



**ACTION FOR
BRAIN INJURY WEEK 2020**



The impact of memory loss on people with brain injury



struggle to recall personal memories



feel personal relationships have been affected



experience a negative impact on their life

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1. Introduction

One of the most common issues reported by brain injury survivors contacting Headway's helpline or posting on our social media platforms is the profound and debilitating impact that memory problems can have on their lives and relationships.

Our Action for Brain Injury Week 2020 campaign, ***Memory Loss: A campaign to remember***, aims to raise awareness of the ways in which memory problems can affect brain injury survivors and their families.

In January 2020, we launched a survey into the effects of memory loss, to be completed by brain injury survivors or their family members and carers acting on their behalf. We advertised the survey via our website, social media and Headway's network of groups and branches across the UK. The survey was completed by 2,150 participants, providing a large sample to gain an accurate picture of the difficulties memory problems can cause.

The results are striking, with 85% of survivors experiencing a negative impact on their lives and 65% feeling that their personal relationships have been negatively affected as a result of their memory problems.

In addition, survivors told us about the daily challenges caused by an overall lack of awareness. 72% feel that the people in their lives do not understand their memory problems and 81% feel that their lives would be improved if they did.

These findings highlight the vital importance of raising awareness of this often-hidden effect of brain injury, with many survivors continuing to struggle long after the initial injury.

2. Key findings

- 70% of brain injury survivors struggle to recall personal memories, such as their wedding or the birth of their child
- 65% of brain injury survivors feel that their personal relationships have been affected as a result of their memory problems
- 85% of brain injury survivors feel that memory problems have a negative impact on their life
- 72% of brain injury survivors feel that the people in their life don't understand their memory problems
- 71% of brain injury survivors feel unfairly judged or treated as a result of their memory problems

3. How memory is affected by brain injury

By Professor Barbara A. Wilson, OBE

Although people tend to talk about memory as if it were one skill or function or ability, there are in fact many kinds of memory and many ways it can be classified.

We can consider memory in terms of the length of time for which memories are stored; the type of information to be remembered; the modality the information is in; the stages in the process of remembering; explicit or implicit memory; whether recall or recognition is required; whether the memory is retrospective (for things that have already occurred) or prospective (remembering what has to be done) and whether the memory dates from before or after an injury or illness.

The typical situation for most memory impaired people is for their immediate memory to be normal or nearly normal, to have problems after a delay or distraction, to have difficulty learning most kinds of new information, and to remember things learned a long time before the accident or illness better than things which happened a short time before.

The three main approaches to current memory rehabilitation are improving learning, compensating for memory difficulties through the employment of external memory aids, and adjusting or modifying the environment so people can survive without a functioning memory system.

New learning includes spaced retrieval, vanishing cues and errorless learning. External memory aids such as diaries, notebooks, tape recorders and mobile phones, widely used by the general population, are often problematic for memory-impaired people simply because their successful use involves memory.

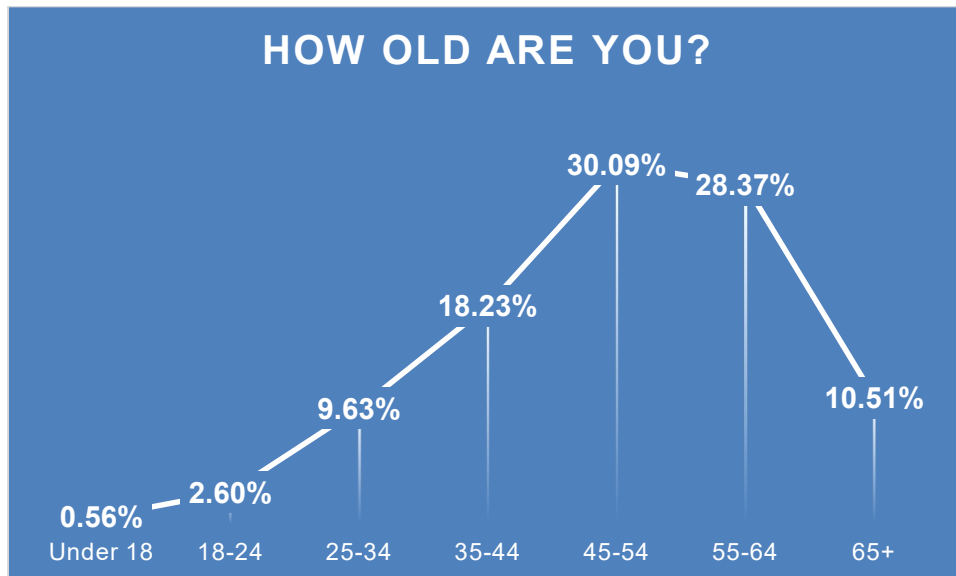
For those with severe and widespread problems, the best method may involve restructuring or organising the environment.

The emotional consequences of memory impairment such as anxiety, depression and loneliness should also be dealt with in rehabilitation through counselling, anxiety-management techniques and treatment in memory or psychotherapy groups.

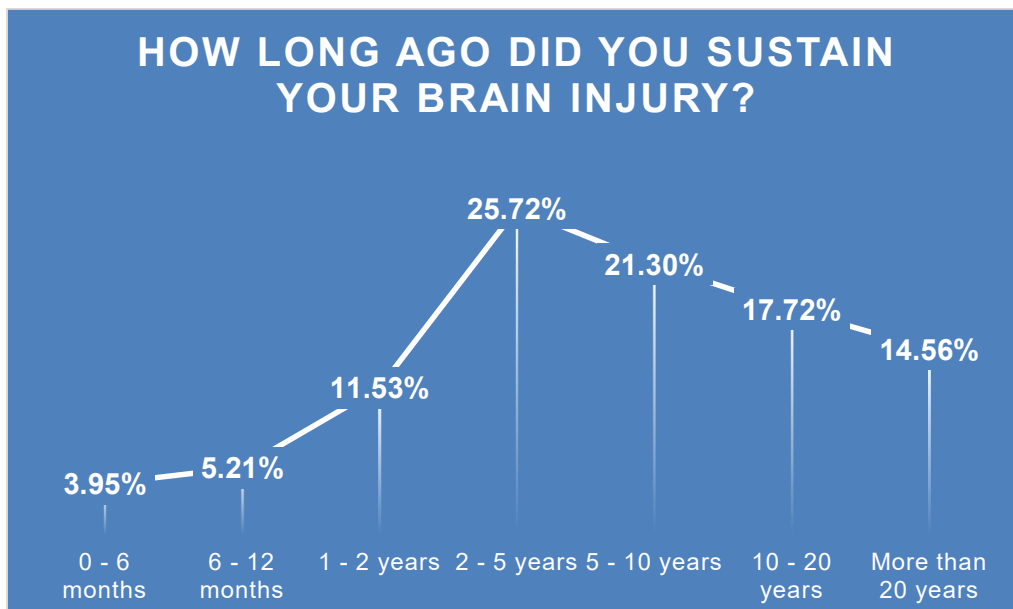
4. Demographics

The survey was completed by 2,150 people, of which 53% (1,150) were female.

Participant ages ranged from under 18 to over 65, with the most common age group being 45-54-year olds. 89% of participants are of working age, between 18 and 65.

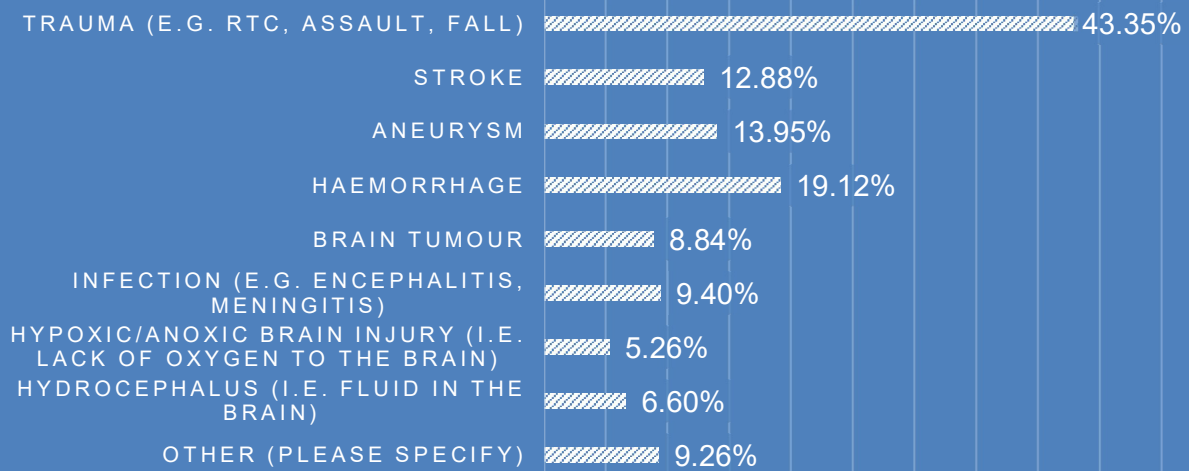


The vast majority of respondents (91%) sustained their brain injury more than a year before completing the survey, however with 197 people having sustained their injury more recently, this still provides a useful sub-set of data to analyse the difference in the effects of memory loss.



We asked participants what caused their brain injury. For this question we allowed respondents to select multiple answers, reflecting the fact that some people sustain more than one brain injury.

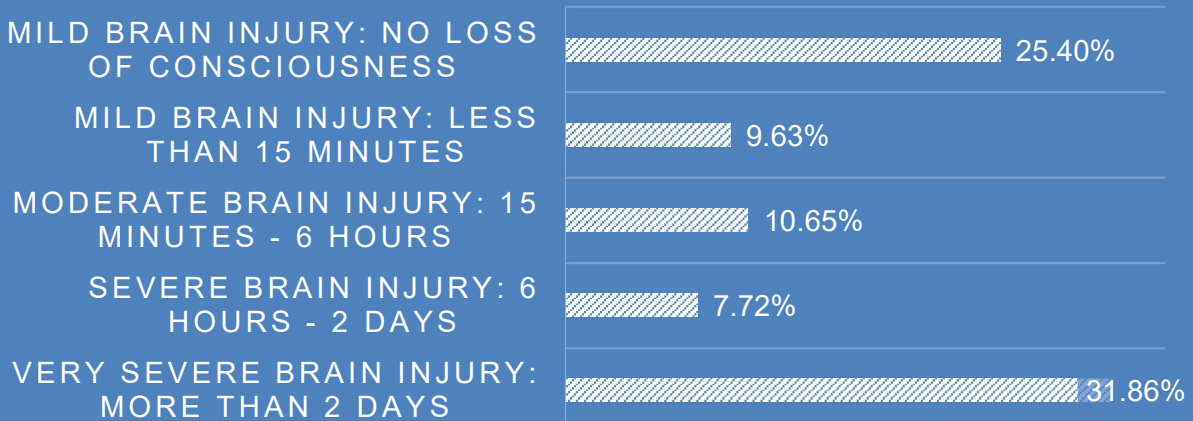
WHAT CAUSED YOUR BRAIN INJURY?



The most common cause (43%) is a traumatic injury, caused by road traffic collision, assault, fall or sports injury, for example.

We asked participants to indicate for how long they had been unconscious/in a coma. While this is not an exact measure, it does allow us to estimate the severity of their injury, helping us to find the changes in memory problems between minor, moderate and severe brain injury. 15% of respondents were unsure, but of those who answered:

HOW LONG WERE YOU UNCONSCIOUS/IN A COMA FOR?



5. Survey results: The effects of memory loss

5.1 Overview of memory loss

We asked participants to tell us how memory problems affect them by indicating to what level they agree or disagree with a series of statements.

<i>Please tell us what impact memory problems have had on the following aspects of your life:</i>					
	Strongly disagree	Slightly disagree	Neutral	Slightly agree	Strongly agree
I struggle to remember day-to-day things	4.35%	4.35%	4.91%	37.28%	49.11%
I struggle to recall personal memories	8.71%	11.42%	10.16%	33.80%	35.91%
I struggle to remember important dates/appointments	4.21%	4.91%	7.24%	29.30%	54.35%
I struggle with recognising people or places that were familiar to me before my brain injury	17.46%	15.27%	16.67%	30.21%	20.40%
Memory problems have a negative impact on my life	3.55%	3.32%	7.76%	31.73%	53.64%
I need/needed help to understand the effect memory problems have on me	6.16%	5.97%	16.94%	28.51%	42.42%
People in my life do not understand my memory problems	7.73%	8.43%	11.83%	33.16%	38.84%
I socialise less because of my memory problems	8.45%	8.73%	12.84%	24.98%	45.00%
I am optimistic about my future despite my memory problems	13.01%	13.80%	21.48%	27.14%	24.57%
Memory problems are the most debilitating effect of my brain injury	11.25%	16.76%	16.67%	27.82%	27.50%
I have found ways to manage my memory problems to reduce their impact on my life	7.57%	9.01%	15.46%	46.15%	21.81%
I struggle with learning new things because of my memory problems	4.15%	6.85%	10.63%	32.91%	45.45%
My memory problems affect my behaviour and emotions	4.38%	5.50%	10.21%	36.78%	43.12%
My life would be improved if people had a better understanding of my memory problems	2.80%	3.54%	12.50%	27.80%	53.36%

Describe your experience of memory problems after brain injury in one word:

Frustrating
Frightening Devastating
Confusing Challenging
Debilitating Scary
Lonely Embarrassing
Hard Lost Upsetting



Positive findings include 52% of participants who feel optimistic about their future despite their memory problems.

However, while 68% of participants have found ways to manage their memory problems to reduce their impact, the results show a strong negative impact overall:

- 86% struggle to remember day-to-day things
- 84% struggle to remember important dates and appointments
- 85% feel that memory problems have a negative effect on their lives
- 78% struggle to learn new things because of memory problems
- 80% find that memory problems affect their behaviour and emotions

“It’s an extremely isolating illness and it robs you of so much, your identity, your ability to communicate and express yourself correctly. The ability to defend yourself... it makes me feel anxious, sad and lonely.” – James Neal

5.2 Impact on daily life

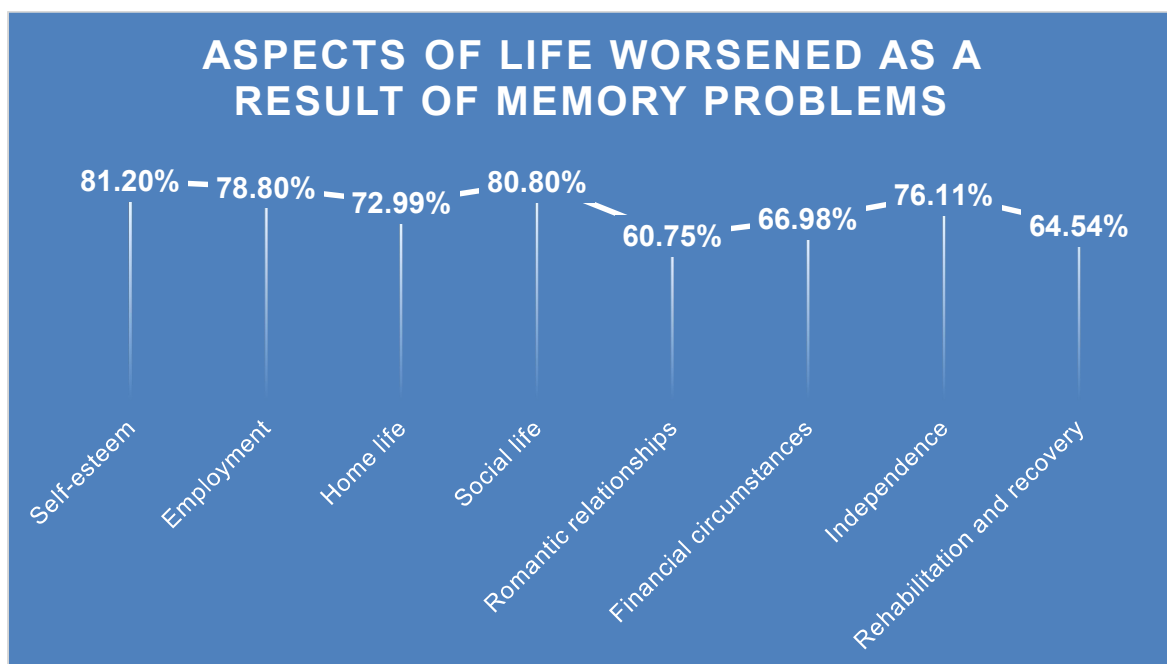
We asked participants about the wider impact of memory problems on their lives, from self-esteem and social life to romantic relationships and general independence.

<i>Please tell us what impact memory problems have had on the following aspects of your life:</i>					
	Much worse	Worse	Not changed	Better	Much better
Self-esteem	29.29%	51.91%	15.81%	2.38%	0.61%
Employment	55.04%	23.76%	20.02%	0.90%	0.28%
Home life	19.35%	53.64%	22.62%	3.46%	0.93%
Social life	38.44%	42.36%	16.63%	2.10%	0.47%
Romantic relationships	30.23%	30.52%	34.98%	3.15%	1.13%
Financial circumstances	36.34%	30.64%	28.77%	3.18%	1.07%
Independence	35.28%	40.83%	20.91%	2.47%	0.51%
Rehabilitation and recovery	20.28%	44.26%	26.74%	7.12%	1.59%

As a result of memory problems:

- 81% have experienced a negative impact on their self-esteem
- 80% have seen their social life worsened
- 79% found a negative impact on employment
- 76% feel memory problems reduce their level of independence

Romantic relationships were the least affected by memory problems, however 61% still feel they have been worsened with only 4% reporting an improvement.



5.3 Relationships

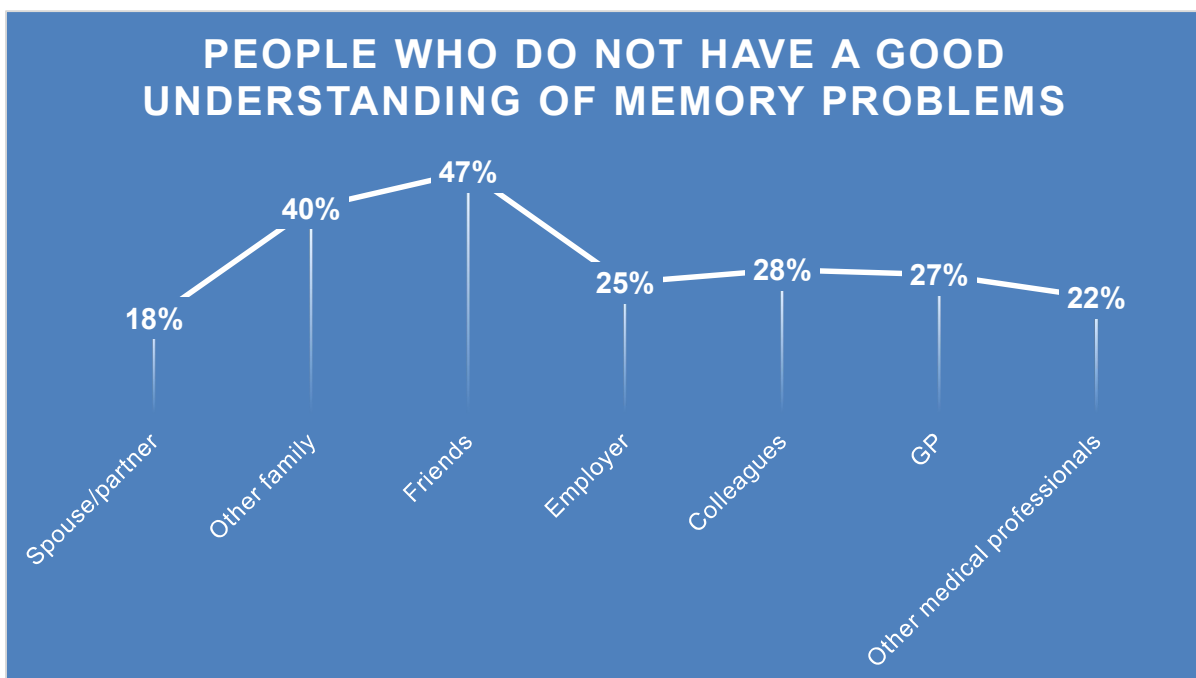
People told us about the lack of understanding from those around them, and the negative impact this has on their relationships:

- 72% feel that people in their life do not understand their memory problems
- 70% socialise less because of memory problems
- 81% feel their life would be improved if people had a better understanding of memory problems

“My relationship with close and distant family changed forever due to memory loss. I don't remember the life I shared with these people. I find this isolating.” – Roberta

Do the following people in your life have a good understanding of how memory problems affect you?				
	Yes	No	Not sure	Not applicable
Spouse/partner	46.50%	18.41%	9.25%	25.84%
Other family	39.03%	39.88%	18.79%	2.30%
Friends	23.15%	46.99%	27.06%	2.80%
Employer	9.54%	25.29%	9.40%	55.76%
Colleagues	9.45%	27.83%	14.95%	47.77%
GP	34.47%	26.86%	35.08%	3.60%
Other medical professionals	37.55%	22.38%	34.41%	5.66%

The chart below helps to visualise this data, showing the people in a brain injury survivor's life who are felt to lack understanding of memory problems:



Analysing this data further shows that:

- 47% reported that their spouse/partner has a good understanding of their memory problems.

People in this group were 32% less likely to experience a negative impact on their relationship due to memory loss, and 7% more likely to feel optimistic about the future.

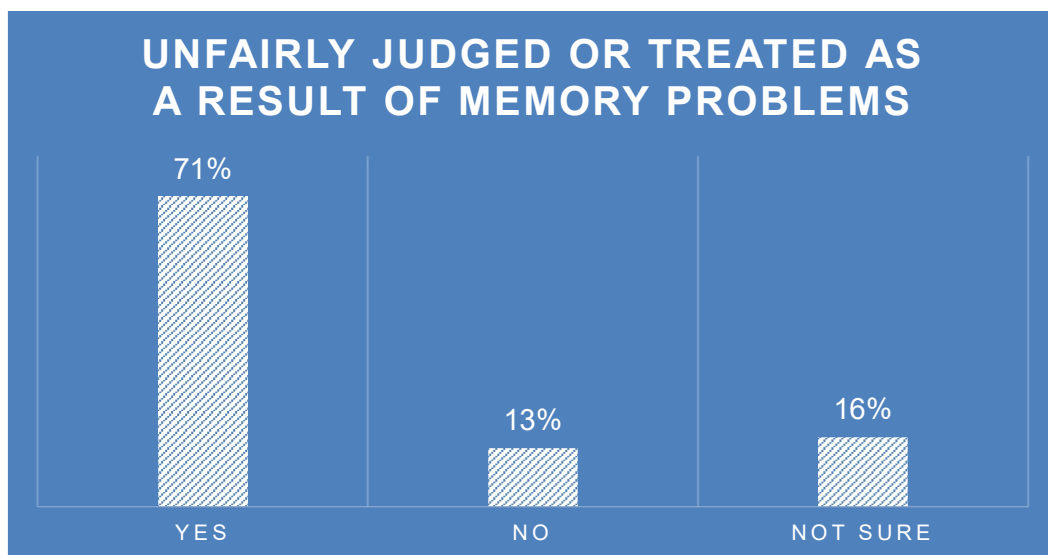
- 23% reported that their friends have a good understanding of memory problems.

People in this group were 7% more likely to feel optimistic about the future.

Encouragingly, GPs and other medical professionals were reported as having among the highest level of understanding.

Overall, 65% of participants feel that memory problems have affected their personal relationships, with 15% reporting no effect.

Worryingly, a high proportion of survey respondents feel that they have been unfairly judged as a result of their brain injury-related memory problems, further highlighting the devastating impact of brain injury – an often ‘hidden disability’.



“I don’t socialise with any friends since my brain injury as they just don’t understand the struggles I have especially with memory loss. I look like a healthy person, but they can’t see what’s going on in my head.” – Lynsay Railton

“My partner feels he can’t discuss/make plans with me because I’m never able to stick to them. This daily battle has worn him down.” – Anonymous

“Some of my family and friends don’t make allowances and I become frustrated, upset, and withdrawn. Other people are worse. I rarely go out now.”
– Fiona Todd

5.4 Seeking help with memory problems

“Headway group is a great help with conversations and exercises which helps me to understand I am not alone and sharpens my brain (a little!).” – Anonymous

In order to adapt to memory problems, it is vital that people with brain injury and their loved ones seek support.

We asked participants to tell us which Headway and medical services they have used relating to their memory problems and provided space for people to tell us about other relevant services.

Which people/services have helped you to cope with memory problems?	
Headway helpline	14.53%
Headway publications (information booklets and factsheets)	37.02%
Headway group/branch	36.39%
Headway Acute Trauma Support (HATS) nurse	1.70%
Headway website	33.53%
Headway HealthUnlocked community	5.57%
Headway Brain Injury Identity Card	35.56%
GP	29.89%
Neurologist, neuropsychologist or other rehabilitation professional	53.59%
Other	26.45%

- 1,518 participants (71%) have used one or more Headway service.
- 1,309 participants (61%) have found help from their GP, neurologist, neuropsychologist or other rehabilitation professional.

In the space provided for ‘Other’, open-text answers included a wide range of rehabilitation professionals, family and friends.

“Headway Glasgow has been a lifesaver for me. After my brain injury I was destroyed and bordering on suicidal. Referral to the organisation has given me my life back. Thank you so much.” – David Fernandez

“Headway saved me. Everyone should go to Headway rehabilitation. And neuropsychology.” – Anonymous

5.5 What would you like other people to say or do in order to support you with your memory problems?

“I value my independence, I like to do things myself but, sometimes I need support. I don't want you to do it for me, I want you to show me.” – Anonymous

“To be patient, to try not to give me too much information in one go, and to appreciate that I may not remember things that we talked about. To be understanding if they have to repeat things more than once.” – Cerys Willoughby

“Realise that I'm not faking and that the struggle is real.” – Anonymous

“Just to understand that it's something I can't help. I don't forget things deliberately. It makes me feel so low, upset and sometimes quite scared when I forget big important things that nobody else understands how that can happen. I just wish they'd reassure me rather than get angry and upset with me.” – Anonymous

5.6 And what should people avoid saying or doing to support you with your memory problems?

“I told you that. Don't you remember. It's your memory. It's you. It's your fault.” – Anonymous

“I'm just like you, I am always forgetting things. It's an age thing. Finishing sentences for you when you are struggling to find the correct word and not always correctly to what you were trying to say.” – Anonymous

“Sometimes I feel I need to make light of it, so as not to get upset or show how scared it makes me. Yet when anyone else makes light of it I feel like crying. I would like for people just to be understanding. Not angry, upset, and not laughing at me.” – Anonymous

“We can choose to listen and be kind or we can judge and be hateful. It really is that simple. The very clumsiest of comments backed up with a warm heart and a kind smile is instantly forgiven. Asking questions, how is it for you, how does it feel, etc is enough.” – Anonymous

6. Conclusion

Our study clearly shows how debilitating memory problems can be for those who experience this common effect of brain injury.

With 86% struggling to remember day-to-day things and 84% having problems remembering important dates and appointments, it is perhaps no surprise that three-quarters of participants reported that memory problems have a negative impact on their level of independence, and 85% reported a negative impact on their life as a whole.

Memory problems also affect employment, with 79% of participants, nearly four in five, reporting a negative impact. Only 10% told us that their employer had a good understanding of their issues, with the 56% who selected 'not applicable' demonstrating low levels of employment among this predominantly working-age group. It seems reasonable to assume that greater awareness of the hidden effects of brain injury could help more survivors to achieve and maintain a rewarding career.

Among the many negatives there were some positive findings, demonstrating the resilience and adaptability of many brain injury survivors. 68% of participants have found ways to manage their memory problems, with just over half saying that they feel optimistic about their future.

Relationships seem to play a large role in this. Those who reported that their close family and friends had a good understanding of their memory problems also had increased feelings of optimism about their future and saw less negative impact on these relationships. This highlights the vital importance of information and support not just for the survivor, but for their family and wider support network.

Unfortunately with over 70% of participants reporting that they have been unfairly treated as a result of their memory problems, it is clear that there is much work to be done in raising awareness to help brain injury survivors improve their self-esteem, gain independence and feel supported by society as a whole.