

You, me and brain injury: Relationship changes after brain injury

A report into the findings of the Headway survey *Relationship changes after brain injury*, which sought to explore the ripple effect of brain injury



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Introduction

In spring 2018 Headway conducted a survey to explore how relationships are affected after brain injury. The survey was designed to be filled in by brain injury survivors, as well as partners, family members, friends and co-workers of brain injury survivors. The aim of the survey was to study the ‘ripple effect’ of brain injury. The survey also sought to explore how brain injury affected the way people feel about themselves and their lives.

This report presents a summary of the findings of the survey and their implications.

The survey was designed to inform Headway’s 2018 *Action for Brain Injury Week* campaign entitled *You, me and brain injury*. The campaign set out to demonstrate the rippling impact of brain injury among a much wider network than just the brain injury survivor.

The questionnaire was hosted on the Survey Monkey website (www.surveymonkey.net) and promoted via email to all Headway groups and branches, and on the Headway website and social media channels. Groups and branches were asked to encourage as many service users as possible to take part and provide any help necessary. Hard copies were also made available to download from the Headway website or sent out on request.

The survey was open from 15 March 2018 to 16 April 2018. It consisted of both closed and open-ended questions to gather quantitative and qualitative responses.

1,002 people responded to the survey. Headway would like to take this opportunity to thank everyone who took the time to participate.

If you would like to discuss any aspect of the research please contact Tamsin Ahmad on publications@headway.org.uk.

Media requests should be directed to James Coxon on press.manager@headway.org.uk or 0115 947 1901.

Key findings

35% of brain injury survivors felt that their relationship with their partner had strengthened after their injury. 38% of partners also felt that their relationship with the survivor had improved.

47% of brain injury survivors reported improvements in the relationship they had with family members after the injury. 40% of partners also reported improved relationships with family. However, 44% of survivors reported breakdowns in their family relationships.

69% of brain injury survivors reported breakdowns in their friendships after brain injury. 65% and 55% of partners and family members, respectively, also reported friendship breakdowns.

33% of brain injury survivors felt that some friendships had strengthened since the injury. 29% of partners also reported strengthened friendships.

49% of brain injury survivors' relationships with their employer broke down after their injury. Around a quarter of family members and partners (25% and 26% respectively) also had relationship breakdowns with their employers since the injury.

Relationship improvements were attributed to there being a good understanding of brain injury, practical and emotional support offered and renewed appreciation of others.

Relationship breakdowns were attributed to a lack of understanding about brain injury, having less time to see one another and challenges of managing the effects of brain injury.

Self-esteem and life satisfaction were related to the number of relationship breakdowns reported by brain injury survivors, where more relationship breakdowns were associated with lower self-esteem and life satisfaction.

Executive summary

The survey *Relationship changes after brain injury* collected responses from over 1,000 brain injury survivors, spouses/partners, families, friends and co-workers into how they feel their relationships have changed since their experience of brain injury and therefore to examine ‘the ripple effect’ of brain injury.

The survey results show that relationship breakdowns between couples are not as common as people often think, with some relationships even being found to strengthen after the injury.

Friendships were the largest category of relationship breakdowns, reported by survivors, partners, family members and even friends themselves.

Relationships with family members were reported to be the highest category of relationship improvements, reported by survivors, partners and family members.

Relationships with employers and colleagues were mostly affected negatively, although in some instances positively, following the brain injury experience; this was mainly reported by survivors and their partners.

Factors found to improve relationships included having a good understanding of brain injury, offering emotional and practical support, going through shared experiences and renewed appreciation of others.

Factors found to cause relationship breakdowns were not having an understanding of brain injury, lack of interest in offering support and challenges with coping with the effects of the injury.

This report was produced as part of Headway’s Action for Brain Injury Week 2018 campaign *You, me and brain injury*. For more information on the campaign, visit www.headway.org.uk/get-involved/campaigns/you-me-and-brain-injury.

Survey results - You, me and brain injury: Relationship changes after brain injury

This questionnaire was intended for anyone affected by brain injury. This included the family, friends and colleagues of brain injury survivors, as well as brain injury survivors themselves. The aim was to assess how people felt the relationships in their life had changed after being affected by brain injury.

Section one: Demographics

We asked participants for their age and how long ago the injury had been sustained. Respondent ages and time since injury can be found in the tables below.

| Age of respondent | Frequency |
|-------------------|-----------|
| Under 18 | 6 |
| 18-24 years | 26 |
| 25-34 years | 115 |
| 35-44 years | 247 |
| 45-54 years | 308 |
| 55-64 years | 217 |
| 65+ years | 78 |

Table 1. Age of respondents

| Time since brain injury | Frequency |
|-------------------------|-----------|
| 0-6 months | 32 |
| 6-12 months | 49 |
| 1-2 years | 139 |
| 2-5 years | 274 |
| 5-10 years | 236 |
| 10-20 years | 169 |
| 20+ years | 99 |

Table 2. Time since brain injury

As the survey was open to anyone affected by brain injury, we also asked participants what their connection was to brain injury. The majority of respondents were brain injury survivors, followed by partners and family members.

| Connection to brain injury | Frequency |
|--|-----------|
| Brain injury survivor | 594 |
| Partner of brain injury survivor | 210 |
| Family member of brain injury survivor | 172 |
| Friend of brain injury survivor | 14 |
| Colleague of brain injury survivor | 2 |
| Other | 7 |

Table 3. Connection to brain injury

'Other' respondents included professionals working with brain injury survivors and people who previously had relations with a survivor.

Section two: Relationship changes: breakdowns

We asked respondents about relationships that had broken since the injury. Overall results are provided in the chart below.

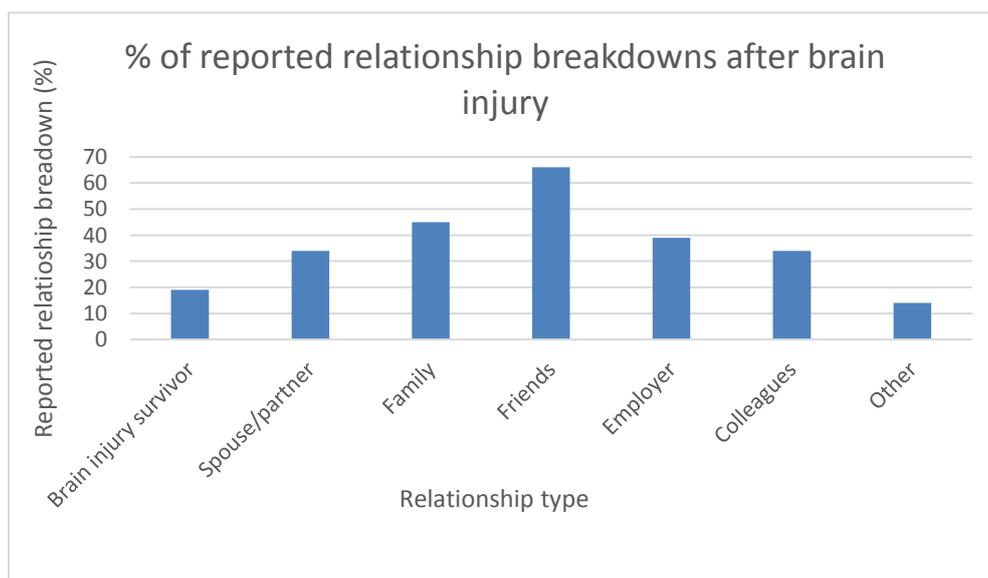


Chart 1. Relationship breakdowns after brain injury

Due to the range of respondents' connections to brain injury, the following section will examine responses given by each category of respondent (brain injury survivors, spouse/partners, family, friends, colleagues) in turn.

2.1. Brain injury survivors

Spouse/partners

Despite the belief that relationships between couples commonly break down after brain injury, our survey found that only 38% of brain injury survivors felt that their relationship with a partner or spouse had broken down, whilst only 28% said that the relationship had categorically ended. These findings indicate that only a third of relationships breakdown after brain injury, contrary to popular belief.

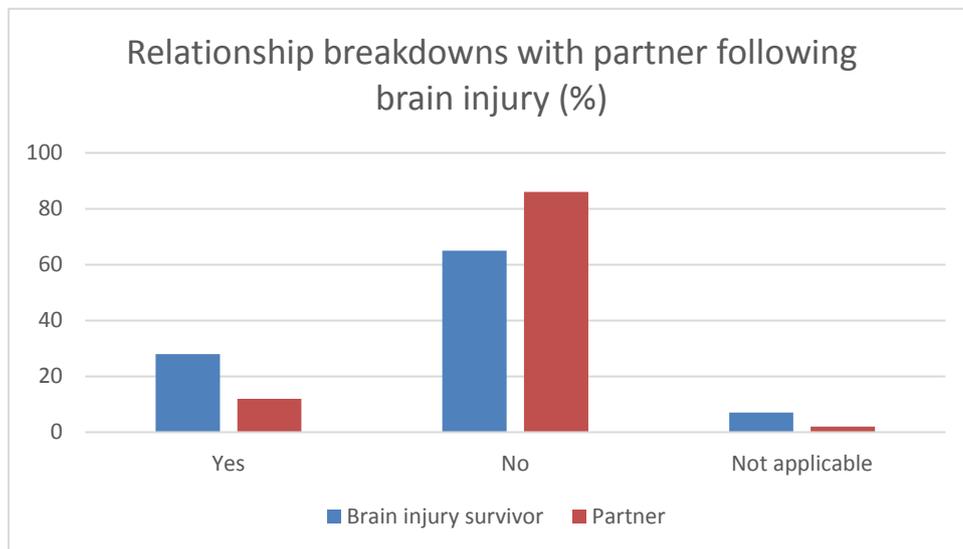


Chart 2. Relationship breakdowns between survivors and partners after brain injury

These results are in keeping with recent research about the rates of divorce and separation after brain injury. For instance, Kreutzer et al (2007) found that among brain injury survivors who were married at the time of the injury, the rates of divorce and separation were 17% and 8%, respectively, indicating that among their sample 25% of brain injury survivors' relationships had categorically ended after the injury. Even smaller relationship breakdown rates were reported by Arango-Lasprilla et al (2008), who found that only 15% of survivors reported being separated or divorced 2 years after their injury.

Brain injury survivors gave self-reports of the effects of their injury causing the relationship with their partner to break down, especially when the effects caused an overall change in personality.

"My wife left me as my personality changed."

"Heartbroken my husband left me saying I'd changed."

“My new husband could not or was not willing to cope with the chronic fatigue and depression that I suffered in the months after surgery.”

“Former girlfriends could not cope with my forgetfulness and fatigue.”

“My partner left me when she doesn’t understand brain injury.”

Many survivors felt that the relationship broke down due to the partner not fully understanding or appreciating the impact of the injury on the survivor.

“I am a different person since the removal of my brain tumour, my relationship has broken down, some of which was due to the lack of knowledge my husband has of what to expect.”

The change in role from partner to carer was also seen to have a negative impact on relationships.

“There has been a strain on my relationship as my boyfriend has turned more into a carer.”

“I needed a lot of care and help which partners were unable to give.”

Some survivors made the decision to end the relationship themselves.

“I separated from my husband as he was abusive before and after my injury. I think the accident made me look at life from a different perspective and also for the first time I had so many professionals supporting me and asking me how I was feeling so I felt strong enough to leave.”

“I broke up with my girlfriend, I couldn’t drag her through this.”

Family

44% of brain injury survivors reported relationship breakdowns with other members of their family. For some survivors, the relationship breakdown was attributed to frustration being felt at family members being ‘over-protective’.

“As for family, I feel my dad has been way too overprotective and this in turn can frustrate me, which has resulted in me not getting on so well.”

“My relationship with my mother is difficult... she has not moved on from my brain injury, treats me like a child still and tries to wrap me in cotton wool.”

“I got frustrated with my family as they became over-protective.”

Conversely, other survivors expressed their hurt over family members appearing to not care about their injury.

“My relationship with my mother was never good, but her total failure to visit/ offer any support was upsetting.”

Again, lack of understanding about the effects of brain injury was found to affect some family relationships.

“Unfortunately, a lot of my family members think they understand what I am going through but have no idea of the actual reality... lack of understanding of the effect of brain injury has and is causing huge conflicts and relationship breakdowns.”

“My relationship with my sister broke down when I became flustered during a conversation with her.”

“Family particularly think I am better but don’t understand the fatigue and emotions I’m dealing with.”

“I’ve lost family members because they think I’m faking it.”

Change in sense of self-identity and personality also contributed to some family relationship breakdowns.

“Relationships with family have also deteriorated due to changes in personality.”

“Lost my status in the family, had to find myself again.”

Friends

The highest reported category of relationship breakdowns was friendships, with 69% of survivors feeling that the relationship they had with friends had broken down since their injury. This loss of friendship networks has been widely reported across research (Salas et al, 2016; Callaway, Sloan & Winkler, 2005).

A common theme emerging from the responses we yielded was that a lack of understanding about brain injury caused friendships to break down.

“I’ve lost friends who simply just don’t understand...”

“Difficulty with friends not understanding me.”

“My friends again found it hard to understand my changes, however over time this has improved. Needless to say, I felt very isolated and alone coping with the changes.”

“My relationships with friends have broken down due to a lack of understanding and labelling and stigma attached to brain injury.”

“We were 17 at the time of my injury, my friends went to University, I didn’t and we drifted apart, they couldn’t understand the changes in me.”

“Friends just don’t understand what you are going through as you look normal and they have no real understanding from my condition.”

Survivors also discussed how the effects of their brain injury hindered their opportunities to meet up with friends.

“A large factor has been that I can no longer work so don’t have the finances to maintain relationships i.e. go out with friends, meet for drinks etc.”

“My personality changed and people didn’t like it. I couldn’t get out to meet friends.”

“With friends I look the same but I no longer keep up communications... I can’t meet up in places I used to due to lights and noises and can’t follow conversations and in their eyes I am not fun anymore. I don’t look different so they don’t understand.”

“I feel more panicky and scared of the outside world, so my social life is almost nil. So I don’t see friends so often.”

“Stuck in the house while all my friends are out playing. I have mobility issues now.”

A number of survivors recollected that friends would visit them in the early days of their injury, such as when they were in hospital or during their rehabilitation, but gradually tapered off over time.

“At the beginning of my rehabilitation, friends were keen to come and see me in hospital and always messaged me. After I was allowed to come home, they don’t bother. I message to see what they are up to and I don’t get a response, or they will say ‘I will come see you soon’ and it just never happens.”

“My friends were pretty supportive but as soon as school was over so was my relationship with these ‘friends’, or most of them. I guess you could say I found out their true colours in the end. Some friends have stuck by me. I think a couple of my friends didn’t fully understand my situation before but now that I am older and can explain better to them about it, they have opened up a little toward me.”

“Someone I thought was one of my best friends, who sat with me everyday whilst I was in a coma and was a huge support when I first came home started to become critical of my recovery rate and when I retaliated she just stopped talking to me. It was devastating.”

Losing friends had a negative impact on a number of survivors’ well-being.

“I feel like I’m not worth having as a friend... every time I lost another friend I felt bereft and unworthy, unlikeable. It has added so much to my depression.”

“When it comes to friends I feel that they don’t know how to deal/speak to me so have shied away from me. And at times I have felt very, very lonely.”

“I feel angry that friends don’t realise that I always have to live with these effects. I want people to make allowances for me – but not patronise me!”

As with some survivors and their partners, some survivors themselves broke off the relationships they had with friends.

“I alienated myself from family and friends as I struggled to figure out what was wrong.”

“I pushed my friends away as they didn’t understand.”

Employment relationships

Employment relationships were also found to commonly break down, with 49% and 43% of survivors saying that relationships had broken down with their employers and colleagues, respectively. Research has found that 60% of brain injury survivors are unable to return to work after their injury, which could account for the loss of these relationships. Indeed, comments from survivors found this to largely be the case.

“Couldn’t work. Lost touch with colleagues.”

“I’ve lost contact with loads of work friends. I guess because I’m not with them at work we have just lost contact.”

“I’ve lost contact with people at work as I have had to leave my job.”

Survivors who were able to return to work after their injury commented on how the effects of their injury affected their work performance, and therefore their relationships with co-workers.

“Relationships with colleagues have been impaired by my organisational ability being questioned at times of high pressures.”

“My colleagues view me differently and my employer took a long time to take me seriously.”

“Two employer’s relationships have broken down and I’ve left because they haven’t understood my brain injury/ being off with migraines/ headaches/ dizziness.”

As with other relationships, lack of understanding was a major factor in relationship breakdowns between survivors and their co-workers.

“I don’t feel that my employers understand my brain injury.”

“Lack of understanding of how I am affected, employer wanted me to be as before with my abilities.”

“Some of my previous employers failed to comprehend effects of injury.”

“My employer who kept my job open for me compared me to a child in my abilities, not fully understanding that recovery takes time after a stroke.”

Relationship changes reported by survivors

A common theme that emerged from the brain injury survivors is that lack of understanding can have a major impact on the relationships in their lives. Indeed, through a survey we conducted last year, *Experiences of life after brain injury*, we found that many survivors feel that the people in their life do not understand their injury and further feel that their life would be improved if people did have this understanding.

2.2. Spouse/partners

Brain injury survivor

Spouses/partners of brain injury survivors were asked whether their relationship with the survivor had broken down since the injury. Only 27% of partners felt that their relationship with the survivor had broken down, whilst only 12% reported that a relationship had categorically ended.

Where relationships had broken down, effects of the injury pertaining to personality, cognition and behaviour were factors. Research has also reported on the impact of these effects on partners' experiences in relationships (Bodley-Scott & Riley, 2015).

“My husband the survivor had behavioural changes which mean I am now suffering anxiety and depression. We are currently living separately due to his behaviour.”

“My partner is a different person now. She's lost her softness.”

“My husband misinterprets things and we end up arguing about things regarding his behaviour in front of others.”

“After 10 years of excusing behaviour because of the injury I finally reached my tipping point and asked for a divorce.”

“Lack of understanding and support. I'm living with a different person, someone I don't know and wouldn't have chosen to marry.”

The need to take on additional responsibilities was also seen by some partners as causing difficulties with the relationship with the survivor, which has also been widely reported in research (Kratz et al, 2017).

“I can no longer talk to my husband in the way that I could before. I can't count on his judgement. I have taken on responsibility for everything.”

“The pressure of caring and working full time. Made our relationship strained and eventually break down.”

“Had to focus so much on caring for partner everything else got excluded. Lost myself.”

Some partners explained how caring for the survivor made them feel more like a carer than a romantic partner (a feeling that had been reciprocated by some survivors themselves). Research has also noted that some partners feel more like a parent than a partner due to needing to make decisions for the survivor (Gosling and Oddy, 1999), and this was remarked on by some partners.

“My relationship with my partner, who has a brain injury, has changed negatively due to me having to take on much more a caring/paternal role.”

“Complete breakdown. I am now a carer for my husband and nothing more.”

“I became the carer and no longer the partner.”

Severe injuries and subsequent loss of functions were the cause of some relationships ending. Indeed, research has found that the severity of injury is a factor in marital stability after brain injury (Kreutzer et al, 2007).

“My husband resides in a nursing home without speech or capacity, and he is paralysed so could never be cared for at home... eventually I asked for a divorce via my in-laws. That killed the relationship.”

Family

45% of partners reported that the relationship they had with their own family had been affected by the survivor’s brain injury. Riley (2016) discusses some of the common reasons as to why relationships between partners and their families may be negatively affected after their injury. In our survey, we found that some partners felt that their family had not been supportive enough.

“My family have still wanted my attention for their needs but provided no support or respite for myself or my children. They do not hear what I say about how our lives are now and make comments that reflect their continued lack of understanding.”

“Family not understanding fully how hard everyday life is.”

“It’s the lack of support from some family.”

A lack of understanding from family members was also seen to be a contributing factor, especially when family members would not make allowances for behavioural issues.

“I am the wife of a brain injury survivor. My family met my husband after his brain injury and due to his lack of filter he can say things that others take offence to or the wrong way. My father, step-mother and sister refuse to speak to him and my mother has only just reconnected with us.”

“A breakdown in relationship with the in-laws due to lack of understanding.”

Some partners felt that the breakdown in the relationship with their families was simply due to no longer having time to see one another.

“Not having enough time to visit and meet family as often as the past because of not being able to do as much in a day.”

Friends

Over half (65%) of the partners who responded to our survey reported breakdowns in friendships after the brain injury. Some partners explained that this was often due to no longer having time to see friends due to their new caring role, also reported by Riley (2016).

“Lost my friends as I had no time for them and most of them could not come to terms with my new demanding lifestyle.”

“Cannot see friends as much due to my caring role.”

A lack of understanding about brain injury was found to also affect the friendships that partners had, also reported by Kratz et al (2015).

“Friends lost contact because they didn’t know what to say.”

“Friends have lost contact, sometimes because they don’t know how to cope or don’t make contact, or visit as our life is limited.”

“Friends also struggled to know how to support and invites dried up.”

“Family and friends didn’t understand or were afraid of the brain injury or didn’t understand why my husband couldn’t understand.”

Some partners even reported that their friends drifted away as a result of them no longer being able to support the friend in the manner they did prior to the injury.

“Since my partner’s brain injury, I have lost a lot of friends because I was no longer beneficial to them. I had my own problems now and couldn’t help them with their own.”

Employment relationships

26% of partners felt that the relationship they had with their employer was negatively

affected by the survivor's brain injury and this was largely attributed to lack of empathy and understanding from employers.

"I don't feel supported by my employer. I feel they could have done much more in my time of need."

Similarly, and for similar reasons, 23% of partners reported breakdowns in the relationships with their colleagues.

2.3. Family members

Brain injury survivor

A third of family members (33%) felt that their relationship with the survivor had broken down after the injury. As with partners, the changed role to becoming a carer affected some family members' relationships with the survivor, especially regarding parent-child relationships.

"We don't have an adult mother/daughter relationship. My life revolves around her and her specific needs and it's a different kind of closeness."

"I no longer have a mother daughter relationship. I am treated like any other carer."

"Our relationship suffered due to the effects of the injury. I was so angry and mum couldn't express herself in the right way and would say something strange or hurtful. I tried to distance myself to avoid the pain."

"Both me and my daughter who used to love going to spend holiday time at mum's or talk on the telephone now feel that it is always such a drama and often ends in arguments which we didn't do before."

Partner

A small number of family members (18%) reported that their relationship with their partner had broken down since the injury, with 5% even reporting that the relationship had ended. Some family members explained that the pressure of looking after a brain injury survivor had caused their marital breakdown.

Friends

55% of family members reported that the relationship they had with their own friends also broke down following the injury, mainly because they no longer had time to socialise.

"The pressure and strain of caring for a loved one with a brain injury means there has been little time for anything else. This can lead to feelings of resentment as

family and friends go about their lives forgetting you in the process.”

“People were uncomfortable around my son due to his behaviour and temper and I did not have any spare time to see them.”

“Friends don’t get in touch anymore.”

“I do not see my friends as much as I used to because I now feel that time is so precious with my family that I would always choose to see my family over anyone else.”

Employment relationships

The emotional impact of a loved one sustaining a brain injury affected some family members’ employment relationships as well. Indeed, a quarter of all family members (25%) reported having breakdowns in the relationship with their employer.

“Employer and colleagues – initially unable to work due to emotional state, personality shift to depressive and anxious state resulted in forced redundancy.”

“My employer hasn’t understood the ongoing impact of the effect on myself after my son’s brain injury.”

2.4. Friends

A small number of friends of brain injury survivors (14) responded to the survey. Over half (56%) felt that the relationship they had with the survivor had broken down since the injury. These respondents commented on the changed behaviour and personality of the brain injury survivor, which made it hard for them to continue having a reciprocated relationship.

Spending less time with one another was also stated as a reason for growing apart from the survivor.

Half of the friends who responded to our survey did not have a partner. Of those who did, one friend reported experiencing a relationship breakdown with their partner because of the survivor’s injury, however, the relationship did not categorically end. One friend also experienced a relationship breakdown with their family, but this was not discussed in any further detail so it is not possible to draw conclusions about this.

2.5. Work relationships

Due to only receiving one response from a colleague, it has not been possible to analyse these results.

2.6. Other

A small number of respondents did not fit into the specified categories of

This included professionals and ex-partners of brain injury survivors. One ex-partner’s comment summarised the key underlying issues of relationship breakdowns after brain injury, especially between partners and survivors.

“Having cared for the brain injury survivor throughout the duration of their recovery, my mental health became affected due to the changes in their behaviour and the stresses of taking care of someone on my own. I felt here was little support available for myself, I felt trapped, hopeless and like I wasn’t good enough, our communication broke down, we stopped going out, we weren’t intimate anymore, not even cuddling, we didn’t share a bed any more, I couldn’t go out with my friends as I was too scared to leave the brain injury survivor on their own in case anything happened to them. I was unable to see friends, unable to go to my voluntary job, finances became an issue and it became stressful and too much to bear.”

Section three: Relationship changes - improvements

We asked respondents about relationships in their lives that had improve since the injury. Overall results are provided in the graph below.

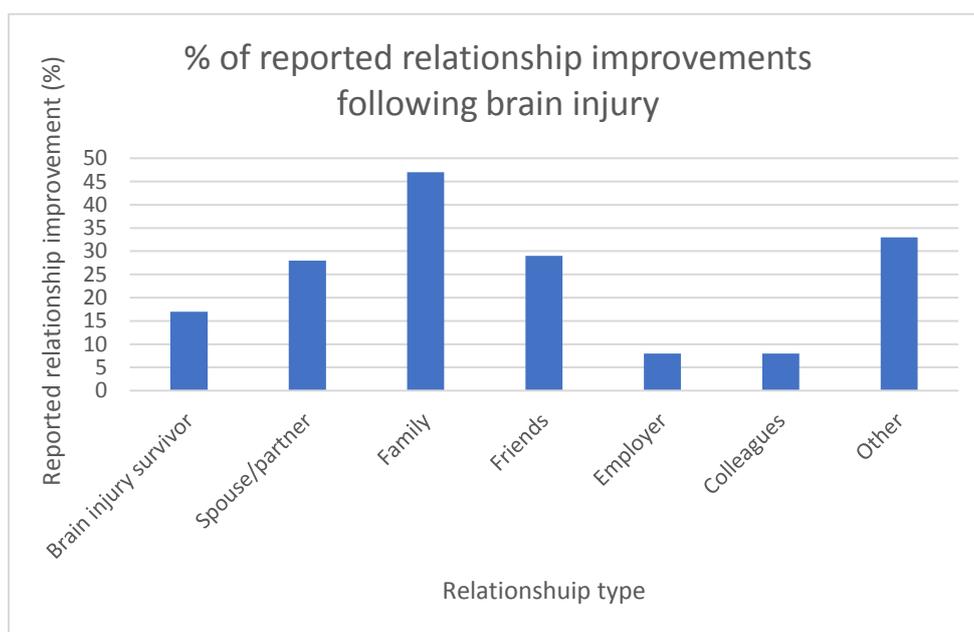


Chart 3. Relationship improvements after brain injury

Due to the range of respondents’ connections to brain injury, the following section will examine responses given by each category of respondent (brain injury survivors, spouse/partners, family, friends, colleagues) in turn.

3.1. Brain injury survivors

Spouse/partner

Over a third of brain injury survivors (34%) felt that the relationship they had with

their partner strengthened after their injury. Some survivors explained that this was due to being able to spend more time with their partner after their injury.

“Spent more time with partner.”

“Since brain injury my husband has stepped up and beyond to support and assist me. Took early retirement so we can enjoy my good days.”

“I was either working or at the gym. Now my wife and my family do more together.”

A number of survivors commented on the fact that their injury gave them and their partner a renewed realisation of how important they were to each other.

“Removal of my tumour made my husband and I grow closer together and appreciate one another.”

Survivors expressed a sense of gratitude and appreciation of partners who had an active involvement in their care, which was a factor in their improved relationship.

“My partner is so much more loving. We always had a great relationship but now he needs to look after me and he’s great at that.”

“It made me realise how much he cares for me and is willing to support me. I have so much more respect for my husband, more now than I did before. It’s made us become closer than ever.”

“My partner is very supportive; he and my mum were involved in my initial treatment after the accident.”

“My husband helped me relearn the basics, walking, toilet, control of movement etc.”

Having a spouse that helped out more with domestic chores since the survivor’s injury also increased survivors’ appreciation of them.

“My husband takes the time to listen more carefully to what I have to say. He also helps more with laundry, housework and shopping for groceries.”

The general support gained from partners who were willing to make accommodations for the effects of brain injury, and continue to provide love and care, strengthened many relationships.

“My brain injury has brought me and my partner closer together. He has been my rock and I wouldn’t have gotten through the last 9 months without him.”

“My new partner doesn’t try to label me and accepts each day as it comes. He doesn’t criticise, and if he doesn’t understand, asks questions and tries to.”

“My husband has been very supportive and reassuring on my continuing needs and encouraging me to rest more and take life at a slower pace.”

Family

47% of brain injury survivors felt that the relationship they had with family members had improved following the injury. Once again, relationships with family members were perceived to be better when family members were understanding of the survivor’s injury.

“We have become a lot closer and understanding of each other.”

“The relationships with my daughter and twin sons have improved due to them trying to understand my sometimes odd behaviour and the fact that I am able to see that they are sometimes more patient with me.”

“My family have developed a better and more in-depth knowledge of brain injury, its effect on me and how to effectively support me. They are much more supportive and understanding. We feel much closer.”

Some survivors commented on how supportive their family have been through their experience, and how invaluable this support was.

“I have come closer to my family, they have all done so much for me since my brain injury, I would have struggled without them.”

“Closer to siblings who have consistently tried to help and be supportive.”

“He is incredibly patient and understanding, and helps me with chores. Never moans if I want silence in the evening, or can’t manage going to a film or gig.”

A number of survivors even explained that they had lost contact with some family members before their injury, but the injury reunited them and strengthened the relationship again.

“My sister and I lost contact for some before my TBI. My accident bought us back together and we are now in frequent contact.”

Despite several brain injury survivors and partners commenting on the negative impact the changed role to carer had on the relationship, one survivor remarked that this changed role improved the relationship due to forcing the couple into looking after one another more than they previously had done.

“Our relationship was poor before the injury but the new roles we were forced into with me being ill and him needing to take charge was good for us.”

Friends

Many survivors had commented on their broken friendships, and indeed, this was the largest reported category of relationship breakdowns. Nevertheless, a third of survivors (33%) still felt that some of their friendships had strengthened following the injury. Friends who supported the survivor and stayed with them through their journey of brain injury were seen to be true friends, with whom the survivor shared a strong relationship.

“Best friend proved she will always be there for me no matter what.”

“I’ve realised how caring my pre-ABI friends are.”

“I’ve realised who my true friends are and cherish them even more.”

Work relationships

Just under 10% of survivors felt that the relationship they had with their employers and colleagues strengthened following the injury, once again due to the support they received from those around them within the workplace.

“My colleagues have been very helpful in my recovery and were very helpful in getting me back to work.”

“Closer to work colleagues who have been supportive.”

“I built new and better relationships with my colleagues, all of them respect based.”

Other

Some survivors explained that their injury made them closer to people in the community, such as neighbours or their local services.

“I feel closer to the community and have done new things that I would not have experienced before.”

“Neighbours have come forth to support in times of acute need such as when I need to go to the hospital or medical appointments.”

3.2. Spouse/partners

Brain injury survivor

38% of partners felt that their relationship with the brain injury survivor had been strengthened since the injury. This was sometimes attributed to the survivor’s effects changing their personality for the better.

Many partners also felt that the experience of going through a traumatic life event together made them appreciate the survivor more.

“We spend more time together as husband and wife... taking time to do those things we never had time to do before, you are more precious of what you have.”

Some partners commented on the fact that their new role of being a carer made them feel closer to the survivor.

“Because I am now a full time carer for my husband, we have grown very close.”

Family

40% of partners felt that the relationship they had with their family improved after the injury, the highest rated category of improved relationships both in general and specifically by partners. Some partners explained that this was due to the support they had received from their family.

“My husband and I could not have done as much as we could have without the close support of my sister. She has been my rock through everything from watching our children when my husband was in hospital for a year to helping out caring so I could return to work.”

Improved relations were particularly felt with family on the survivor’s side.

“I am now much closer to my brother and sister-in-law. They have been supporting me since the day of the accident.”

“He (brain injury survivor) never particularly enjoyed a close relationship with his sister but she has proved to be my rock. Despite living a 2.5 hour drive away, she has visited every week.”

“I am now much closer to my sister-in-law.”

“Closer to my in-laws.”

“Closer to partner’s parents through support and common difficulties.”

“I have also become close and have a stronger relationship with my mother-in-law than before, even though we did previously get on well anyway.”

Being able to spend more time altogether also improved many family relationships.

“The family connections are much closer too because we all make time for one another now – sometimes we allow unimportant things in our lives to take over from the most important family times. We have readdressed this now and feel we have a better family and life balance.”

Friends

29% of partners felt that going through a traumatic life event made them appreciate their friends even more, thus strengthening the friendships they had.

“It is very sad but we do not really appreciate our friendships until someone very major happens in our lives. We now totally appreciate the true friends that have been there for us and we give thanks everyday for their presence in our lives.”

Friends who offered support through things were also appreciated more.

“The friends that stuck by us are friends indeed.”

“Certain friends have been very supportive and helpful for both of us. Inviting us round for meals more frequently and regularly. Keeping in contact, offering to help with tasks and events.... asking how we are and listening when we respond.”

“My friends and his friends have been fantastic, both with emotional and financial support.”

Employment relationships

Partners who received support from their employer or colleagues felt that these relationships also improved.

“Work was very understanding, colleagues are understanding too, even those who didn’t know me when it happened.”

3.3. Family members

Brain injury survivor

Almost a third (32%) of family members who responded to our survey felt that the relationship they had with the survivor improved following the injury. Reasons given were largely similar to those given by partners.

“My brother-in-law, since his accident is more open with his feelings and we talk more about that.”

“My husband and I work as a team and support each other. We are more aware of each others’ feelings.”

“My father has become more loving and ready to discuss his feelings since his brain injury. He had had to accept help from us and this has brought us closer together.”

Other family members

Family members also reported that the shared experience of the injury brought

in the family closer together. In fact, over half (54%) of the family members responding to our survey felt that their relationship with other family members had improved.

“It was the biggest challenge of our lives, but my dad and my brother and I all faced it together... facing adversity like that made us incredibly close and grateful for each other.”

“I think our whole family has become a lot closer since the accident as we all now know you cannot take anyone or anything for granted and also know how precious time is.”

“Brought us closer as a family and more protective.”

“My father has the brain injury and he is more open about things since. It’s also caused our wider family to come together.”

Partner

Some family members also remarked on how well supported they were by their partners, deepening this relationship as well. Almost a quarter (21%) of family members said that the relationship they had with their partner improved after the injury.

“My partner has supported me through my darkest days and continues to consider my needs sensitively. Our relationship is stronger and solid.”

“My husband was a rock through the whole ordeal and has always been there to listen and advise.”

Family members who were the parent of a brain injury survivor commented on how the relationship with their partner (the survivor’s other parent) was strengthened.

“Became closer and stronger because of having to put up a united front and fight for help for our son.”

“Our son was only 14 when his accident happened. My husband and I are much closer now having gone through all we did with our son. It’s a battle, but we never tire of his little achievements. We celebrate them. We love our son and are very proud of him. This has made my hubby and I so much stronger.”

Friends

A small number of family members felt that their friendships had improved following the injury (17%). Once again, this was due to the support given by friends through a time of difficulty.

“My friends offered a great deal and support which I feel strengthened our relationships.”

“I have a network support system of four very close friends who took in my youngest daughter as I spent 320 days in a rehab centre with my injured daughter 300km away. I couldn’t have gotten through it without them, and you realise that you really can count true friends on one hand.”

Work relationships

Some family members felt that the relationship they had with their employer (7%) and colleagues (6%) improved following the injury, yet again due to the support they were offered through this time.

“My employer also took a sympathetic stand and my colleagues were very supportive.”

3.4. Friends

Only a few friends of brain injury survivors responded to our survey, and of those who responded only a few commented on improved relationships. Of the friends who did, 20% felt that their relationship with the survivor had improved due to the survivor’s new personality being more manageable than before the injury.

“I’m better friends with the brain injury survivor now than I was before, mainly due to her personality change. She is less wild now, but more opinionated.”

30% of friends commented on their improved relationships with their own family and friends, due to having a renewed appreciation of the importance and value of significant people in their life.

3.5. Work relationships

Due to only receiving one response from a colleague, it has not been possible for us to analyse these results.

Section four: statements

In this section we asked brain injury survivors to what extent they agreed with a few statements, which comprised the following:

- *My friends are a source of support for me*
- *My family is a source of support for me*
- *My partner is a source of support for me*
- *I have high self-esteem*
- *I am satisfied with my life*

Due to the range of respondents' connections to brain injury, the following section will examine responses given by each category of respondent (brain injury survivors, spouse/partners, family, friends, colleagues) in turn.

4.1. Brain injury survivor

Over half of the brain injury survivors (57%) who responded to our survey agreed that their friends were a source of support for them. This came despite the fact that almost 70% of brain injury survivors reported breakdowns in their friendships following the injury. However, those survivors who reported having a stronger relationship with their friends following the injury gave a number of reasons for this, which could underlie the sense of support received from their friends reported in this section.

71% of survivors felt that their family was a source of support them, with only 14% feeling that their family was not a source of support for them. Indeed, this was the highest rated category where relationships had been perceived to be improved following the injury, with practical support and renewed appreciation being listed as key reasons for strengthened relationships with family members.

24% of respondents did not have a partner, so this statement did not apply to them. However, of all of the brain injury survivors, just over half (56%) felt that their partner was a source of support for them, whilst only 13% felt they were not.

There were slightly more brain injury survivors who were dissatisfied with their life (41%) than those who were satisfied (33%).

Over half of the survivors disagreed with the statement that they had high self-esteem (55%) whilst only 23% agreed.

These findings reflect a generally negatively-oriented outlook towards life and oneself following brain injury. We examined whether these low ratings of self-esteem and life satisfaction were related to relationship breakdowns in brain injury survivors' lives.

We found that where survivors had higher numbers of relationship breakdowns, this was reported with a stronger disagreement of the statement 'I have high self-esteem' This is illustrated in Chart 4 on the following page.

A similar pattern was found when examining agreement with the statement regarding life satisfaction. However, this pattern was most prominent for the category of work relationship breakdowns, and barely apparent for the relationships of friends, family and spouse/partner. This is illustrated in Chart 5 on the following page.

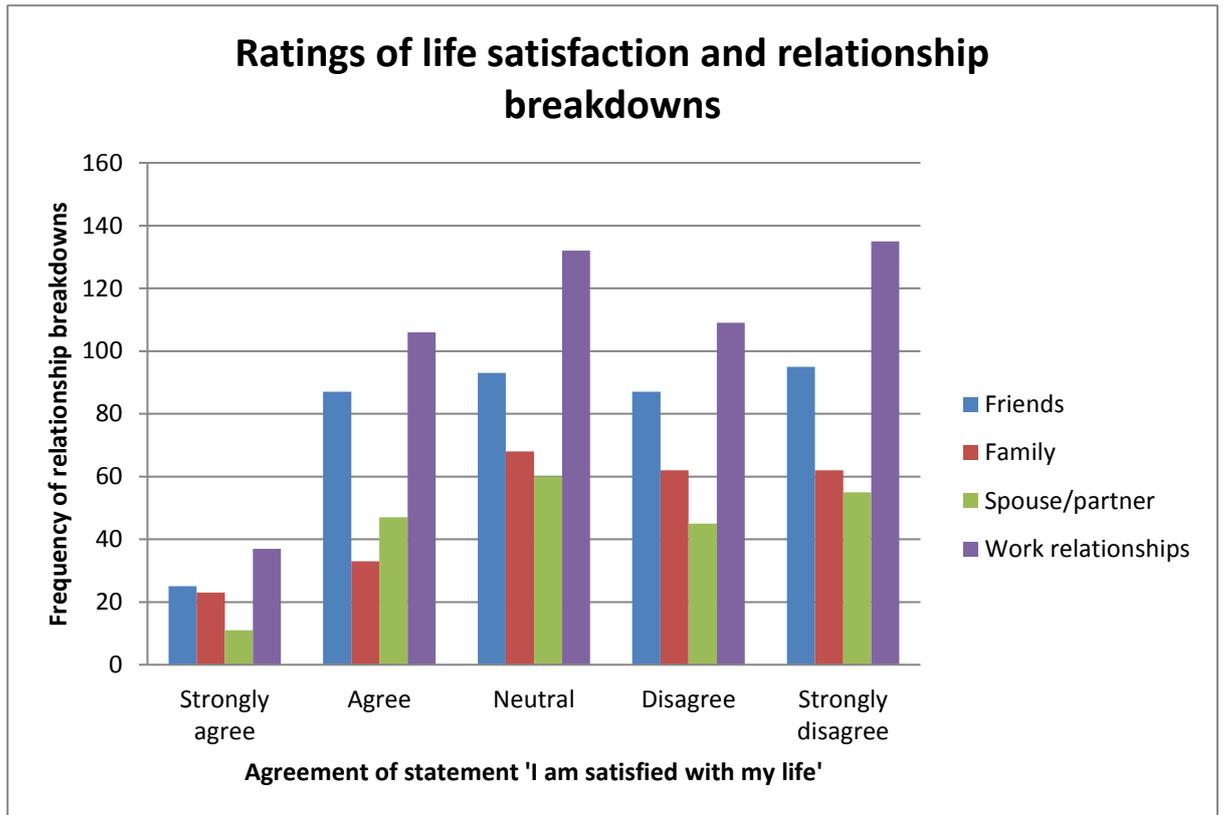


Chart 4. Ratings of life satisfaction and relationship breakdowns

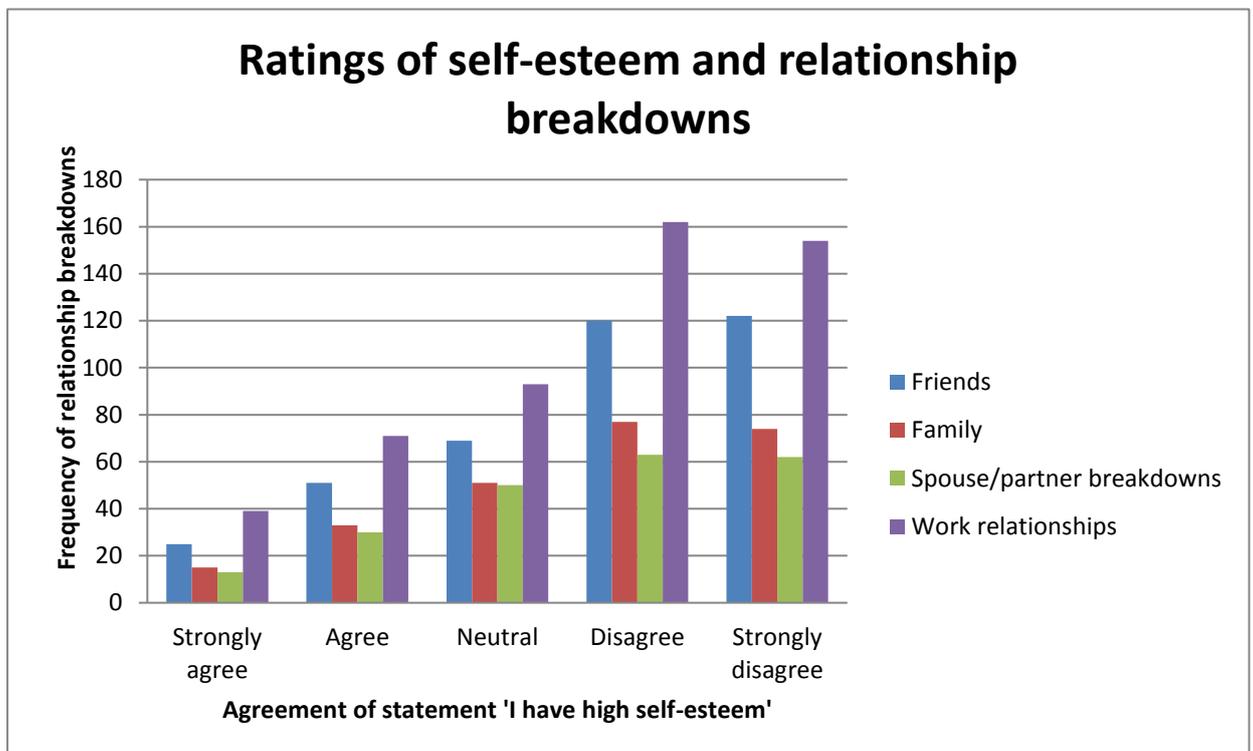


Chart 5. Ratings of self-esteem and relationship breakdowns

Statements from survivors regarding work relationship breakdowns show that an inability to return to work following injury is the main cause for their relationships with employers and colleagues to break down. Being unable to work can, for many, be a major source of fulfilment and life satisfaction, which could account for why this category of relationship breakdowns was more strongly associated with low life satisfaction than other categories.

4.2. Spouse/partner

Over half of the spouses/partners to complete our survey (64%) felt that their friends were a source of support for them. Similar to brain injury survivors, this comes despite the fact that over half of the spouses/partners reported a high number of friendship breakdowns following the injury. However, spouses/partners who gave further information on this explained that those friends who had stayed with them through their difficult time had been very supportive.

Many spouses/partners had talked about the support they received from their family, and this was reflected by the number of spouse/partners who agreed with the statement 'My family is a source of support for me', to which 66% agreed. Only 14% disagreed with the statement.

Only 37% of spouses/partners felt that their partner (i.e. the brain injury survivor) was a source of support for them. However, only a slightly higher number of spouses/partners disagreed with the statement (39%); therefore, leading us to conclude that there almost equal numbers of spouses/partners who felt their partner, the survivor, was a source of support for them and those who did not.

More spouses/partners disagreed than agreed with the statements regarding being satisfied with life and having high self-esteem; however, not by a large amount. 42% of partners/spouses disagreed about being satisfied with life, whilst 29% agreed that they were satisfied. 47% of partners/spouses did not have high self-esteem, whilst 30% did. However, for each of the statements regarding life satisfaction and self-esteem, around a quarter of spouses/partners (29% and 22%, respectively) felt neutral.

4.3. Family members

Half of the family members responding to our survey agreed that their friends had been a source of support for them (50%). In fact, very few family members (20%) disagreed with the statement, whilst almost a quarter (24%) felt neutral towards it.

78% of family members felt that the rest of the family were a source of support for them. Again, very few disagreed with the statement (8%), whilst just over 10% felt neutral (13%).

Almost 20% of the family members responding to our survey did not have a partner, but despite this 60% of these respondents felt supported by their partner whilst only 7% did not. 14% felt neutral about this.

We can infer from the levels of agreement towards the above statements that family members therefore tend to feel well supported, especially by others in the family and partners.

We also found that family members generally reported higher levels of life satisfaction and self-esteem than the other categories of respondents so far discussed. Almost half of the family members felt satisfied with life (46%), which could be explained by the level of support they receive from others in their life. Only 25% of family members reported being dissatisfied with life, whilst 23% felt neutral towards this.

Despite high ratings of life satisfaction, ratings for high self-esteem were more or less evenly spread across respondents, with almost a third agreeing with low, neutral and high self-esteem (36%, 31% and 28%, respectively). We can therefore conclude that these constructs were perhaps not influenced by the experience of brain injury in the family, possibly due to their being more removed from the survivor and therefore spending less time with them than, for instance, a partner.

4.4. Friends

Around a third of the friends who responded to our survey did not respond to the questions regarding agreement with the statements. Of those who did, the majority agreed that their own friends (63%), family (88%) and partners (where relevant, 50%) were a source of support for them.

Life satisfaction and self-esteem were generally more negatively rated than positively, however as this was more or less equally rated across the categories of 'agree', 'neutral' and 'disagree', it is not possible to draw firm conclusions on these statements.

4.5. Work relationships

Due to only receiving one response from a colleague, it has not been possible for us to analyse these results.

Conclusion

The results from this survey show that relationships can change after brain injury, not only between the survivor and the people in their life, but also between those in the survivor's life and the social network around them. Thus, our survey results clearly demonstrate the wide-reaching ripple effect of brain injury.

Further, we found that there is an almost equal split in the number of people who feel relationships improve, to those who feel they break down after brain injury in the relationship categories of brain injury survivor, family and spouse/partner, demonstrating that these relationships are not predominantly negatively affected following brain injury, as some may suppose. Rather, experiences vary across individuals, and rely on several factors such as support gained and levels of understanding of brain injury.

Friendships, however, are mostly reported to break down after brain injury, leading to a loss of social support that can affect many survivors' and partners' quality of life. Relationships with colleagues and employers are also commonly reported to break down after injury, however this can be attributed to being unable to return to work, and therefore seeing less of the employer/colleagues, in many instances.

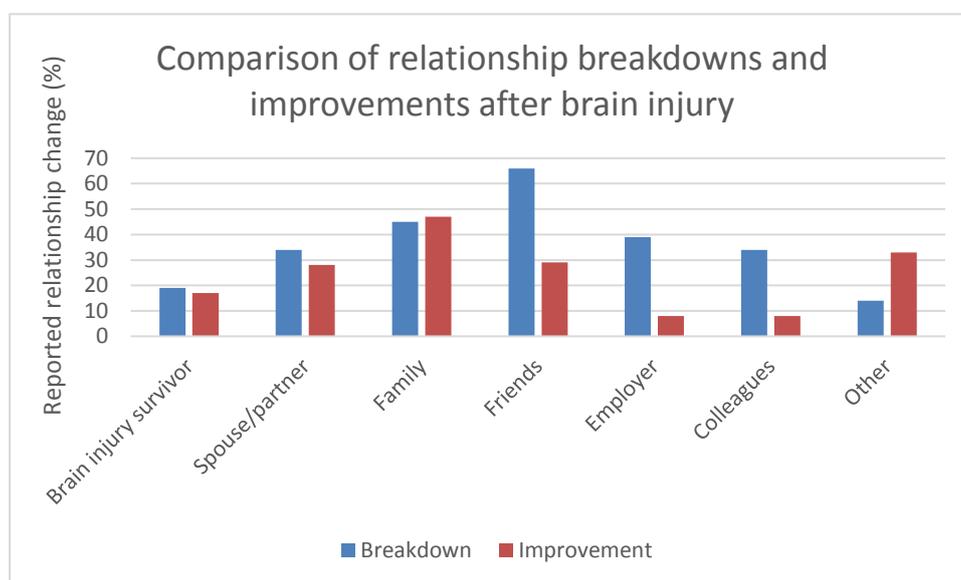


Chart 6. Relationship improvement and breakdown comparisons after brain injury

A number of reasons have been given by survivors, families and friends alike as to what typically improved relationships and what caused them to break down. Having a good understanding about brain injury, receiving practical and emotional support, having a renewed appreciation of life and the survivor, and having shared experiences all, understandably, caused relationships to strengthen.

Changes in the survivor's personality were considered to be a major factor in relationship breakdowns. Although this was discussed by partners, family members and friends, survivors themselves were often aware of this.

A lack of understanding about brain injury also strained many relationships, as allowances were not made for things such as the survivor's behaviour (for instance

by family members), or no longer having time to socialise (for instance by partners' friends.)

While the changed role from partner to carer was seen by many survivors and their partners as having a negative influence on relationships. Other partners felt that this actually brought them closer to the survivor, therefore ultimately strengthening the relationship. We can therefore conclude that such factors may not, in fact, be inherently bad, but depend on subjective interpretation and personal attitudes.

Our findings highlight the importance of ensuring that practical and emotional support, as well as information is offered to people around the survivor, as well as the survivor themselves, as this can ultimately serve to strengthen relationships. This, in turn, often improves the survivor's self-esteem and life satisfaction.

Headway strives to provide information to people in the brain injury survivor's life, to raise awareness of how brain injury affects different relationships. A series of publications providing bespoke information and advice to partners, friends, co-workers and other family members is available from www.headway.org.uk/information-library.

For more information about getting support from Headway, visit www.headway.org.uk.

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