

A New Me: Experiences of life after brain injury

A study to explore how brain injury survivors feel their lives and sense of identity change following their injury



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Introduction

In Spring 2017 Headway conducted a survey to explore how brain injury survivors feel their lives and sense of identity change as a result of acquired brain injury. The survey also sought to explore brain injury survivors' attitudes towards the anniversary of their injury, and what the phrase 'a new me' meant to them.

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

The survey was designed to inform Headway's 2017 *Action for Brain Injury Week* campaign entitled *A New Me*. The campaign set out to challenge misperceptions of brain injury while demonstrating the value of having access to the right help at the right time.

The questionnaire was hosted on the Survey Monkey website (www.surveymonkey.net) and promoted via emails 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 20 February 2017 to 24 April 2017. It consisted of both closed and open-ended questions to gather quantitative and qualitative responses.

862 brain injury survivors 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.

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Key findings

How brain injury survivors' self-identity changes following their injury.

74% of people living with brain injury agree that they feel like a new person following their brain injury.

76% of people living with brain injury agree brain injury had a negative impact on their life. Despite this, **53% still feel positive about the future.**

62% of people living with brain injury acknowledge the anniversary of their brain injury. Of those who positively commented on their anniversary, **1 in 10** explicitly mentioned acknowledging it as **a new birthday.**

85% of people living with brain injury feel they have had to accept that they will never be the person they once were.

How brain injury survivors' lives change following their injury.

69% of people living with brain injury feel that their self-esteem is worse following their brain injury.

76% of people living with brain injury feel that their employment opportunities are worse following their brain injury.

56% of people living with brain injury feel that their home life is worse following their brain injury. **75% of people did feel that their spouses have a good understanding** of their brain injury; however, only **52% feel that other family members have a good understanding.**

77% of people living with brain injury feel that the people in their life do not understand their brain injury. Further, **81% of people feel that their life would be better if people did understand their injury.**

72% of those who had returned to work following their injury feel that their employer does not have a good understanding of their injury. **73%** of those feel that their colleagues do not have a good understanding either.

Executive summary

The results of the Headway survey demonstrate that brain injury survivors feel a change in their sense of self-identity following their injury, and that there are many aspects of life, both personal and social, that are affected. Nevertheless, many survivors continue to feel positive about the future, and harbour positive feelings on the day of the anniversary of their injury.

The survey also found very mixed responses towards said anniversary, and life in general, with some survivors expressing feelings of new-found resilience and appreciation of life, and others expressing a sense of loss and grief for the 'old life'. There were also survivors who expressed mixed feelings, and some that preferred not to acknowledge their anniversary date at all.

These mixed attitudes highlight the fact that every brain injury is unique and that the experiences and feelings survivors have vary from person to person.

There were high figures among brain injury survivors who felt that others in their life do not understand their injury, which can have a negative impact on their rehabilitation process and ability to play an active role in their local communities. This is highlighted by the statistic that 81% of survivors feel that their life would be improved if people had a better understanding of their injury.

These figures substantiate the need for there to be greater public awareness of how brain injury can affect a person, which Headway strives to do through the *Action for Brain Injury Week* campaign and ongoing awareness-raising work by the charity.

Survey results - A New Me: Experiences of life after brain injury

This questionnaire was intended for anyone with a brain injury. The aim was to assess how people felt their lives and sense of identity had changed following their brain injury.

Section one: Demographics

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

Age of respondent	Frequency
Under 18	6
18-24 years	27
25-34 years	106
35-44 years	194
45-54 years	267
55-64 years	198
65+ years	59

Table 1. Age of respondents

Time since brain injury	Frequency
0-6 months	28
6-12 months	46
1-2 years	109
2-5 years	247
5-10 years	174
10-20 years	144
20+ years	105

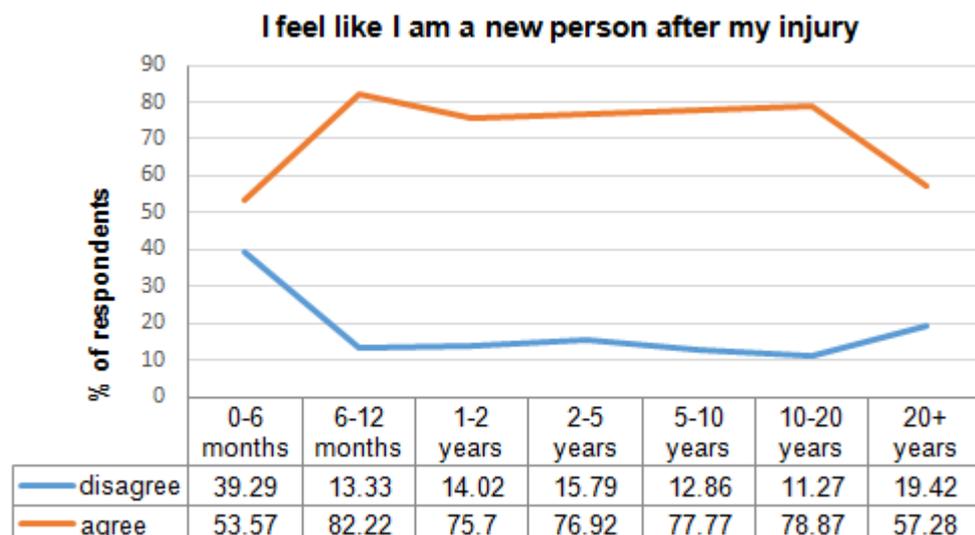
Table 2. Time since respondents' brain injury

Section two: Positive and negative statements

In this section we asked brain injury survivors to rate how strongly they agreed or disagreed with a number of statements pertaining to attitudes towards life after brain injury. We used a 5-point Likert scale of the following items: strongly disagree, disagree, neutral, agree, strongly agree.

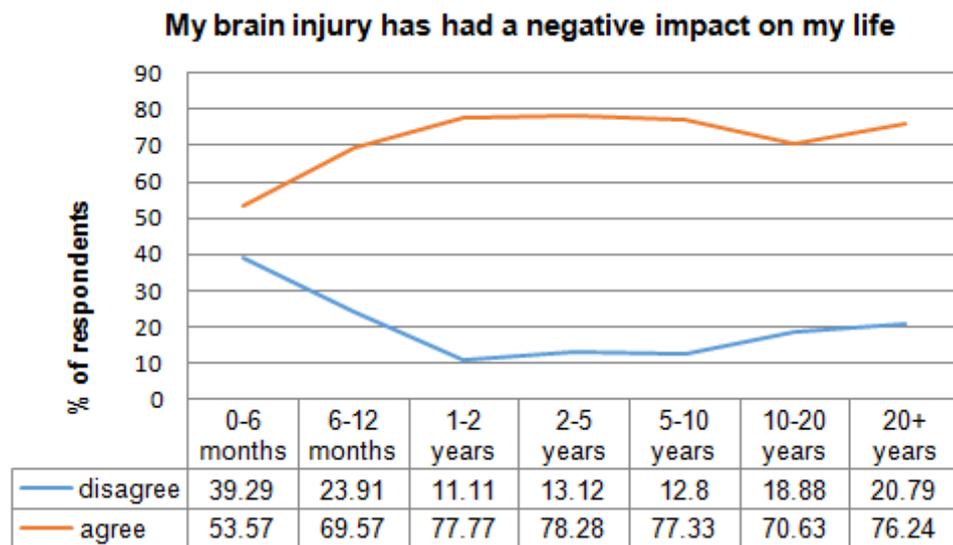
1. I feel like I am a new person after my brain injury

- 74% of respondents agreed that they feel like a new person following their injury. Of these, 45% 'strongly agreed' with the statement. Only 15% of respondents disagreed with the statement, and 10% felt neutral.
- Qualitative responses of what the phrase 'a new me' means to brain injury survivors are discussed in section four.
- Feelings of being a new person following their injury were related to length of time since the injury. During the first six months of the injury, there wasn't a great difference between respondents who agreed and disagreed with the statement (54% and 39% respectively). This difference increased by 6-12 months in an inverse correlation, with the number of respondents who agreed with the statement rising to 82%, and those who disagreed dropping to just over 10%. This indicates that following the first year, brain injury survivors mostly agree that they are a new person. This trend continues up to 20 years, at which point the number of respondents who agreed with the statement dropped. Nevertheless, even 20 years later, over half the respondents felt they are a new person after their injury.



2. My brain injury has had a negative impact on my life

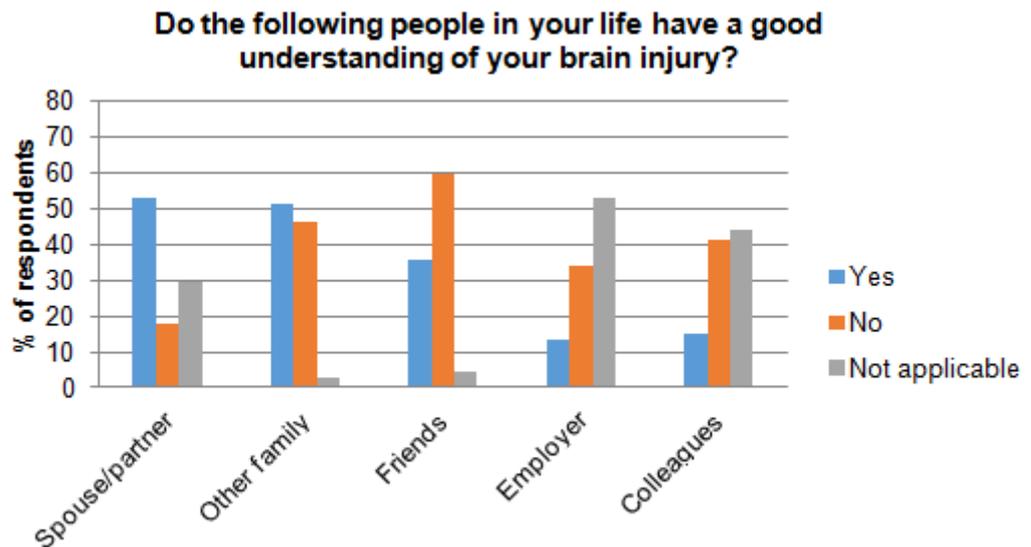
- 76% of respondents agree that brain injury has had a negative impact on their life. Of these, almost half (49%) strongly agreed with this statement. 15% disagreed with the statement and 9% felt neutral.
- Feelings of brain injury having a negative impact on respondents' life were related to the length of time since the injury. During the first two years, the number of respondents that agreed with this statement increased, indicating that as time goes on, more people feel that their life has been negatively affected following their injury.
- Even after 20 years had passed, over three quarters of respondents (76%) still felt that their brain injury had a negative impact on their life, demonstrating the long-term negative impact of brain injury.
- Aspects of life that were rated to be worse following the brain injury are discussed in section three.



3. People in my life do not understand my brain injury

- 77% of respondents agreed that the people in their life do not understand their brain injury. 14% of people disagreed with this statement, while 9% felt neutral about this.
- Brain injury survivors were asked in a separate question which people in their life they felt had a good understanding of their injury.

Responses to this are displayed in the chart below.



- Of those respondents with a spouse/partner, 75% feel that their spouse/partner does have a good understanding of their brain injury, compared to only 52% who feel other family members have a good understanding of their injury.
- 'Friends' was the highest-rated category of people who do not have a good understanding of brain injury, at 63%.
- 53% of respondents do not have an employer while 44% do not have colleagues. For those respondents who do have both, 72% felt their employer does not have a good understanding, while 73% felt colleagues do not have a good understanding.
- Feelings of people in the respondents' life having a good understanding of brain injury were not related to time since the injury.

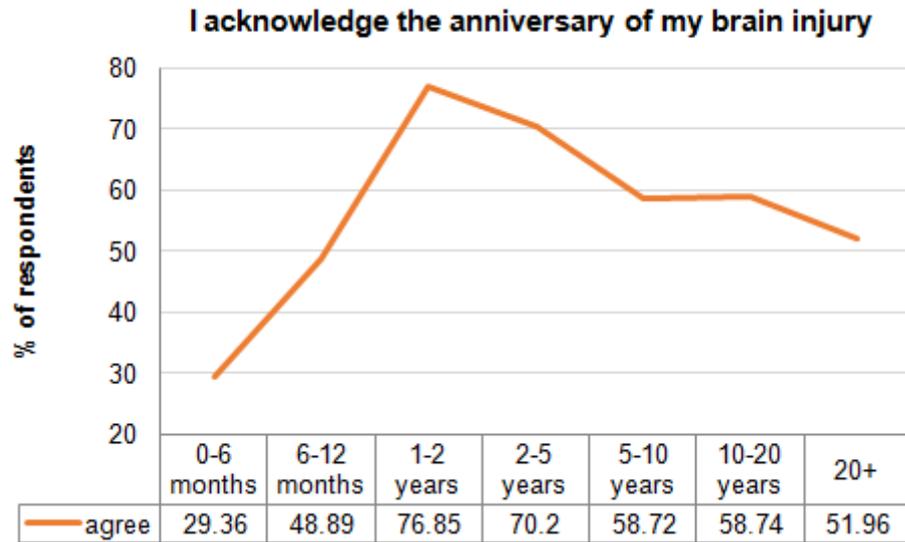
4. I acknowledge the anniversary of my brain injury

- 62% of respondents acknowledge the anniversary of their brain injury, with 42% strongly agreeing with this statement. 21% of respondents did not acknowledge their anniversary, while 17% felt neutral.
- Feelings towards acknowledging the anniversary were varied, with some respondents reporting positive feelings, marking it as a time of positive reflection over their recovery since the injury and celebration of achievements.

- *“Remembering how life was and how it is now gives a greater appreciation of everyday things we take for granted like sight, was blind but can now see to a degree.”*
- *“Positively, I say it's the best thing that could have happened to me, it's taught me so much about myself and made Me an even stronger and determined individual than I was before, it's made me see life from a different perspective, yes I will never be able to do my dream job because of it but I'm still able to achieve my dreams and goals in other ways, if it had never happened to me I wouldn't be anywhere near as hungry to succeed as I now am!”*
- *“Positive as I would never have become a trauma therapist if I did not have my own story to tell and inspire other people.”*
- Of the respondents that reported positive feelings, 1 in 10 people explicitly mentioned acknowledging it as a new birthday.
 - *“Every year on my anniversary I go out and celebrate it as a new birthday as I can't remember my birthdays before my accident.”*
 - *“I celebrate it like my actual birthday with cake, cards, and sometimes the odd present, I celebrate with my new ‘adopted’ (not actually adopted but my new friends who accept me as my brain injury and all) family.”*
- Some respondents had negative feelings towards their anniversary, commenting on the sense of loss of their self and ‘old life’.
 - *“I cry for the woman that I was, the children that I haven't been able to have. The loss of my career (I was a senior OT with 20 years experience including neuro rehab). It's like one big sick joke that isn't funny. I become extremely low every year on the anniversary of my 'worst day'.”*
 - *“I do think about the experience that changed my life. How I have progressed beyond expectations of professionals and how stubborn I have had to become. I am still grieving for the old*

Jane who was independent, worked, drove and had a social life.”

- *“I leave flowers at the crash location and ask “Why???”*
- A number of respondents commented on the fear and anxiety they experience on the anniversary of their injury.
 - *“It is scary. I always feel something terrible will happen.”*
 - *“Don't go out. In case something happens or I cannot control my reactions to any situation beyond my control.”*
- Others acknowledge the anniversary but feel ambivalent towards it, while 47 respondents reported having mixed feelings.
 - *“I do feel sad when I look back to how my life has changed beyond recognition, but I have met new friends with brain injuries who have become my second family!”*
 - *“I reflect on both I feel sad for the person and life I once had but then I feel happy I survived and feel proud of my achievements and how I have and still am coping with the new me and in some aspects my life is better as I have a totally different outlook on life.”*
 - *“I acknowledge the date and I'm grateful that I survive but I also mourn the loss of the person I was before it happened as I was at the best I'd ever been and that was taken away from me by my brain haemorrhage.”*
- Acknowledgement of the anniversary of the injury was related to length of time since injury.



- Acknowledgement of the anniversary of the injury increased over the first two years, peaking at 1-2 years following the injury, indicating the first year being the most acknowledged anniversary. Following two years, acknowledgement reduced. However, even 20 years on, over half of the respondents (52%) still reported acknowledging the anniversary of their injury.

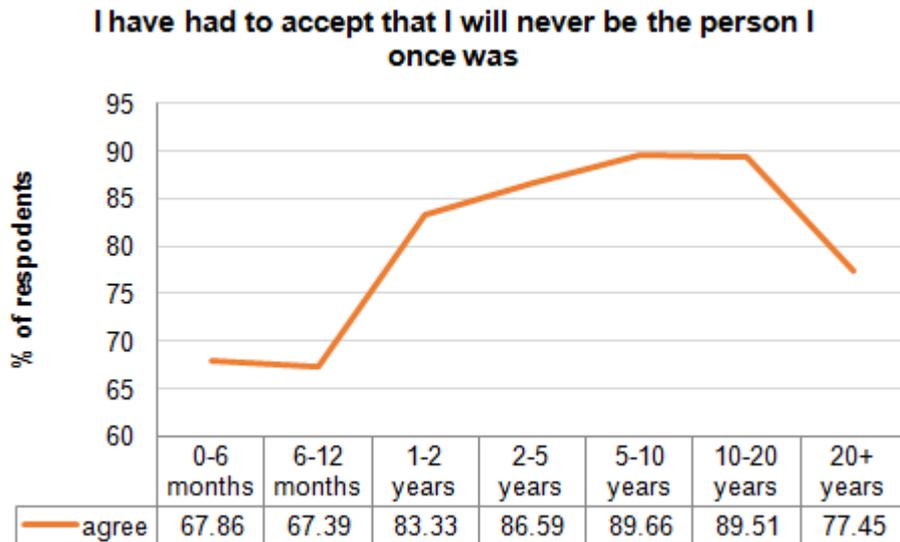
5. My life would be improved if people had a better understanding of my brain injury

- An overwhelming 81% of respondents feel that their lives would be improved if people had a better understanding of brain injury. Only 7% disagreed with this statement, while 11% felt neutral.
- As reported earlier, many people feel that friends, colleagues and employers do not have a good understanding of their brain injury.
- Feelings of life being improved if people had a better understanding of brain injury were not related to length of time since the injury.

6. I have had to accept that I will never be the person I once was

- 85% of respondents agreed that they have had to accept that they will never be the person they once were, with 67% strongly agreeing with this statement. Only 9% of people disagreed with this statement and 6% felt neutral.

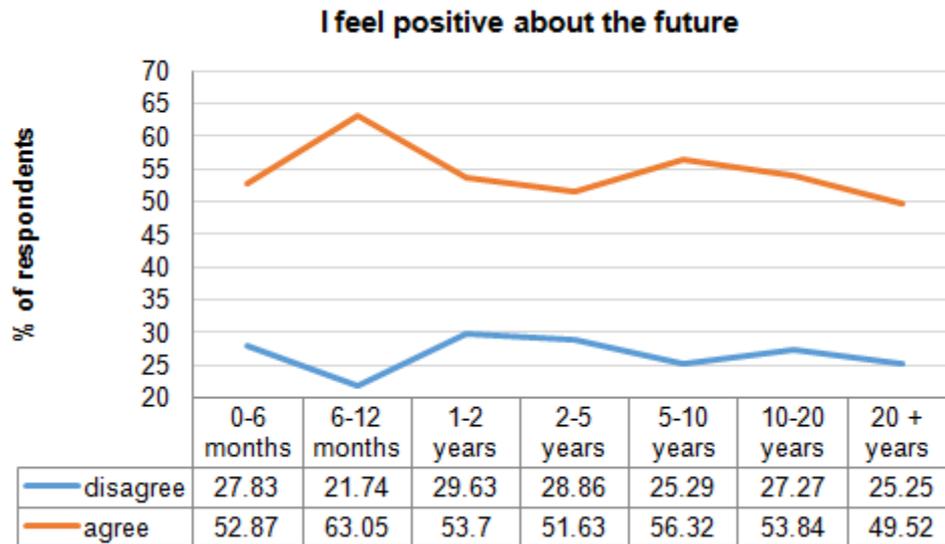
- Acceptance of never being the pre-injury self was related to length of time since the injury.



- Acceptance of never being the same person increases after the first year and continues to steadily increase in the years that follow. After 20 years acceptance drops, although this still remains high at 77%.

7. I feel positive about the future

- Despite many respondents reporting that brain injury has had a negative impact on their life, over half agreed that they felt positive about the future (53%). 28% disagreed with this statement, 19% felt neutral.



- Respondents felt most positive about the future one year after their injury; however, following the first year, feelings of positivity reduced. These findings show that during the first year, many brain injury survivors feel optimistic about the future; however, as time goes on, positive feelings reduce as the full impact of the brain injury is realised. Indeed, this is reflected in research which found that in the first year, brain injury survivors may not fully realise the full effects of their injury and may experience a degree of denial and dysfunctional self-awareness (Teasdale et al, 1997).

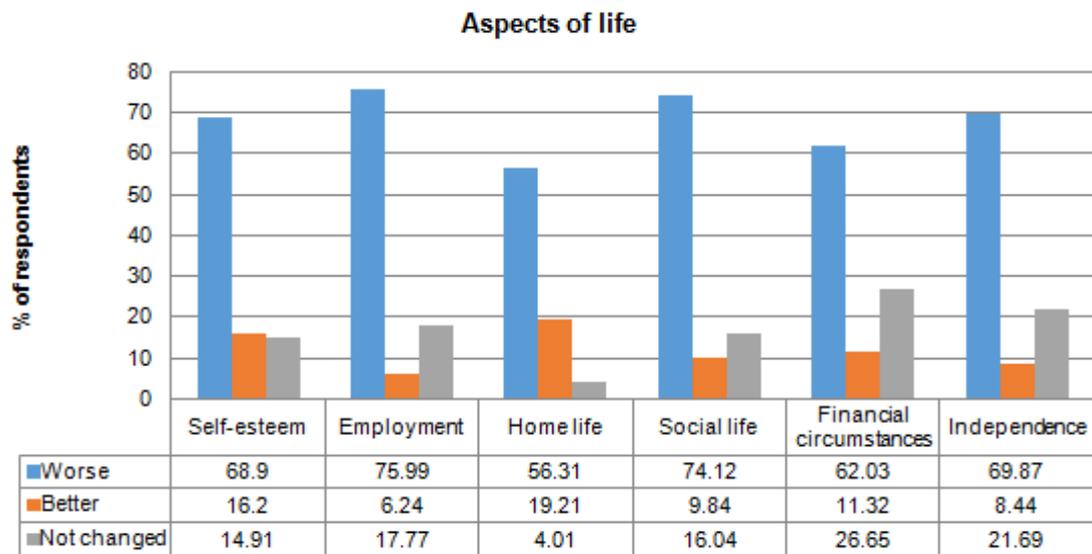
Summary

Brain injury survivors reported changes in their identity and life following their injury. These changes were mostly reported to be negative, although this improved in some respondents over time. Many changes in attitudes towards the injury change following the first year of the injury.

Despite the negative impact of brain injury on survivors' lives, many survivors continue to feel positive about the future, even many years later.

Section three: Aspects of life

In this section we asked brain injury survivors to rate whether the following aspects of their life were better or worse following their brain injury: self-esteem, employment, home life, social life, financial circumstances and independence. We used a 5-point Likert scale of the following items: much worse, worse, not changed, better, much better.



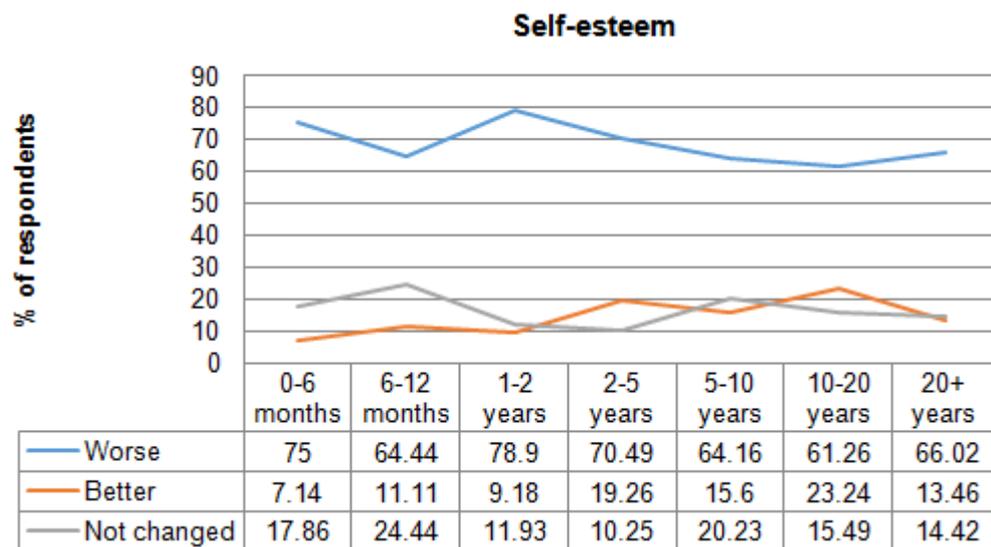
- Around three-quarters of respondents felt that their employment (76%) and social life (74%) are the most negatively affected aspects of their life following their brain injury.
- Over two-thirds of respondents feel that their self-esteem (69%) and independence (70%) are worse after their brain injury.
- 62% of respondents feel that their financial circumstances are worse after their brain injury.
- Over half of respondents (56%) feel that their home life is negatively affected after brain injury. However, they feel that out of the six aspects of life, their home life is the least negatively affected. Almost 20% reported that their home life had improved, and 4% said it had not changed at all.

1. Self-esteem

- 69% of respondents feel that their self-esteem is worse following their injury. Out of these respondents, three-quarters feel that their self-esteem is worse at 0-6 months. However, after 1-2 years, the percentage of respondents who felt that their self-esteem got worse

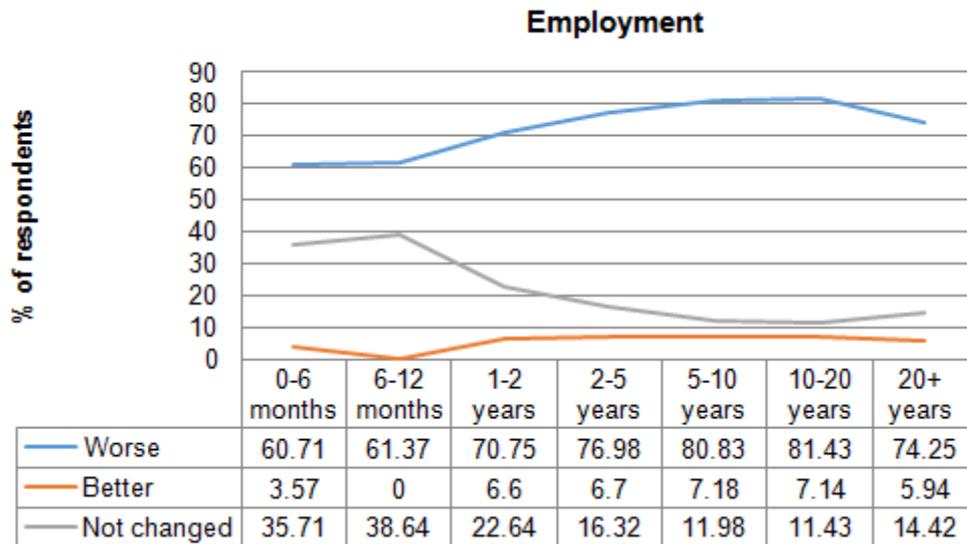
decreased as time passed since their injury, while the small number of respondents who felt their self-esteem was better increased following this same time point. Self-esteem was therefore seen to improve over time following brain injury.

- Despite this, only 16% of brain injury survivors feel that their self-esteem is better following their injury and 15% feel that it hasn't changed.



2. Employment

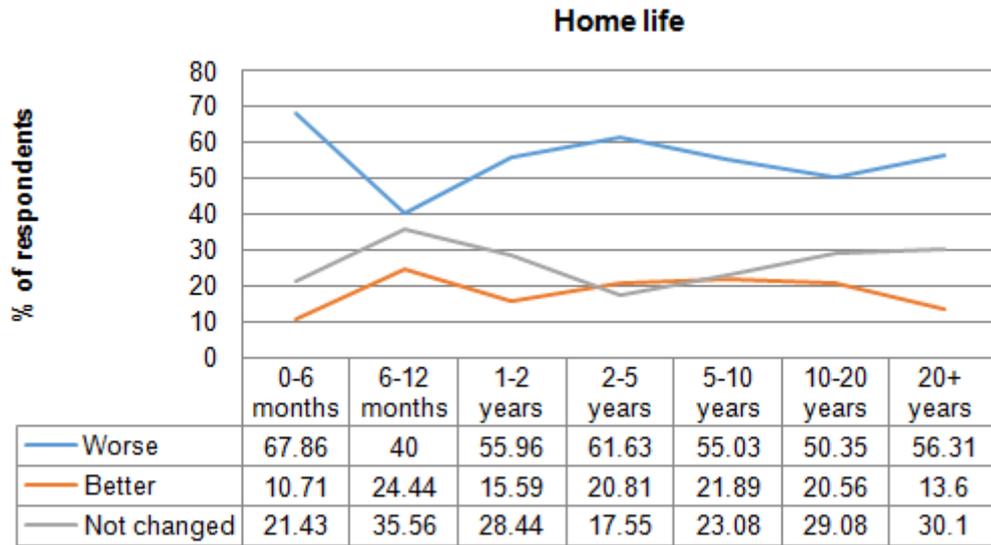
- Over three-quarters of brain injury survivors (76%) feel that their employment circumstances are worse after brain injury. Only 6% of respondents feel that their employment circumstances are better.
- At 0-6 months, 61% of respondents feel that their employment circumstances are worse following their injury.
- Following one year, employment improved for a very small number of respondents, although many more people report employment getting worse as time goes on.



- Research has found that of brain injury survivors who returned to work in the first few years of their injury, 32% were unemployed five years later (Olver, Ponsford & Curran, 1996). Further, work stability is reported to be low among brain injury survivors (Hoofien, Gilboa, Vakil & Donovanick, 2001).

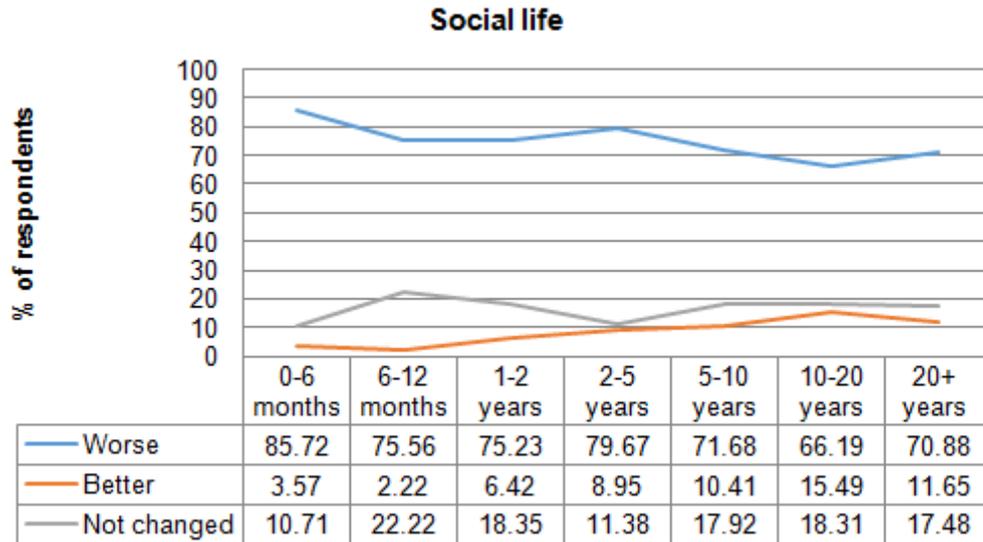
3. Home life

- Home life was the least negatively affected aspect of life, with just over half of the respondents (56%) feeling that their home life was worse.
- At 0-6 months over two-third of respondents (68%) feel that their home life was worse since their brain injury. However this improved over time and after 10-20 years only half of the respondents (50%) feel that their home life was worse.



4. Social life

- 74% of brain injury survivors feel that their social life was worse since their brain injury. This can be understood in light of the finding that many survivors feel their friends, employers and colleagues do not have a good understanding of their injury.
- This supports research previously conducted by Headway which examined the experience of social isolation among brain injury survivors who lose their friends and relationships following brain injury (*Experiences of stigma and discrimination among individuals with brain injuries – Headway/the University of Exeter, 2008*).
- Social life was seen to gradually improve as time goes on following the injury; however, even 20 years later over 70% of respondents still reported their social life being worse.

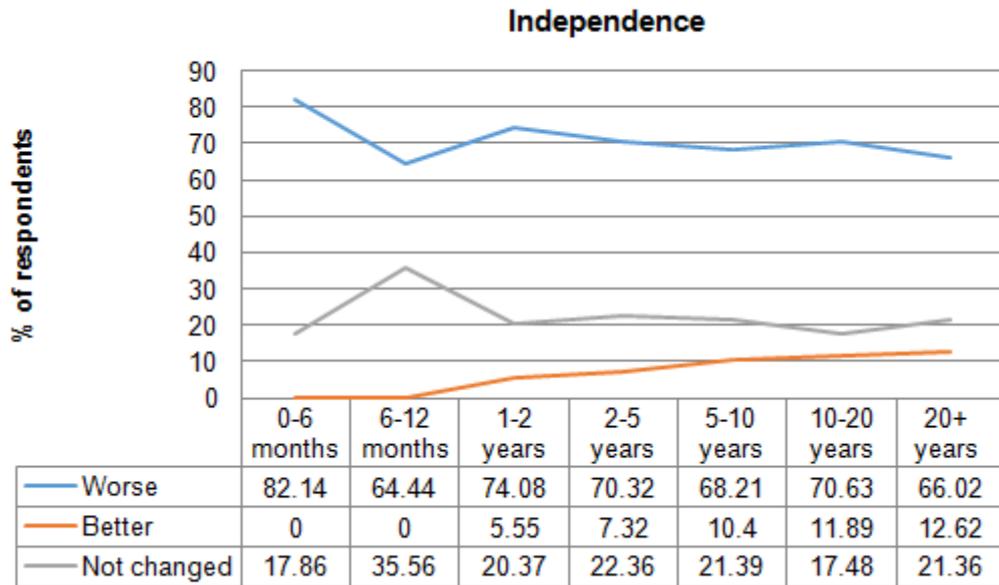


4. Financial circumstances

- 62% of respondents feel that their financial circumstances are worse after brain injury.
- 27% feel that their financial circumstances have not changed since their brain injury. Out of the other five aspects of life, financial circumstances were the least changed after brain injury.

5. Independence

- 70% of respondents feel that their independence is worse after brain injury. 8% reported feeling that their independence got better and 22% reported that it had not changed.
- Independence was rated to be at its worst at 0-6 months, with 82% of respondents feeling that it was worse during this time. Independence was seen to improve for respondents in the following years; however, after 20 years 66% still felt that their independence was worse.
- At 6-12 months there is a sudden decrease in respondents feeling that their independence has worsened, while simultaneously independence is reported to improve during this time. This is likely a reflection of the improvements gained through early rehabilitation and the brain's recovery process during the first year of brain injury.



Summary

Many aspects of life are negatively affected after brain injury. Employment and social life are rated as being the most negatively affected aspects of life after injury. Even after 20 years, brain injury survivors still feel that various aspects of their lives are negatively affected. However, some aspects do improve over time, especially independence.

Section four: interpretation of 'a new me'.

In this section we asked brain injury survivors to explain what the phrase 'a new me' meant to them.

Responses to this question were varied, with most respondents commenting on it meaning a new identity following their injury. Even within this feelings were mixed, with some respondents feeling as though they preferred their new identity and others commenting that they missed their 'old selves'.

Some respondents described how they preferred their 'new self' to their pre-injury self, and that their brain injury changed the way they navigated through life for the better.

- *"Not the person I once was. I much prefer the 'new me' now."*
- *"I'm more empathetic now, and take things very slowly too, and that's good! I always was so busy, but now I do mindfulness."*
- *"More time with family and friends and better quality of life. No meetings to attend any more and no more stress of work on my mind."*
- *"An improved me - someone who appreciates life and loved ones and seeks to help others/give back as a way of being grateful for the opportunity."*

Acceptance to the 'new' self was commented on by many respondents as being a central part of adapting to their new life.

- *"I am determined to adapt to the changes in me and although at the moment the fatigue dictates what I'm able to do, I'm making slow improvements. So the new me is trying to stay positive and accepting and adapting to all the changes. Acceptance that I am different to before the stroke is a big thing for me."*
- *"I have changed it did not matter if I wanted to, it happened. I had to start again and did. You cannot walk forward looking over your shoulder. So I have a new me, a new life and I intend to live it as best I can."*
- *"Having to learn to accept new physical and mental limitations. Having to learn to be patient and forgiving with myself. Mourning what I have lost, adapting to and being grateful for what I have."*

Others felt that they struggled with their 'new self' and adapting to the changes the brain injury had brought to their life.

- *"I used to work, study, travel extensively and have a really good social life. All of this is gone. The New Me gets so tired so quickly it's hard work just getting to a spa for a few days so I can rest. Frustrating having to plan and pace all the time"*

and I'm still shattered!"

- *"I think and hear things differently, I feel different not just within myself but near other people. I know I'm slower and can't keep up and can't do the things I used to do."*
- *"A lonely person who is unable to do things he used to."*
- *"A me that cannot manage or do things in the way I used to."*

Others, yet again, took both a positive and negative approach to what being a 'new' person meant to them.

- *"Not being able to do things I used to but finding new things that I can do."*
- *"I am still learning who the new me is. Sometimes I like her sometimes I don't."*
- *"From the outside no different however less confident, less sociable and struggle sometimes with fatigue and word finding. Positives though are finding joy in the little things that seemed unimportant before. Appreciating life!"*

Summary

The responses given in this section highlight how varied people's responses are to their brain injury and new identity. Some brain injury survivors feel positive about their 'new self' and even go so far as to discuss how their brain injury changed the way they perceive and navigate through the world for the better. Other survivors struggle with the loss of former skills and their 'old' life and find it difficult to adjust to and accept their 'new' self.

Conclusion

The results from this survey show that the experiences and attitudes that brain injury survivors have to their injury, and the impact they feel that it has on their lives, vary from person to person. Survivors experience a range of positive and negative feelings about how their injury has affected their life, although survivors predominantly feel as though their life has been negatively affected.

However, over time these negative feelings can improve, reflecting a sense of adjustment and acceptance of the injury. Indeed, it appears that accepting the impact that brain injury has had on a survivor's life affects their acceptance of their new sense of self, their 'new me'.

What is also clear from the survey is that with help, understanding and support there can be life after brain injury.

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