. Reading, listening to music, eating nice food, completing a task or a house chore and going for a walk are just some examples of things other survivors and carers do on their bad days to feel better.
- **Enjoy nature** by going for a walk, gardening, or even sitting by a window to enjoy the birdsong outside.
- **Keep things in perspective** on bad days. Life can be challenging after brain injury but remember how far you have come and all of the things that you have achieved through your recovery. Even small things should be celebrated. Remember that no two days are exactly the same and you may feel better tomorrow. Try to find something to achieve on a bad day, no matter how seemingly small.
- **Slow down** on your bad days and allow yourself time to do things at a gentler pace. If you have tasks that need completing, try to break these down into smaller, more achievable tasks and take breaks in between.

7. Conclusion

The results from our survey for *On a good day* have highlighted the fluctuating nature of brain injury, evidencing how brain injury survivors can have both good and bad days after injury. However, we have found that even good days are often shrouded by a sense of anxiety that circumstances can change at any moment due to the fluctuating nature of this condition.

Further, we found that good days are often followed by bad days due to the 'boom-bust' cycle of attempting to undertake too much activity on good days, subsequently followed by fatigue the next.

Bad days cause a range of negative emotions and affect various aspects of life, among both brain injury survivors and carers. Several factors contributing to bad days have been described throughout, with strategies suggested to combat these.

We found that while survivors and carers generally have a good understanding of the fluctuating nature of brain injury, this generally develops after 6 months and improves over time. Further, we found that while survivors and carers have mixed feelings about GP and benefits assessors' understanding of brain injury, they feel that general society lacks an understanding into the fluctuating nature of brain injury, highlighting the importance of undertaking campaign work in this area, such as through the likes of [*On a good day*](#).

At Headway, we will continue to raise awareness of the various challenges faced by brain injury survivors and carers affected by this often hidden and fluctuating disability.

8. About Headway

Headway is the UK-wide charity that works to improve life after brain injury by providing vital support and information services, including:

- a freephone helpline (0808 800 2244, helpline@headway.org.uk);
- a comprehensive award-winning website containing information and factsheets on all aspects of brain injury (www.headway.org.uk);
- an award-winning range of publications designed to help people understand and cope with the effects of brain injury; an emergency fund to assist people dealing with the financial implications in the immediate aftermath of a brain injury;

- a Brain Injury Identity Card to help in everyday situations and if you come into contact with the criminal justice system;
- directory of approved residential homes, rehabilitation units and respite facilities specialising in ABI.

The charity also lobbies for better support and resources to be made available to people affected by brain injury and works to raise awareness of brain injury and the devastating effects it can have.

In addition to these services, a network of Headway groups and branches across the UK and Channel Islands provides a wide range of services including rehabilitation programmes, carer support, social re-integration, community outreach and respite care to survivors and families in their own communities.

Headway - the brain injury association is registered with the Charity Commission for England and Wales (Charity no. 1025852) and the Office of the Scottish Regulator (Charity no. SC 039992). Headway is a company limited by guarantee, registered in England no. 2346893.