Brain Drain: Experiences of fatigue after brain injury

A study to ascertain the extent to which pathological fatigue can impact life after brain injury

Contents

Introduction

In spring 2019 Headway launched a survey as part of its Action for Brain Injury Week campaign, *Brain Drain: Wake up to fatigue!* (www.braindrain.org.uk). This campaign aims to raise awareness of the debilitating and stigmatising effects of pathological fatigue – or extreme tiredness – that is often caused by brain injury.

As with many of the hidden effects of brain injury, fatigue can be widely misunderstood – not just by those around us, but even by brain injury survivors themselves. This survey was therefore created in order to ascertain the extent to which fatigue can impact life after brain injury, while also examine ways in which we can best support those affected.

The survey was hosted on the Survey Monkey website (www.surveymonkey.com) and was designed to be completed by brain injury survivors. The survey was promoted via email to all Headway groups and branches across the UK, as well as on the charity's website and social media channels to also reach those outside of its network.

Groups and branches were asked to encourage as many service users as possible to take part and provide any help necessary. Paper copies of the survey were also provided upon request.

The survey was open from 5 March until 28 April 2019. It consisted of both closed and open-ended questions to gather quantitative and qualitative responses.

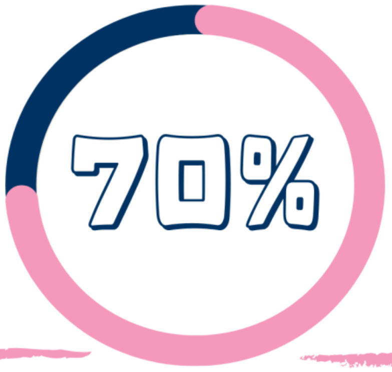
A total of 3,166 brain injury survivors responded to the survey. Headway would like to take this opportunity to thank everyone who took the time to participate.

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

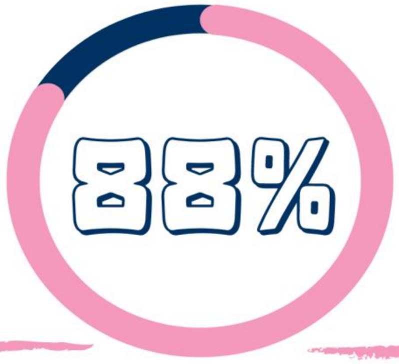
If you would like to discuss any aspect of the research, please contact Amber-Rose Perry, Publications and Research Manager, on publications@headway.org.uk.

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

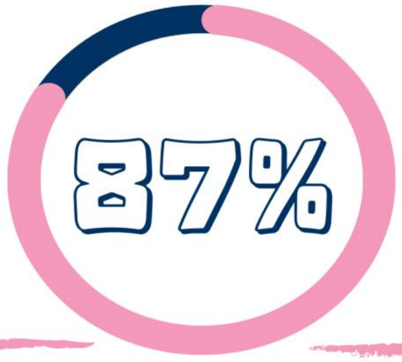
Key findings



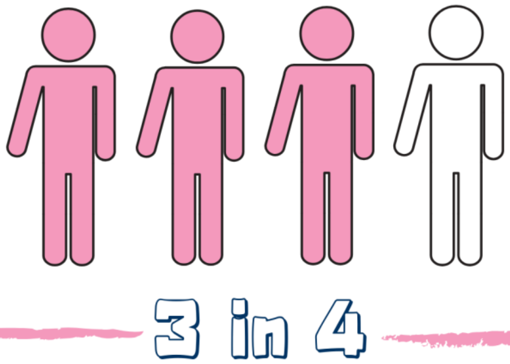
of brain injury survivors report that fatigue is the most debilitating effect of their brain injury



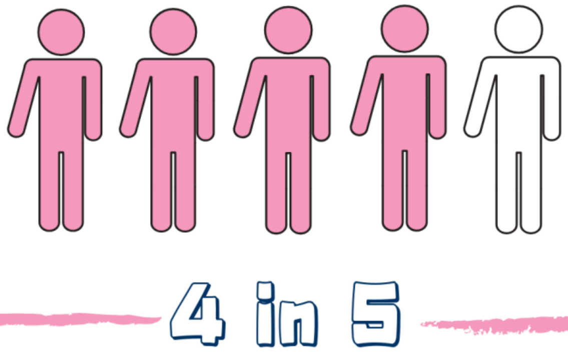
Of brain injury survivors feel that their fatigue affects their behaviour and emotions



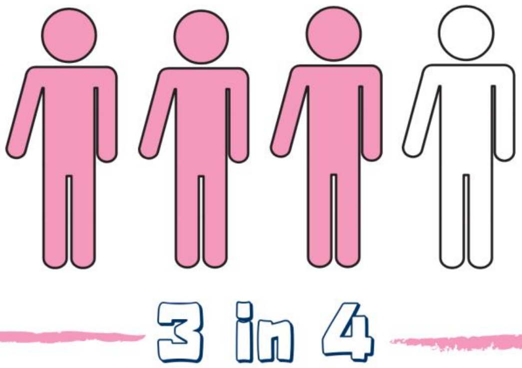
Of brain injury survivors feel that fatigue has a negative impact on their life



Brain injury survivors feel that people in their life do not understand their fatigue



brain injury survivors feel that their life would be improved if people understood their fatigue better



Brain injury survivors need help to understand the effect fatigue has on them

Executive summary

The results of the Headway survey demonstrate that fatigue is a common and very disabling effect of brain injury.

Despite this, it is clear that there is a distinct lack of understanding of pathological fatigue, leaving brain injury survivors feeling isolated and discriminated against. As a result, 80% of survivors report that their life would be improved if people did have a better understanding.

To put it into perspective, think of an old or damaged smart phone. The battery will likely need charging far more often than a newer model. It will struggle to hold its charge and the most basic of functions can rapidly drain its battery – sometimes causing it to shut down without any warning.

Fatigue can also exacerbate many other cognitive and behavioural effects of brain injury, worsening short-term memory and speech, resulting in increased anger and irritation. This is highlighted by the 88% of our respondents who reported that fatigue effects their behaviour and emotions.

Our findings show that this can lead to breakdowns with relationships, work and social life, and the self-esteem of brain injury survivors.

The survey highlights the need for greater public awareness of how brain injury-related fatigue can affect a person, which Headway aims to do through its Action for Brain Injury Week campaign, *Brain Drain: Wake up to fatigue!*.

Survey results – *Brain Drain: Wake up to fatigue!*

This survey was intended for anyone with a brain injury. The aim was to ascertain the extent to which pathological fatigue – or extreme tiredness – can impact life after brain injury.

Section one: Demographics

We asked participants for their age and how long ago they sustained their brain injury. Respondent ages and time since injury can be found in Table 1 and 2 below.

Age of respondent	Frequency (%)
Under 18	17 (0.54%)
18-24 years	76 (2.38%)
25-34 years	278 (8.84%)
35-44 years	663 (21.08%)
45-54 years	1,052 (33.45%)
55-64 years	795 (25.28%)
65+ years	265 (8.43%)

Table 1: *Age of survey respondents*

Time since brain injury	Frequency (%)
0-6 months	150 (4.82%)
6-12 months	212 (6.82%)
1-2 years	432 (13.89%)
2-5 years	897 (28.84%)
5-10 years	652 (20.96%)
10-20 years	459 (14.76%)
20+ years	308 (9.90%)

Table 2: *Time since brain injury*

To ensure our survey was representative of those living with an acquired brain injury, we also asked our participants what caused their brain injury, as well as if they experienced a loss of consciousness. The results can be found in Table 3 and 4 below.

Cause of brain injury	**Frequency (%)**
Trauma (e.g. road traffic accident, assault, fall, sporting injury)	1,246 (39.48%)
Stroke	323 (10.23%)
Aneurysm	328 (10.39%)
Haemorrhage	314 (9.95%)
Brain tumour	347 (10.99%)
Infection (e.g. encephalitis, meningitis)	136 (4.31%)
Hypoxic/anoxic brain injury (i.e. lack of oxygen to the brain)	69 (2.19%)
Hydrocephalus (i.e. fluid in the brain)	45 (1.43%)
Other	348 (11.03%)

Table 3: *Cause of brain injury*

Period of unconsciousness	**Frequency (%)**
No loss of consciousness/coma	1,037 (32.95%)
Less than 15 minutes	342 (10.87%)
15 minutes – 6 hours	258 (8.20%)
6 hours – 2 days	229 (7.28%)
More than 2 days	821 (26.09%)
Not sure	460 (14.62%)

Table 4: *Period of unconsciousness following brain injury*

Section two: Closed-ended questions

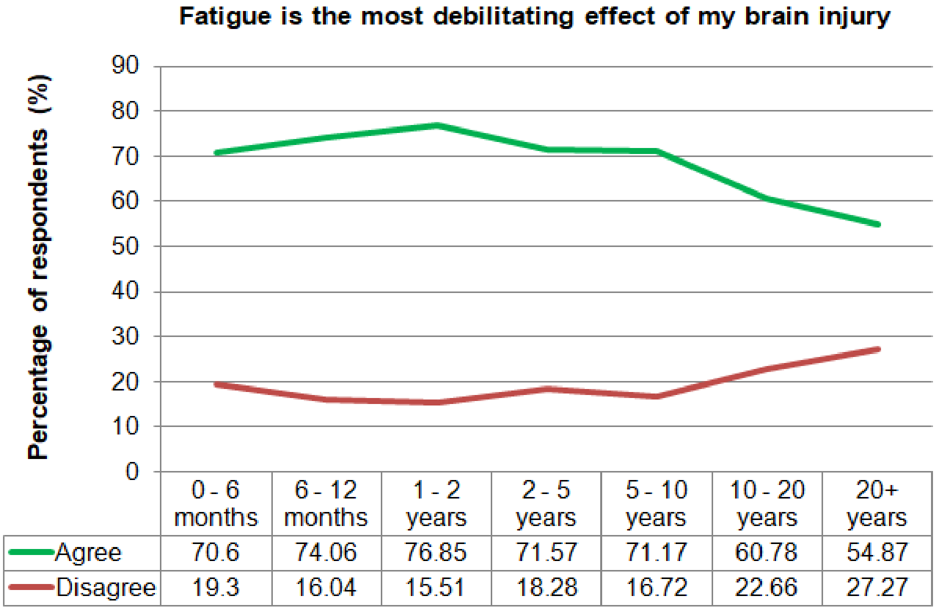
This section included a series of closed-ended questions to gather quantitative data. These questions were made up of pre-populated answer choices for each respondent to choose from.

Positive and negative statements

We asked brain injury survivors to rate how strongly they agreed or disagreed with a number of statements pertaining to attitudes towards living with pathological fatigue after brain injury. We used a 5-point Likert scale to evaluate each statement, which consisted of the following items: strongly agree, slightly agree, neutral, slightly disagree and strongly disagree.

1. Fatigue is the most debilitating effect of my brain injury

- 70% of brain injury survivors reported that fatigue is the most debilitating effect of their brain injury.
- During the first two years post-injury, the number of brain injury survivors that agreed with this statement increased, with fatigue reported to be the most debilitating effect at 1-2 years (76.85%; see Figure 1) (Johansson & Ronnback, 2014).
- Although fatigue levels tend to subside over time, for many people fatigue is still reported to be a persistent problem at 20+ years post-injury (54.87%; see Figure 1).
- Only 19% of respondents disagreed with this statement and 11% felt neutral.



	0 - 6 months	6 - 12 months	1 - 2 years	2 - 5 years	5 - 10 years	10 - 20 years	20+ years
Agree	70.6	74.06	76.85	71.57	71.17	60.78	54.87
Disagree	19.3	16.04	15.51	18.28	16.72	22.66	27.27

Figure 1: *Fatigue is the most debilitating effect of my brain injury*

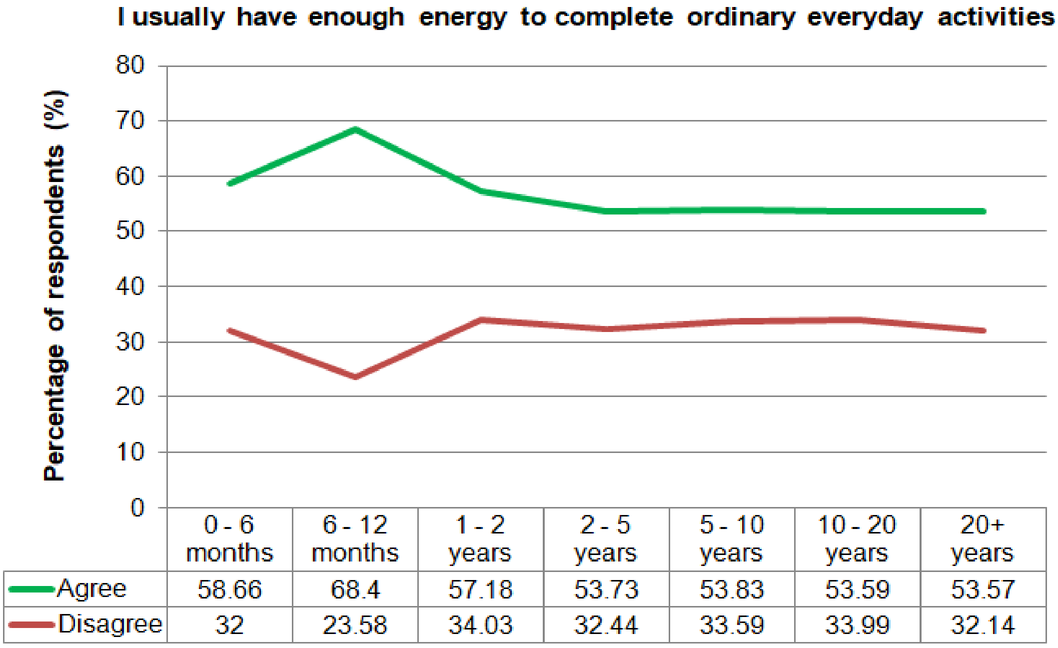
2. I usually have enough energy to complete ordinary everyday activities (e.g. eating, bathing, preparing food)

- Those who experience brain injury-related fatigue often say they feel exhausted, lack energy and are unable to motivate themselves. We found that 33% of respondents find completing ordinary everyday activities, such as bathing and preparing food, very challenging.

- 55% of respondents agreed with this statement and 12% felt neutral, indicating that a number of respondents have found ways to modify their daily activities to enable them to live more effectively within their cognitive and physical limitations.

  "*I use a cooking timer set to ten minutes for everything I do and when the timer rings, I stop and rest.*"

- Respondents 0-6 and 6-12 months post-injury agreed with this statement the most (see Figure 2). However, research demonstrates that within the first year post-injury, brain injury survivors may not understand the full effects of their injury. This period of lack of insight and dysfunctional self-awareness may therefore result in the tendency to overestimate their abilities (Teasdale et al., 1997).



	0 - 6 months	6 - 12 months	1 - 2 years	2 - 5 years	5 - 10 years	10 - 20 years	20+ years
Agree	58.66	68.4	57.18	53.73	53.83	53.59	53.57
Disagree	32	23.58	34.03	32.44	33.59	33.99	32.14

Figure 2: *I usually have enough energy to complete ordinary everyday activities*

3. I have found ways to manage my fatigue to reduce its impact on my life

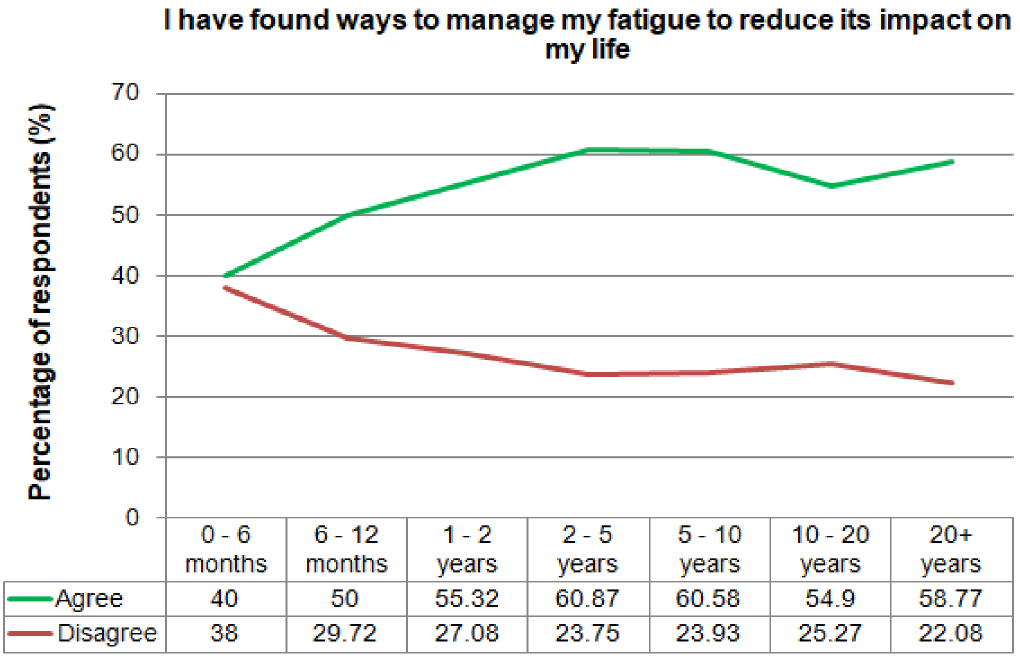
- We found that 57% of brain injury survivors have found ways to manage their fatigue. Section three highlights some of the top techniques that our respondents use to cope with this aspect of their brain injury.

- There is currently no effective treatment for fatigue and the most important recommendations are to adapt work and daily activities to levels that the brain can manage. However, it may take several years of considerable struggle and frustration to find a suitable balance between rest and activity (Johansson & Ronnback, 2014). We found that even at 20+ years post-injury, it is clear many people are still searching for this balance (22.08%; see Figure 3).

  "*Took five years to realise the full impact, then I've tried EVERYTHING in 'the book' for the last 15 years.*"

- 26% disagreed with this statement and 17% felt neutral.

  "*I don't [have ways to manage fatigue] as I am in denial a lot of the time and do not feel I have fatigue even when it is totally disabling me, my interaction with people, my temper and my abilities.*"



	0 - 6 months	6 - 12 months	1 - 2 years	2 - 5 years	5 - 10 years	10 - 20 years	20+ years
🟩 Agree	40	50	55.32	60.87	60.58	54.9	58.77
🟥 Disagree	38	29.72	27.08	23.75	23.93	25.27	22.08

Figure 3: *I have found ways to manage my fatigue to reduce its impact on my life*

4. My fatigue affects my behaviour and emotions

- Fatigue may also exacerbate other difficulties associated with brain injury, for example worsening short-term memory, making word-finding and speech much harder, and resulting in increased anger and irritation. Despite respondents reporting that they are able to manage their fatigue to some extent, 88% still reported that fatigue affects their behaviour and emotions, with 63% strongly agreeing with this statement.

  “*When I am over-tired my mental health gets worse. I feel worried, anxious and depressed.*”

- Even 20+ years post-injury, 81.82% of respondents within this category reported that fatigue affects their behaviour and emotions (see Figure 4).

- Only 7% disagreed with this statement and 5% felt neutral.

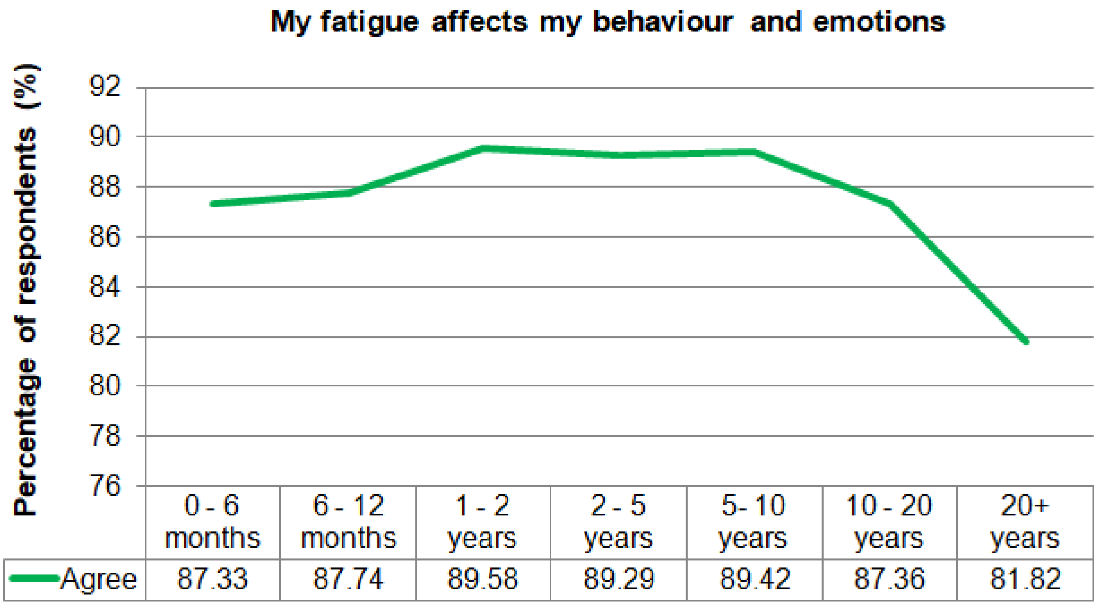


Figure 4: *My fatigue affects my behaviour and emotions*

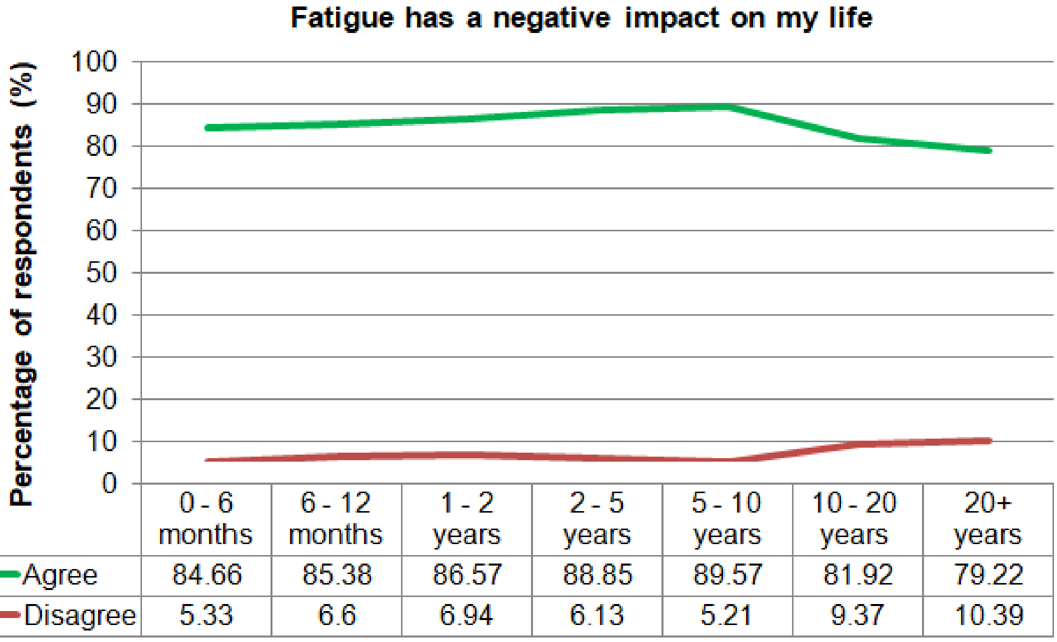
5. Fatigue has a negative impact on my life

- 87% of respondents reported that fatigue has worsened their lives. Of these respondents, 61% strongly agreed with this statement. This is explored further in the section ‘Aspects of life’.

- Many respondents labelled their experiences as “*devastating*”, “*frightening*” and “*lonely*”.

- The number of respondents who agreed with this statement increased over time, slightly dropping 10-20 years post-injury (see Figure 5).

- Only 7% disagreed with this statement and 6% felt neutral.



	0 - 6 months	6 - 12 months	1 - 2 years	2 - 5 years	5 - 10 years	10 - 20 years	20+ years
🟩 Agree	84.66	85.38	86.57	88.85	89.57	81.92	79.22
🟥 Disagree	5.33	6.6	6.94	6.13	5.21	9.37	10.39

Figure 5: *Fatigue has a negative impact on my life*

6. I socialise less because of my fatigue

- 84% of brain injury survivors socialise less as a result of their fatigue, with 59% strongly agreeing with this statement. This is also explored further in the section ‘Aspects of life’.

  “*Take a step back – social isolation.*”

  “*Keep myself to myself and don’t go out.*”

- Only 9% of respondents disagreed with this statement and 7% felt neutral.

7. People in my life do not understand my fatigue

- 75% of respondents reported that people in their life do not understand their brain injury-related fatigue. This is explored further in the section ‘Others understanding’.

  “*I have lost relationships and friendships as a result, and I am sure people think I don’t care about them when I’m just too exhausted to do anything about it, visit, etc.*”

- 15% disagreed with this statement, while 10% felt neutral.

8. I am often accused of being lazy or not trying hard enough

- Almost half of respondents are often accused of being lazy or not trying hard enough (49%). This is reflected in research that found that the effects of fatigue, such as yawning or losing concentration, often lead family members and friends to incorrectly assume the individual is being lazy (Norrie et al., 2010).

- The number of respondents who agreed with this statement increased over time (57.14% of those 20+ years post-injury; see Figure 6). It is not surprising that as time goes on, especially due to the hidden nature of fatigue, many people will expect brain injury survivors to 'recover' and return to their pre-injury self, adding to the frustration of living with a complex and invisible condition.

  "*It's not just me being lazy or not getting on with my life now to them I appear better.*"

  "*Calling me lazy... Just understand that I haven't chosen to be this way, it's the result of an injury I would rather not have had.*"

- 30% of respondents disagreed with this statement and 22% felt neutral.

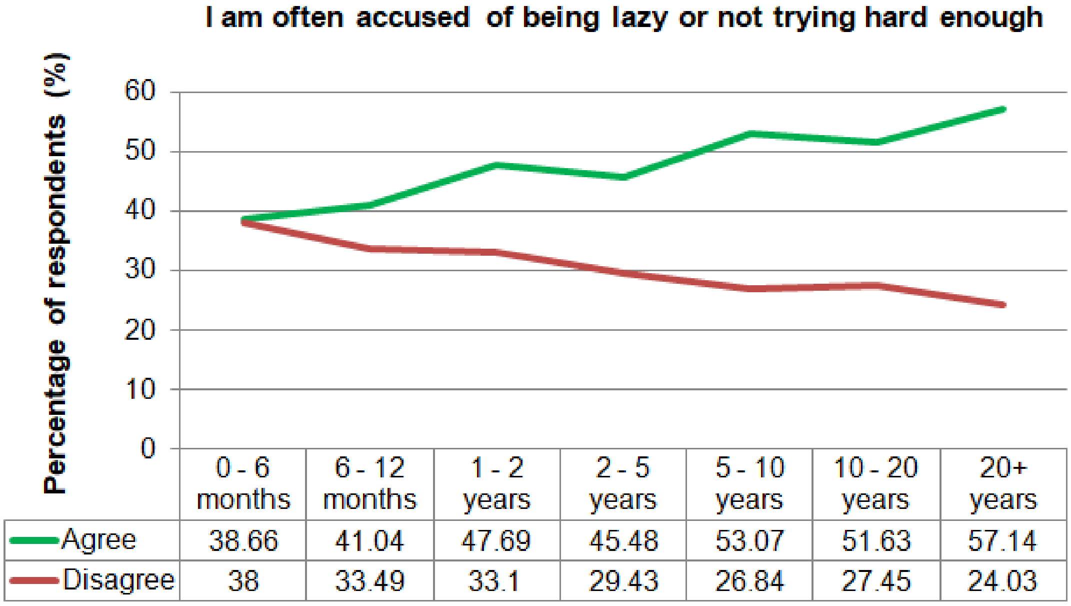


Figure 6: *I am often accused of being lazy or not trying hard enough*

9. My life would be improved if people had a better understanding of my fatigue

- Importantly, four in five brain injury survivors reported that their life would be improved if people had a better understanding of fatigue (80%) – especially friends, employers and colleagues (see section 'Others understanding').

  "*Try to understand what I struggle with, help me with things I'm finding difficult or challenging.*"

  "*Empathy would be greatly appreciated. Often people see it as a competition – oh I know exactly how you feel, I only got five hours of sleep and I'm shattered.*"

  "*Understand it. Realise I'm feeling scared. Don't blame me. Don't judge me.*"

- Only 7% disagreed with this statement and 13% felt neutral.

10. I need/needed help to understand the effect fatigue has on me

- 75% of respondents indicated that they need (or at some point needed) help to understand the effect fatigue has on them. This equates to three in four brain injury survivors and demonstrates just how misunderstood this effect of brain injury is – not just by those around us, but even by the individuals themselves.

- 11% of brain injury survivors disagreed with this statement and 14% felt neutral.

11. I am optimistic about my future despite my fatigue

- Despite many respondents reporting that fatigue has a negative impact on their life, over half reported feeling hopeful and positive about the future (52%).

- Brain injury survivors felt most optimistic about their future in the first six months after their injury (59.33%), with feelings of positivity reducing from this point onwards (see Figure 7). As mentioned previously, it may take a brain injury survivor months or even years before they realise the chronic nature of their fatigue (Teasdale et al., 1997).

- 27% of respondents disagreed with this statement and 21% felt neutral.

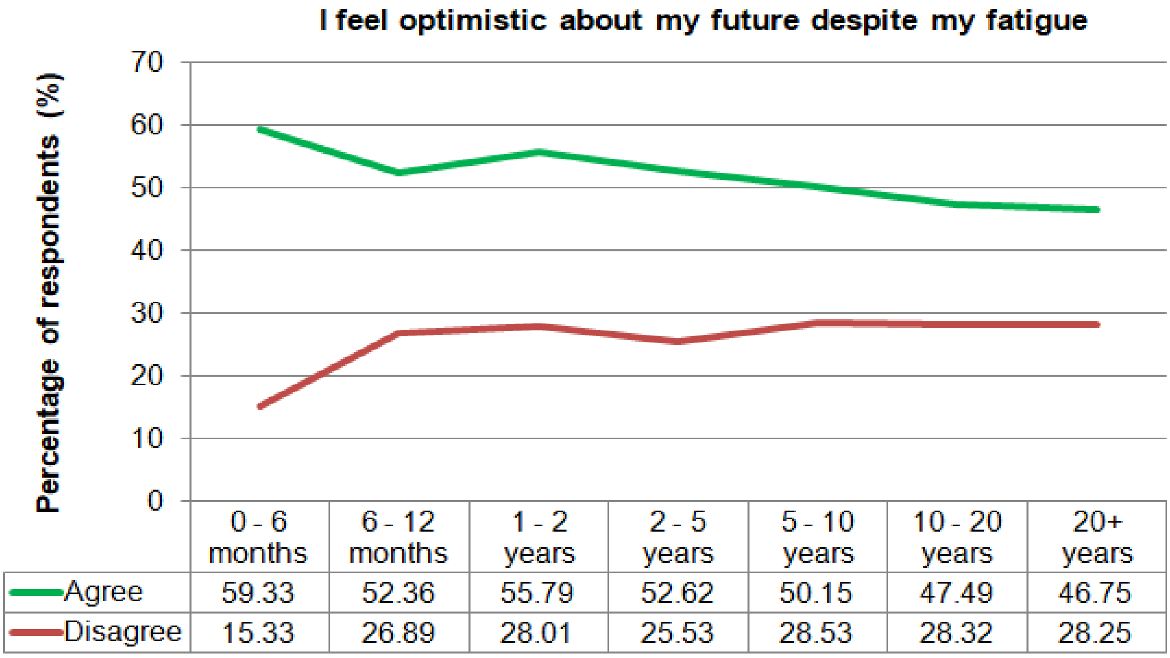
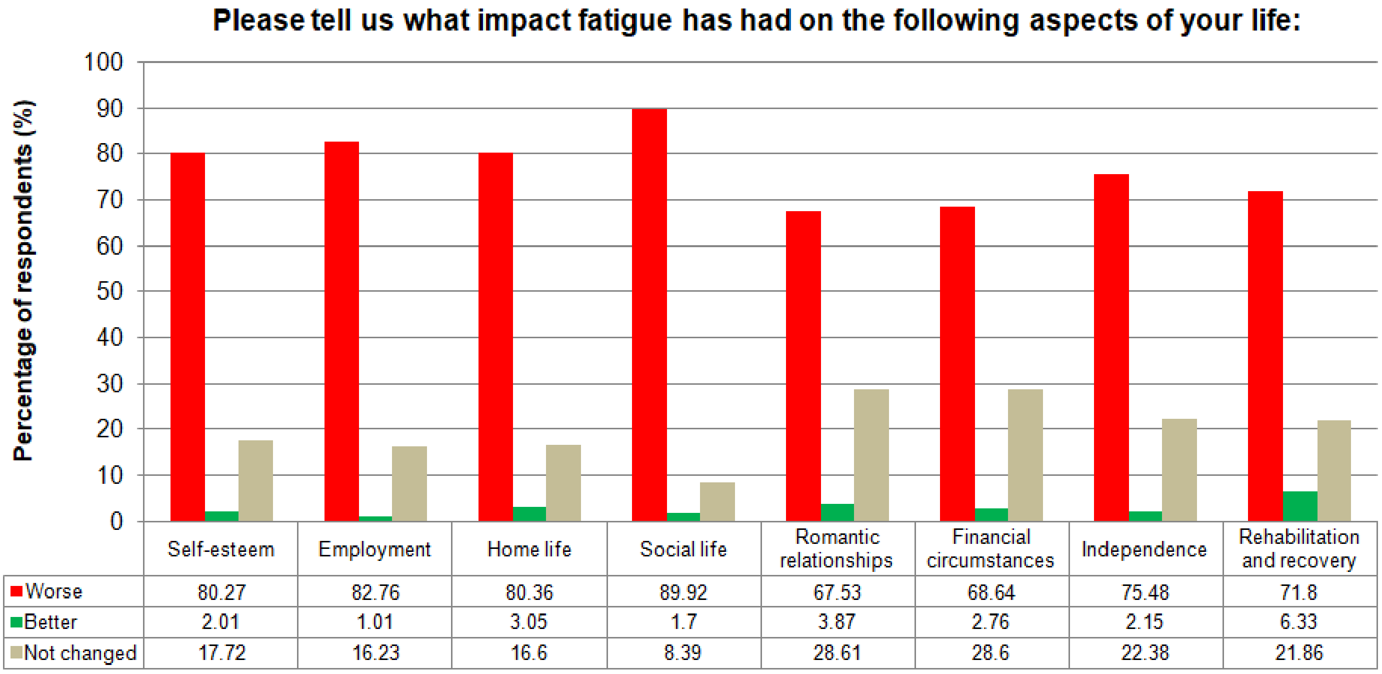


Figure 7: *I feel optimistic about my future despite my fatigue*

Aspects of life

Respondents were asked to rate whether the following aspects of their life were better or worse as a result of living with pathological fatigue after brain injury: self-esteem, employment, home life, social life, romantic relationships, financial circumstances, independence, and rehabilitation and recovery. We used a 5-point Likert scale of the following items: much worse, worse, not changed, better and much better.

The results can be found in Figure 8 below.



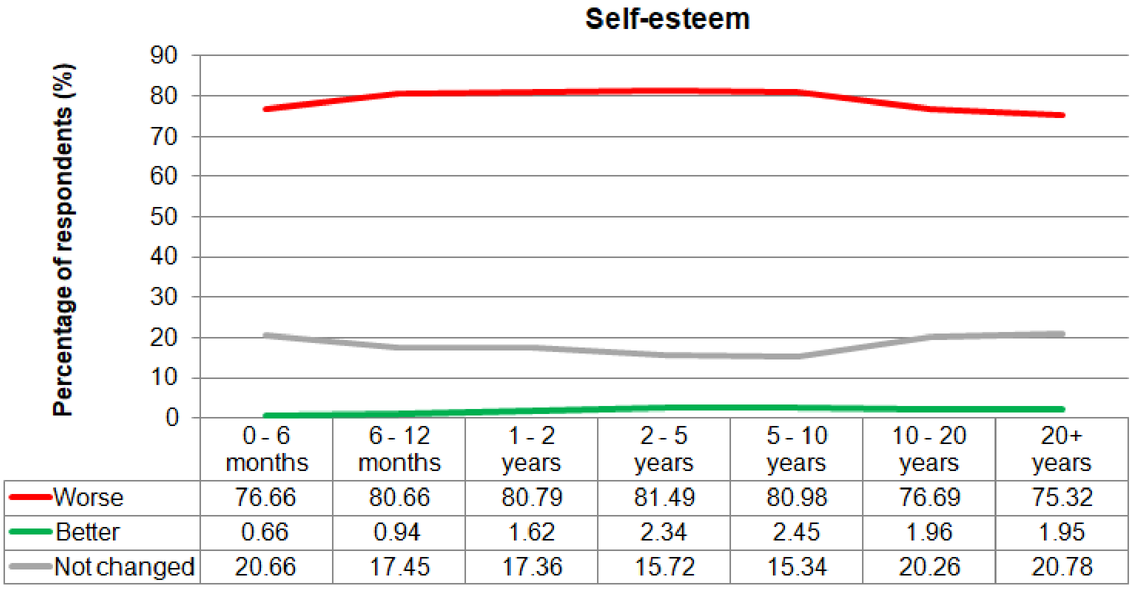
	Self-esteem	Employment	Home life	Social life	Romantic relationships	Financial circumstances	Independence	Rehabilitation and recovery
🟥Worse	80.27	82.76	80.36	89.92	67.53	68.64	75.48	71.8
🟩Better	2.01	1.01	3.05	1.7	3.87	2.76	2.15	6.33
▨Not changed	17.72	16.23	16.6	8.39	28.61	28.6	22.38	21.86

Figure 8: *Aspects of life*

1. Self-esteem

- Four in five respondents reported their self-esteem to be worse as a result of their brain injury-related fatigue (80%) and these feelings remained consistent over time (see Figure 9).

- Only 2% of respondents reported it to improve and 18% reported that it has not changed.



	0 - 6 months	6 - 12 months	1 - 2 years	2 - 5 years	5 - 10 years	10 - 20 years	20+ years
Worse	76.66	80.66	80.79	81.49	80.98	76.69	75.32
Better	0.66	0.94	1.62	2.34	2.45	1.96	1.95
Not changed	20.66	17.45	17.36	15.72	15.34	20.26	20.78

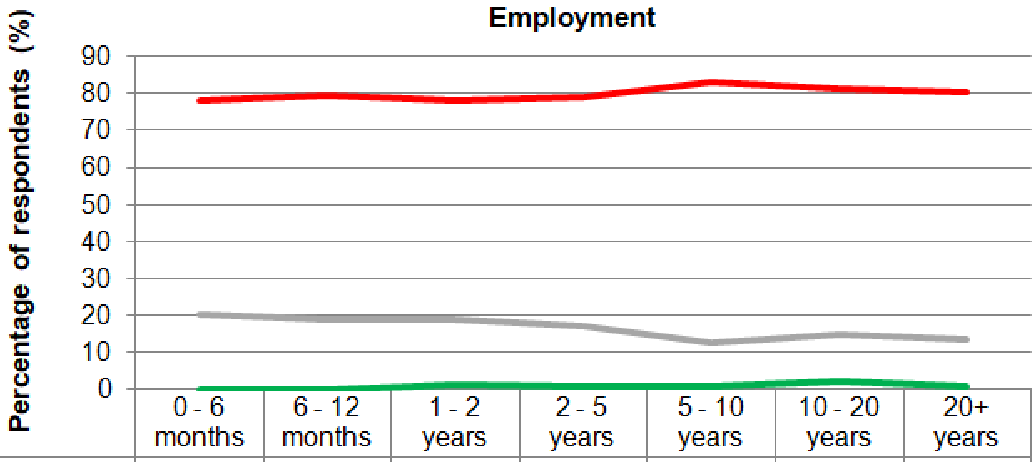
Figure 9: *Self-esteem*

2. Employment

- 83% of brain injury survivors reported their employment circumstances to be worse as a result of fatigue. With over half of respondents reporting them to be much worse (55%), this was one of the most negatively affected aspects of brain injury survivors' lives.

- 78% of respondents 0-6 months post-injury and 79.71% of respondents 6-12 months reported breakdowns in this aspect of their life. Following one year, employment improved for a very small number of people, although many more people reported employment getting worse as time goes on (see Figure 10) (van Velzen, van Bennekom, Edelaar, Sluiter & Frings-Dresen, 2009).

- Only 1% of respondents reported their employment circumstances had improved and 16% indicated that they have not changed.

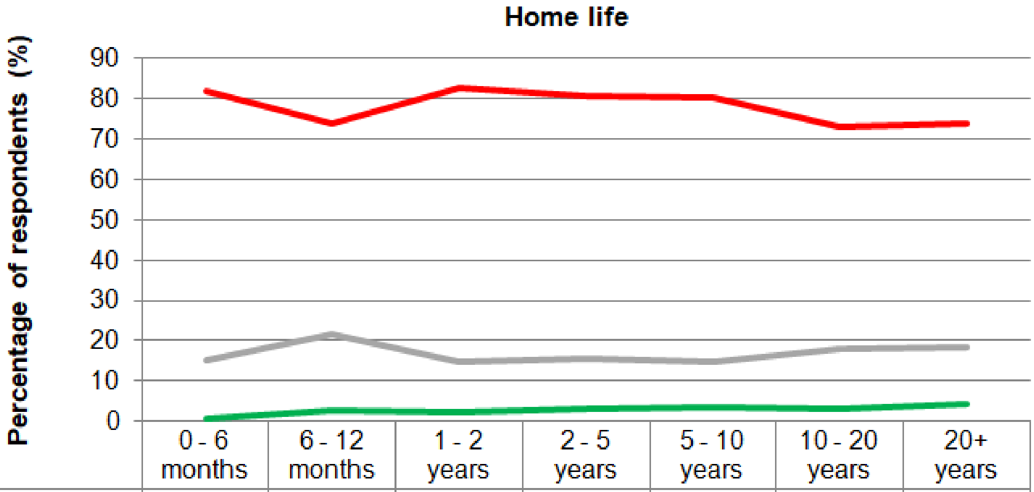


	0 - 6 months	6 - 12 months	1 - 2 years	2 - 5 years	5 - 10 years	10 - 20 years	20+ years
🟥 Worse	78	79.71	78	78.82	83.13	81.26	80.19
🟩 Better	0	0	1.16	0.89	0.92	2.18	0.65
▬ Not changed	20	18.87	18.98	16.83	12.27	14.6	13.31

Figure 10: *Employment*

3. Home life

- Four in five respondents (80%) reported that their home life is worse as a result of fatigue.
- Home life was found to improve slightly over time, although still reported to be significantly affected at 20+ years post-injury (74.03%; see Figure 11).
- 3% reported that their home life has improved, while 17% reported that it has not changed.



	0 - 6 months	6 - 12 months	1 - 2 years	2 - 5 years	5 - 10 years	10 - 20 years	20+ years
🟥 Worse	82	74.06	82.64	80.71	80.37	73.2	74.03
🟩 Better	0.66	2.83	2.08	3.12	3.53	3.1	4.22
▬ Not changed	15.33	21.7	14.58	15.38	14.88	18.08	18.51

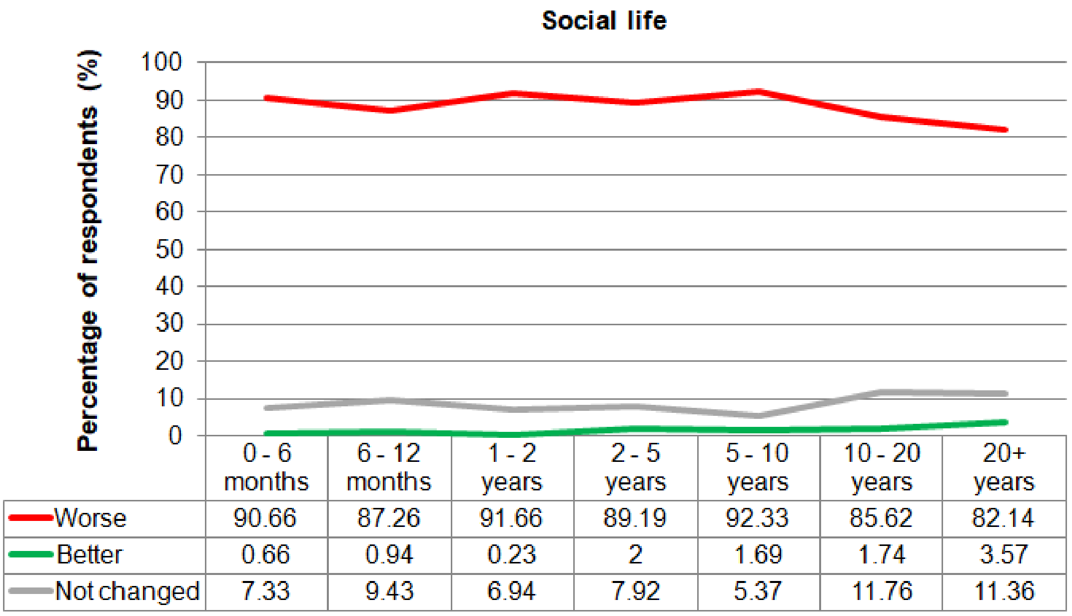
Figure 11: *Home life*

4. Social life

- Nine in ten brain injury survivors (90%) reported their social life to be worse as a result of fatigue, making this the most negatively affected aspect of their life.

- Social life is observed to gradually improve as time goes on following brain injury. However, at 20+ years post-injury, over 80% of respondents still reported this aspect of their life being negatively affected.

- Only 2% reported their social life to be improved and 8% reported that it has not changed.



	0 - 6 months	6 - 12 months	1 - 2 years	2 - 5 years	5 - 10 years	10 - 20 years	20+ years
Worse	90.66	87.26	91.66	89.19	92.33	85.62	82.14
Better	0.66	0.94	0.23	2	1.69	1.74	3.57
Not changed	7.33	9.43	6.94	7.92	5.37	11.76	11.36

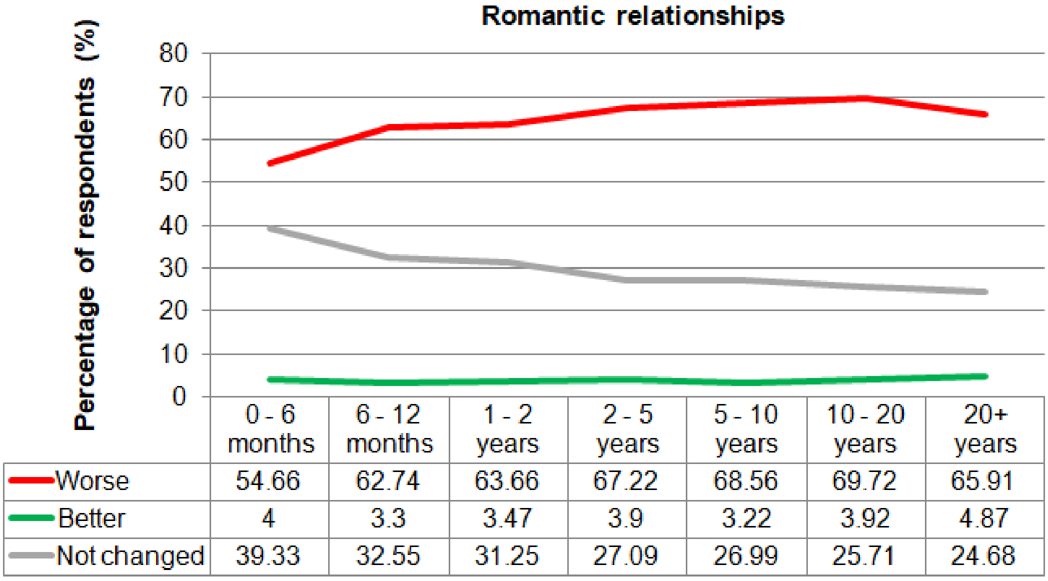
Figure 12: *Social life*

5. Romantic relationships

- If a spouse/partner who previously helped out around the house now struggles to complete the simplest of tasks, it is easy to see how romantic relationships can be affected as a result of fatigue. Indeed, almost two thirds of brain injury survivors (68%) reported breakdowns in this aspect of their life.

- Although reported to worsen over time, our findings demonstrate that romantic relationships are least likely to be affected by fatigue compared to other aspects of a survivor’s life (see Figure 13).

- 4% of respondents reported that their romantic relationships have improved and 28% indicate that they have not changed.



	0 - 6 months	6 - 12 months	1 - 2 years	2 - 5 years	5 - 10 years	10 - 20 years	20+ years
🟥 Worse	54.66	62.74	63.66	67.22	68.56	69.72	65.91
🟩 Better	4	3.3	3.47	3.9	3.22	3.92	4.87
▬ Not changed	39.33	32.55	31.25	27.09	26.99	25.71	24.68

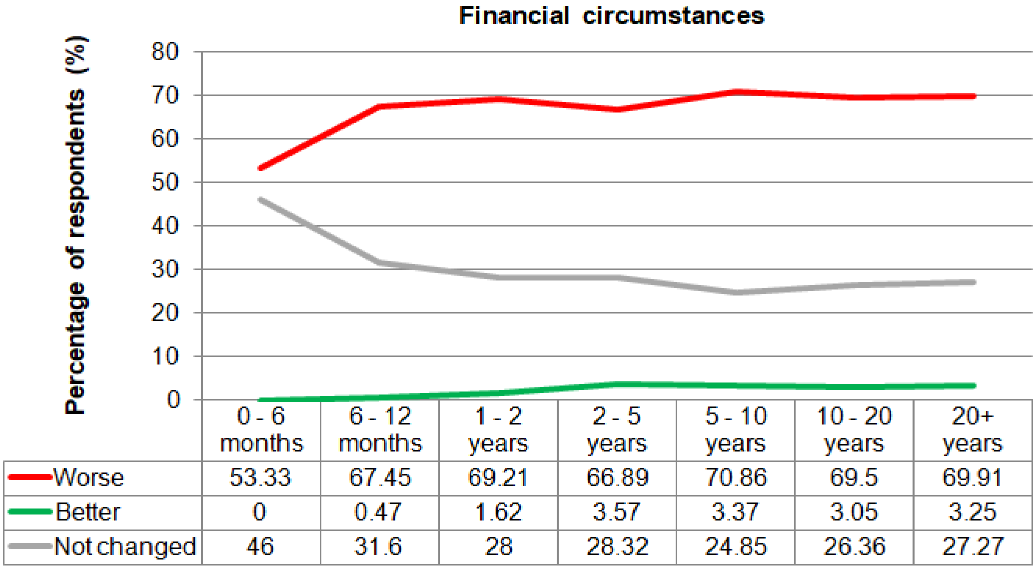
Figure 13: *Romantic relationships*

6. Financial circumstances

- Two thirds of brain injury survivors (69%) feel that their financial circumstances are worse as a result of fatigue.

- Although reported to worsen over time, our findings demonstrate that financial circumstances are also least likely to be affected by fatigue compared to other aspects of a survivor's life (see Figure 14).

- 3% reported that their financial circumstances have improved, while 28% reported that they have not changed.



	0 - 6 months	6 - 12 months	1 - 2 years	2 - 5 years	5 - 10 years	10 - 20 years	20+ years
🟥 Worse	53.33	67.45	69.21	66.89	70.86	69.5	69.91
🟩 Better	0	0.47	1.62	3.57	3.37	3.05	3.25
▬ Not changed	46	31.6	28	28.32	24.85	26.36	27.27

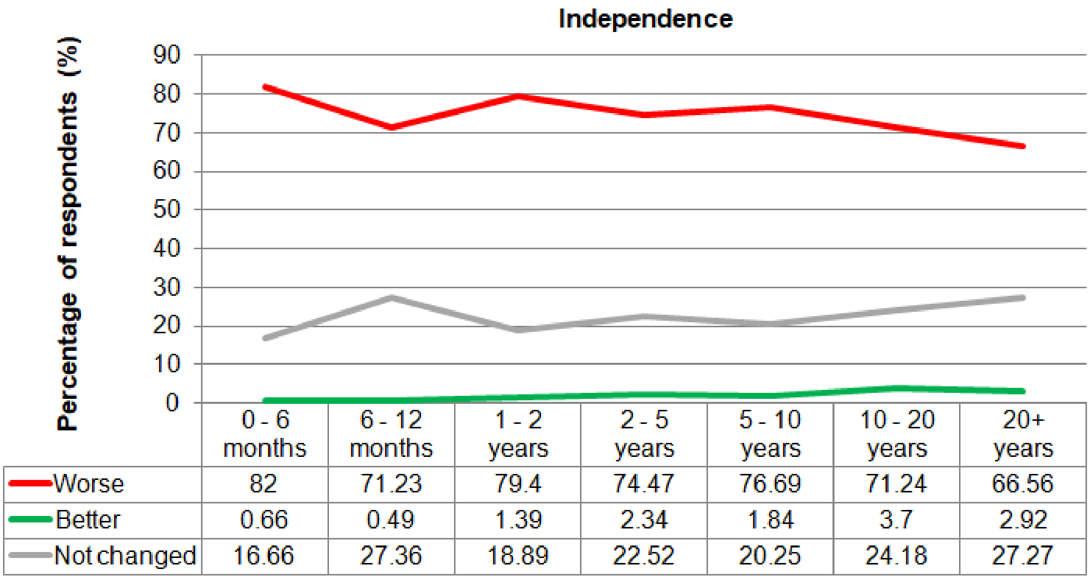
Figure 14: *Financial circumstances*

7. Independence

- Three quarters of brain injury survivors (75%) reported that their independence is worse as a result of fatigue, highlighting the dependency that many will have on carers, loved ones and local authority services as a result of this aspect of their injury.

- Independence was reported to be at its worst 0-6 months post-injury as a result of fatigue (82%), although is reported to increase after this time (see Figure 15). 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.

- Only 2% of survivors reported their independence improving and 23% reported that it hasn't changed.



	0 - 6 months	6 - 12 months	1 - 2 years	2 - 5 years	5 - 10 years	10 - 20 years	20+ years
🟥 Worse	82	71.23	79.4	74.47	76.69	71.24	66.56
🟩 Better	0.66	0.49	1.39	2.34	1.84	3.7	2.92
⬜ Not changed	16.66	27.36	18.89	22.52	20.25	24.18	27.27

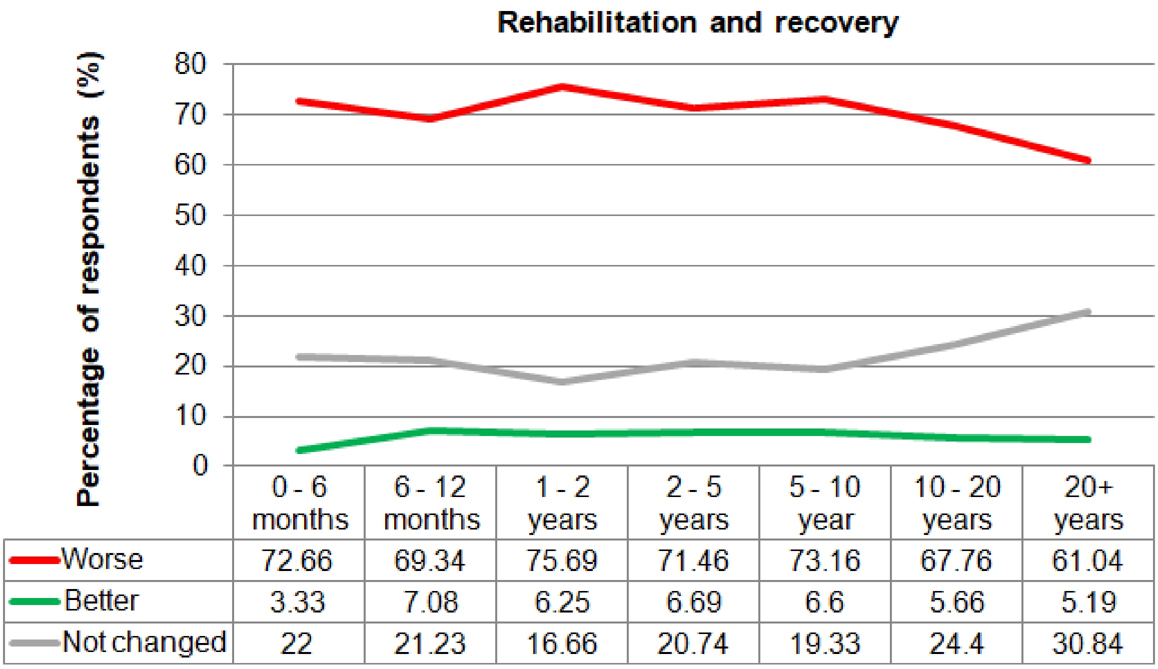
Figure 15: *Independence*

8. Rehabilitation and recovery

- 72% of respondents felt that their rehabilitation has worsened as a result of fatigue, as has their ability to make a meaningful recovery.

- We found that fatigue is less likely to affect one's rehabilitation and recovery as time passes (see Figure 16). As mentioned previously, this may be attributed to the fact that survivors develop techniques to better manage this effect of their injury.

- 6% reported that fatigue has made their rehabilitation and recovery process better, while 22% reported that it has not changed.



	0 - 6 months	6 - 12 months	1 - 2 years	2 - 5 years	5 - 10 year	10 - 20 years	20+ years
Worse	72.66	69.34	75.69	71.46	73.16	67.76	61.04
Better	3.33	7.08	6.25	6.69	6.6	5.66	5.19
Not changed	22	21.23	16.66	20.74	19.33	24.4	30.84

Figure 16: *Rehabilitation and recovery*

Others’ understanding

We asked brain injury survivors whether the following people in their life had a good understanding of their brain injury-related fatigue: spouse/partner, other family, friends, employers and colleagues.

The results can be found in Figure 17 below.

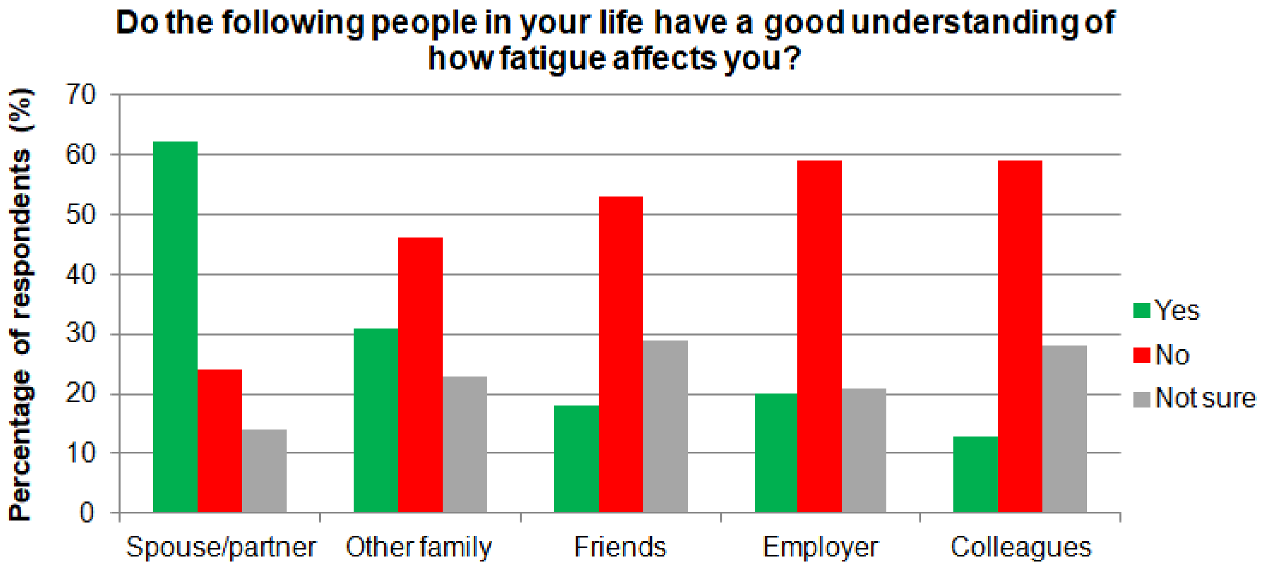


Figure 17. *Others’ understanding*

Friends, employers and colleagues were the highest-rated categories of people who do not have a good understanding – an issue consistent with the findings of previous Headway campaigns *A New Me* and *You, me and brain injury*, as well as the results of this survey (see section ‘Aspects of life’).

1. Spouse/partner

- Of those with a spouse/partner, 62% of brain injury survivors reported that their spouse/partner does have a good understanding of their fatigue, which demonstrates why romantic relationships were least likely to be affected by fatigue (see section ‘Aspects of life’).

- 24% reported that their spouse/partner does not have a good understanding and 14% were not sure.

2. Other family

- Only 31% of respondents felt that other family members had a good understanding of their fatigue.

- 46% reported that other family members do not have a good understanding and 23% were not sure.

3. Friends

- Over half of the respondents (53%) reported that their friends do not have a good understanding of how fatigue affects them.

- 18% reported that their friends have a good understanding and 29% were not sure.

4. Employer

- 50% of respondents did not have an employer. However, of those respondents who do have an employer, 59% believe that their employer does not have a good understanding of their fatigue.

- Only 20% reported that their employer does have a good understanding, while 21% were not sure.

5. Colleagues

- 43% of respondents did not have any colleagues. However, of those respondents who do have colleagues, 59% also feel that their colleagues do not have a good understanding of their fatigue.

- Only 13% believe that their colleagues do have a good understanding, while 28% were not sure.

In a separate question, almost 70% of brain injury survivors told us that they feel as though they have been unfairly treated due to others not understanding their condition – a very concerning statistic (see Figure 18).

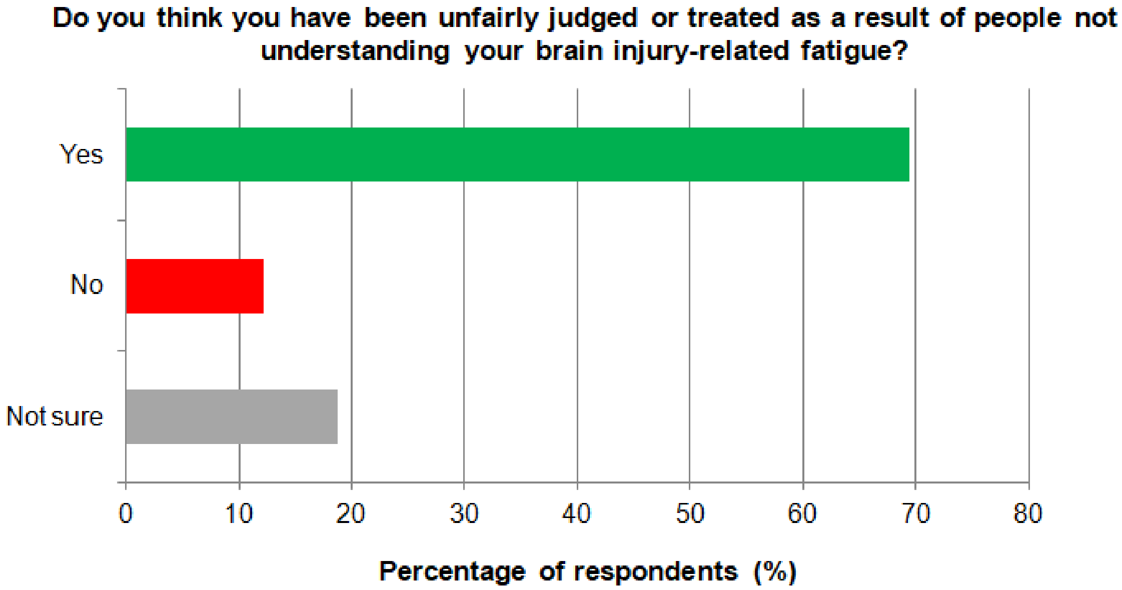


Figure 18: *Unfair treatment as a result of fatigue*

Section three: Open-ended questions

This section included open-ended questions to gather qualitative data.

Respondents were asked to outline some of the top techniques that they use to manage living with fatigue. While this was optional, over 2,500 brain injury survivors chose to reply, which has allowed us to compile a list of the common strategies below.

It is important to note that due to the nature of brain injury, not everyone is able to develop and implement these strategies as effectively as others. Hundreds of brain injury survivors reported that they have struggled to find any techniques that work. Others also indicated that they have no one around who understands their fatigue and its triggers in order to help.

Our campaign, *Brain Drain: Wake up to fatigue!*, hopes to ensure more people have the help and support they need to adapt to life with brain injury-related fatigue.

- **Establish a regular sleeping habits**

  “*I have a regular time to go to bed and wake up in the morning.*”

  “*Keep the bedroom for a place to sleep – i.e. reading in other rooms.*”

  “*Making sure my bedroom is a calm, relaxing environment.*”

- **Watching mood and behaviours**

  “*When I am over-tired my mental health gets worse. I feel worried, anxious and depressed.*”

  “*Fatigue starts to cause my motor and speech skills to deteriorate.*”

- **Light exercise and activity**

  “*Stretching.*”

  “*Daily walks in the morning.*”

  “*Pottering in the garden.*”

- **Monitoring nutrition and hydration**

  “*Avoid caffeine because it makes fatigue worse.*”

  “*Drink plenty of water.*”

  “*Dietary changes with support from a nutritionist.*”

  “*I eat more regularly, but in smaller amounts.*”

- **Time management**

  "*A planned diary helps me ensure that I allow for rest days, that appointments are evenly spaced out, as are any social events.*"

  "*Arrange meetings and appointments at a time of day that I find to be a functional time for me.*"

  "*Staggering jobs and then breaking them down into bite size chunks.*"

- **Using aids**

  "*My occupational therapist gave me aids to use in the home to look after my energy. I have a perching stool and a bath board.*"

- **Making best use of cognitive (thinking) resources**

  "*I use a cooking timer set to ten minutes for everything I do and when the timer rings, I stop and rest.*"

  "*I listen to audio books and podcasts rather than read.*"

  "*Shop via Amazon Prime rather than go to the store.*"

  "*Equipment to save energy e.g. IT that reads documents so less strain in my eyes.*"

- **Mix with others in the same situation**

  "*Reading and learning about others experience and tips.*"

  "*Phone friends that I have met through support groups, it's good to chat and know you are not alone.*"

  "*Come to Headway.*"

- **Positivity**

  "*Accepting it and seeing days doing much less not as failures.*"

  "*Mind over matter – I've done brain surgery, I can do this...*"

  "*I just don't beat myself up about it and try and remind myself why I'm feeling the way I am. It's not my fault!*"

For more information, please refer to the Headway booklet *Managing fatigue after brain injury*.

Conclusion

The results from this survey demonstrate that fatigue is an overwhelmingly common effect of brain injury. While for some people it may decrease over time, for others it is not something they can overcome and rather it is something that they need to learn to manage in the longer term.

Pathological fatigue is a daily challenge and our study demonstrates that brain injury survivors predominately feel as though their life has been negatively affected as a result.

What is also clear is that a little understanding goes a long way in helping someone who is living with the effects of brain injury. By encouraging people to share their experiences and in turn raising awareness of the condition, we hope that together we can help people to *Wake up to fatigue!*

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