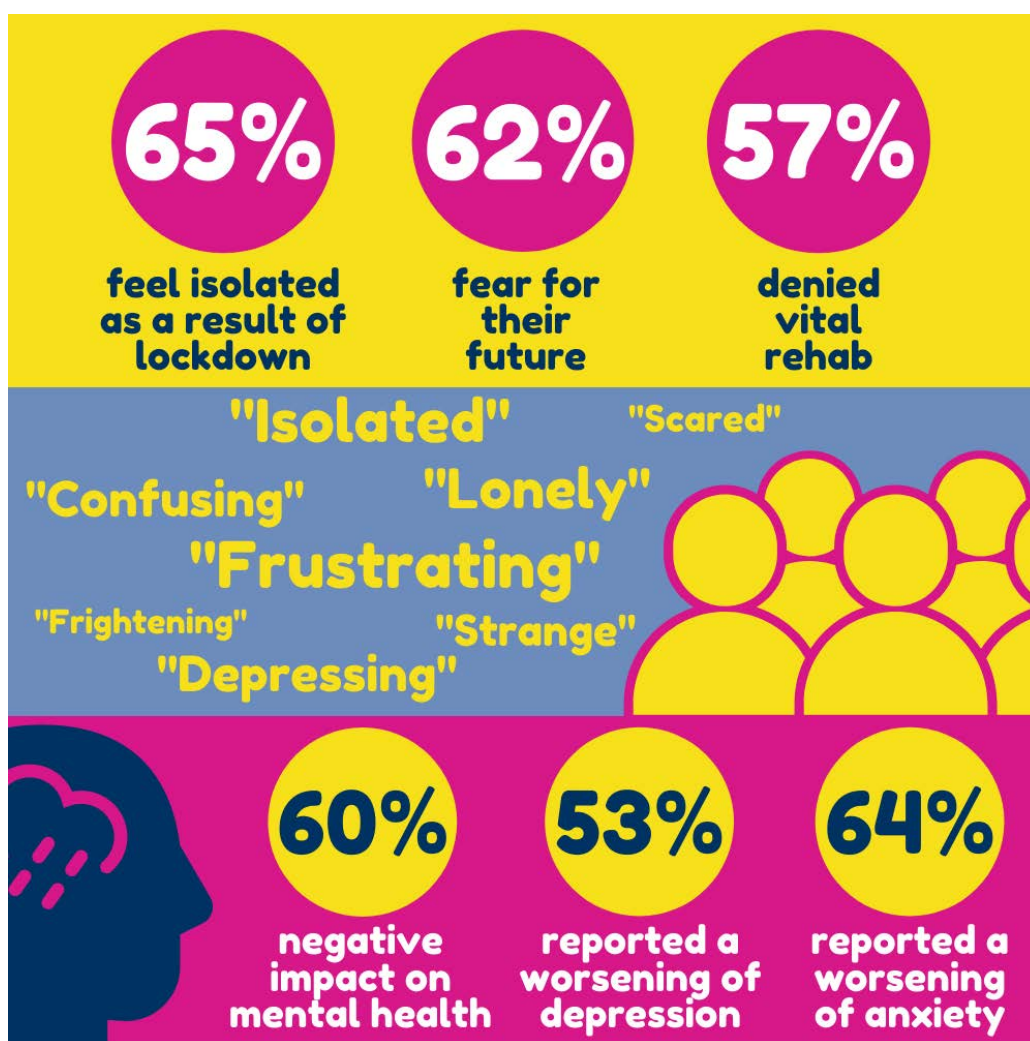




the brain injury association

The impact of lockdown on brain injury survivors and their families



A study into the impact of COVID-19 and the associated lockdown on people who are affected by brain injury.

Supported by Dr Andy Tyerman, Consultant Clinical Neuropsychologist and Trustee, Headway – the brain injury association.

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1. Introduction

The impact of COVID-19 lockdown measures raised immediate concerns about how the far-reaching changes in routine would affect people with brain injury and their relatives. Lockdown has brought unprecedented change for us all. However, the effects of brain injury complicate survivors' ability to adapt to lockdown and increase personal and family impact. Further, lockdown has restricted input from services at a time when support is needed more than ever before.

Depending on the part of the brain affected and the severity of the injury, the effects of the brain injury can differ greatly. Survivors can suffer a physical impact such as reduced mobility and balance and coordination problems, cognitive impairment such as memory loss, impaired reasoning and judgement, and emotional and behavioural effects such as mood swings and sudden emotional outbursts.

Feedback from colleagues at Headway and community brain injury rehabilitation services reinforced initial concerns about increased confusion, irritability, frustration, anxiety, low mood, social isolation and suicidal thoughts. If this was the case for some people receiving ongoing support, then what might be happening to others who are not?

In response Headway – the brain injury association produced a questionnaire to explore the experience of lockdown for people living with the long-term effects of brain injury and their relatives through SurveyMonkey. This was completed by 1,140 people, of which 933 were people with brain injury, 121 partners, 53 parents and 33 other family members or carers.

The responses reinforce the impact and challenge of lockdown for people with brain injury and their families – many of whom were already living with the significant additional challenges that a brain injury can cause. Some key findings are highlighted below.

2. Key findings

Questions about the effects of lockdown highlighted the extent of disruption arising from loss of daily routine, high levels of social isolation and a negative impact on mental health.

2.1 Brain injury survivors fear for their futures due to lost rehab



Over half (57%) of those who sustained their brain injury in the past two years and 42% of all respondents reported that their rehabilitation had been negatively impacted by lockdown. Rehabilitation aims to help the brain learn alternative ways of working in order to minimise the long-term effects of brain injury. A loss of rehabilitation, particularly in the early stages but also in the longer-term, can lead to a lifelong impact on a brain injury survivor's level of disability, and the entire family's ability to cope.

Almost two out of three (62%) respondents reported an increased fear for their future due to lockdown, contrasting sharply with the results of a 2017 Headway study¹ that showed just 28% of people had negative feelings about their future.

Respondents reported being confused about changes in their daily lives, difficulties in coping with the effects of brain injury with less contact with family and friends – often a vital source of support that helps them to cope.

¹ A new Me: Experiences of life after brain injury 2017 <https://www.headway.org.uk/media/4655/a-new-me-experiences-of-life-after-brain-injury-report.pdf>

2.2 Two thirds of respondents report a negative impact on their psychological wellbeing

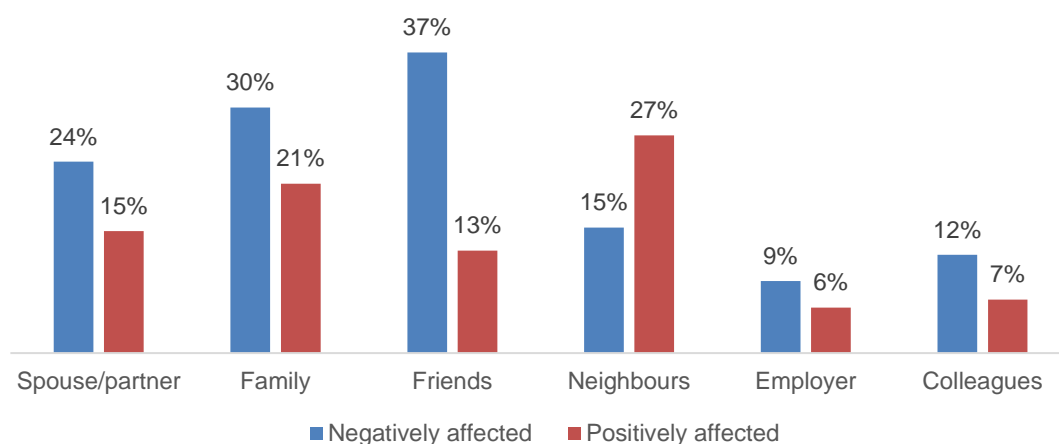


Responses to questions about the impact of lockdown on psychological wellbeing is of major concern, with two thirds of respondents reporting a negative impact on their psychological wellbeing and mental health.

In addition, over half of respondents reported an increase in their frustration, anxiety, stress, fear of the future, loneliness and depression with up to a quarter reporting marked increases.

This is particularly troubling among brain injury survivors as the psychological effects of brain injury can often overlap with or exacerbate those of mental health conditions, making these effects significantly more difficult to cope with.

2.3 Impact on relationships



Specific responses of particular concern include the increase in loneliness reported by 73% of people living alone and 70% of partners reporting increased stress.

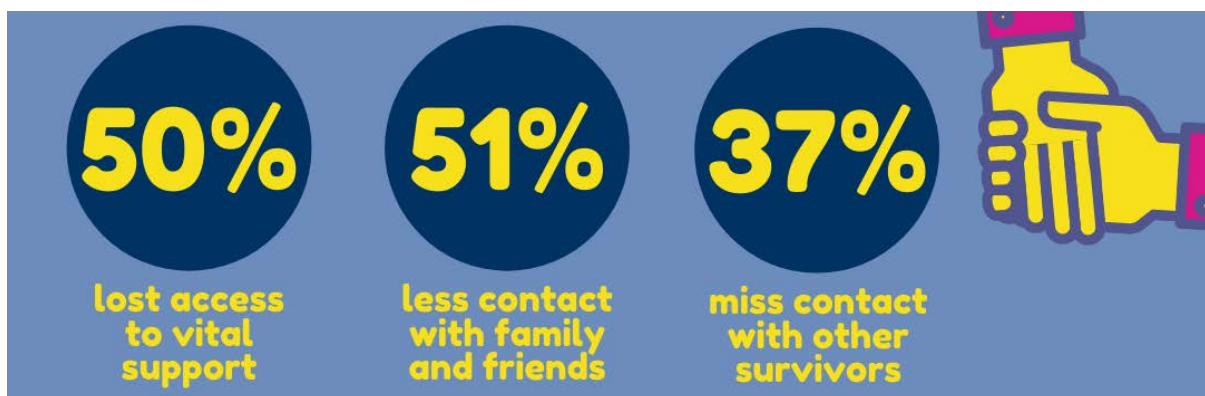
Lockdown was reported to have a significant impact on relationships with family and friends for people with brain injury and their relatives. Whilst around 40% of respondents reported no change in relationships and up to 20% reported positive

changes, 37% reported a negative effect on relationships with friends, 24% with partners and 30% with family as a whole.

Again, these changes should be seen in the context of relationships that may already have been experiencing significant strain due to the effects of brain injury and the pressures of caring. A 2018 Headway study² showed that 69% of brain injury survivors experienced loss of friendships and 44% reported breakdowns in their family relationships even without the additional impact of the recent lockdown.

In contrast, 27% of respondents reported a positive change in relationships with their neighbours. This highlights how local communities have come together to support each other during COVID-19 and the lockdown, with many neighbours having communicated and supported each other more than ever. While this is a welcome and positive finding of our study, the informal support of neighbours cannot be expected to replace specialist services such as Headway groups and branches and other rehabilitation services.

2.4 Half of respondents have lost access to vital support to help them cope



In terms of support during lockdown, half of respondents reported a loss of vital support that helps them to cope, with 51% highlighting less contact with their family and friends as a particular issue alongside the loss of rehabilitation services.

In addition, 37% of people with brain injury have struggled to cope without regular contact with other survivors, a vital aspect of the face-to-face support that Headway groups and branches provide.

² Relationship changes after brain injury <https://www.headway.org.uk/media/5734/relationship-changes-after-brain-injury.pdf>

3.2 The effects of lockdown

We asked participants to review a series of statements, phrased both positively and negatively, and indicate to what extent they agreed or disagreed. The results are in some cases striking and have helped us to identify the key areas in which people with brain injury are struggling to cope.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	N/A
I have found the changes to my daily life in lockdown to be confusing	6.26%	19.22%	20.19%	32.54%	18.87%	2.91%
Lockdown has had a negative impact on my mental health	6.79%	11.38%	19.84%	34.83%	25.04%	2.12%
Lockdown has given me a chance for a break and to recharge	17.34%	25.44%	24.03%	19.89%	9.33%	3.96%
Lockdown has had a negative effect on my behaviour	7.68%	19.15%	23.74%	32.66%	13.95%	2.82%
I have found ways to manage self-isolation during lockdown	5.83%	12.97%	21.80%	45.54%	9.71%	4.15%
My alcohol consumption has increased during lockdown	24.56%	18.31%	13.03%	17.08%	5.63%	21.39%
I have enjoyed spending more time with my family during lockdown	13.90%	13.63%	23.48%	23.57%	10.82%	14.60%
I am struggling to cope with the effects of brain injury with less contact with family and friends	6.53%	14.12%	19.86%	29.13%	22.15%	8.21%
I feel socially isolated during lockdown	5.83%	11.84%	15.11%	35.34%	29.33%	2.56%
I feel adequately supported during lockdown	9.89%	20.12%	25.86%	31.24%	10.41%	2.47%
My rehabilitation has been negatively impacted during lockdown	6.81%	12.56%	21.75%	25.11%	16.62%	17.15%
I have found it easy to access food and essential items during lockdown	9.79%	22.57%	16.31%	36.33%	12.87%	2.12%
I feel less positive about the future as a result of COVID-19	5.29%	13.13%	22.11%	35.68%	21.94%	1.85%
Changes to my routine have disrupted my daily life	4.59%	11.21%	13.24%	39.89%	28.42%	2.65%
Since lockdown my household income has decreased	13.32%	23.46%	24.34%	15.43%	11.55%	11.90%
Since lockdown my household spending has increased	8.47%	28.60%	23.12%	26.13%	11.03%	2.65%
I have struggled to cope without regular contact with other people with brain injury	8.15%	17.45%	25.86%	20.99%	14.61%	12.93%
I have lost access to vital support that normally helps me to cope	6.09%	15.09%	20.39%	29.83%	19.95%	8.65%

From these responses there are several strong trends that highlight the impact of lockdown on those affected by brain injury:

- 51% of participants have found changes to their daily life in lockdown confusing
- 60% feel lockdown has had a negative impact on their mental health
- 47% feel lockdown has had a negative effect on their behaviour
- 23% have seen their alcohol consumption increase – a particular problem that has a significant impact on many brain injury survivors
- 28% have struggled to cope with spending more time with family during lockdown
- 51% are struggling to cope with the effects of their brain injury with less contact with family and friends
- 65% feel socially isolated during lockdown
- 42% feel adequately supported during lockdown, although 30% disagree with this statement
- 42% report that their rehabilitation has been negatively impacted by lockdown, rising to 57% among brain injury survivors who sustained their injury within the last two years
- 32% have found it a struggle to access food and essential supplies
- 58% feel less positive about their future as a result of COVID-19
- 68% report that changes in their routine have disrupted their daily lives
- 27% report a decrease in their household income
- 37% report an increase in their household spending
- 35% have struggled to cope without regular contact with other brain injury survivors
- 50% have lost access to vital support that helps them to cope

Further analysis shows that 23% (262) of participants are brain injury survivors who live alone. This potentially vulnerable group reports:

- An increase in feelings of social isolation (72% vs 65% for all respondents)
- A significant increase in the number of people struggling to cope (40% vs 26%)
- A greater loss of access to vital support (56% vs 50%)
- Significantly less likely to have enjoyed spending more time with their families (6% vs 34%)

These figures indicate that alternative ways to communicate, such as with telephone and video calls, have not compensated for the sense of isolation that many people feel, while many brain injury survivors will not be able to access or operate digital technologies.

3.3 Psychological wellbeing

We asked our survey respondents how COVID-19 and the associated lockdown has affected their mental health:

- 64% reported increased anxiety
- 54% reported an increase in boredom
- 69% were more frustrated
- 43% reported a worsening in their anger levels
- 57% reported an increase in loneliness
- 63% have seen an increase in their stress levels
- 53% reported a worsening of their depression
- 62% reported an increased fear for their future

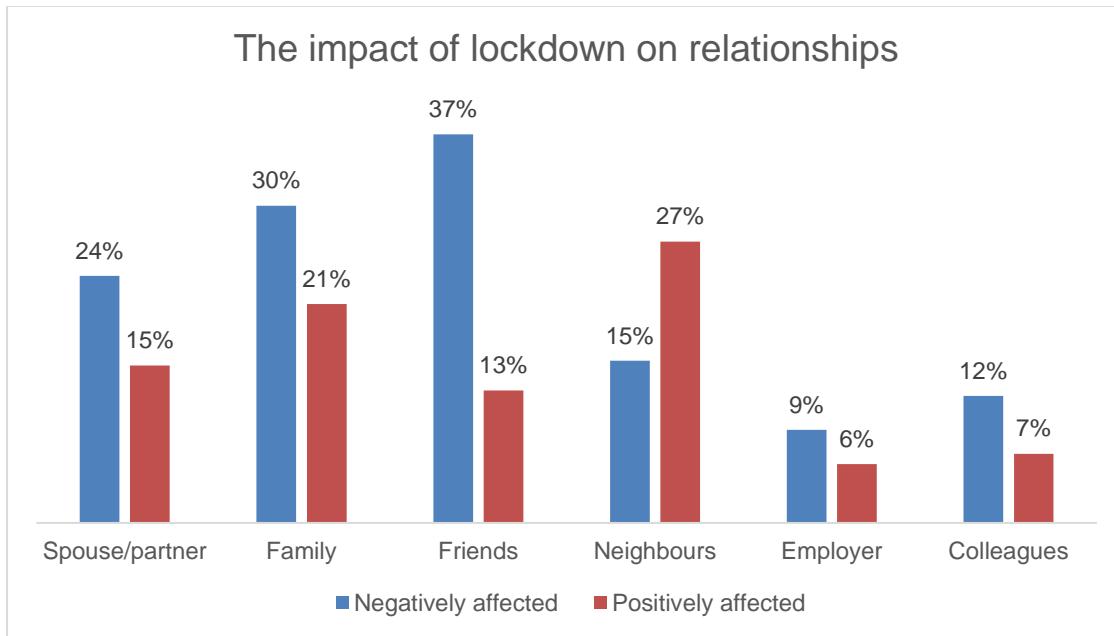
Demonstrating the impact of isolation on immediate family, among the partners of people with a brain injury there was an increase in stress levels (70% vs 63% for all participants) and fear for their future (68% vs 62% for all participants).

Results also showed a sharp increase in loneliness among brain injury survivors who live alone (73% vs 57% for all participants).

	Much worse	Worse	No change	Better	Much better
Anxiety	26.10%	38.10%	30.60%	4.06%	1.15%
Boredom	21.90%	32.27%	40.34%	3.37%	2.13%
Frustration	24.62%	44.73%	26.57%	3.19%	0.89%
Anger	14.44%	29.05%	50.13%	4.96%	1.42%
Feelings of loneliness	21.52%	35.71%	38.98%	2.82%	0.97%
Stress	24.45%	38.83%	28.68%	6.09%	1.94%
Fear of the future	19.27%	42.62%	35.81%	1.59%	0.71%
Depression	19.38%	33.72%	42.12%	3.54%	1.24%

3.4 Relationships

Overall, the lockdown has had a negative impact on the personal relationships of people affected by brain injury, particularly with their friends. However, a significant number of people have also reported a positive impact on their relationships with their neighbours.



“I’ve found a lot of people who had been in touch with me, including some supposed good friends, haven’t been there as much as I needed and so I’ve decreased my circle of who I’m chatting to more. My family are great, we’re chatting over zoom and messages every day.” – Caroline Brady

“I am alone 24-7, my only contact to ‘the outside world’ is social media and the internet.” – Anonymous

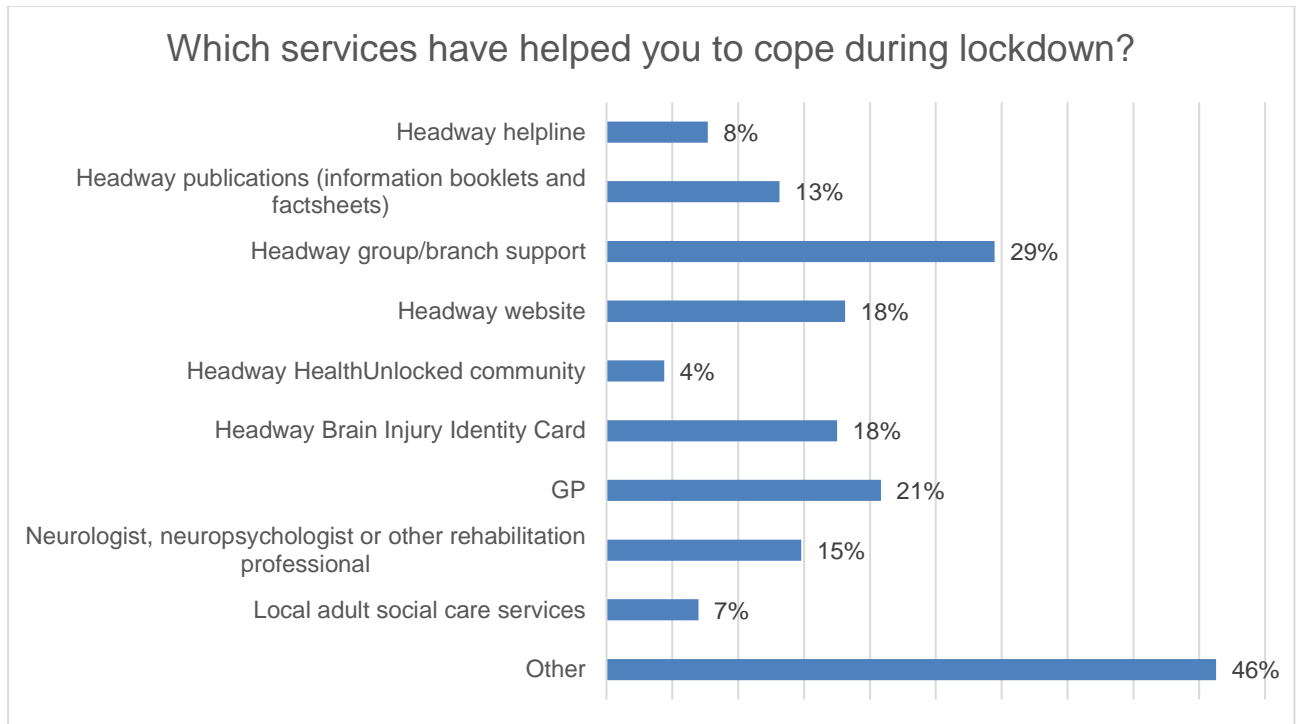
“Not being able to visit my son who is in a care home and worry about his physical wellbeing as all his physio and hydrotherapy has had to stop.” – Anonymous

“I am not in touch with any relatives. Due to my injury, I am unable to work. I don’t have many friends and my closest friend lost her life due to underlying conditions, but Covid-19 was what killed her. :(– Steve Wilden

“Not seeing my children and grandchildren is heart-breaking, I do speak to them on the phone but that’s hard work with my speech problem.” – Anonymous

3.5 Support

Despite 50% of respondents losing access to vital support during lockdown, there are still services that are continuing to support people, including many Headway groups and branches that have implemented innovative remote services to address the significant requirement for support.



51% of respondents have received support from one or more Headway services during lockdown, while 31% have received support from their GP, neurologist, neuropsychologist or adult social care services.

People in the 'other' category highlighted that support from their friends, neighbours and online groups was helping to fill the gaps.

“HEADWAY have ALWAYS been there for me since discharge from hospital three years ago. I would NEVER have managed to ‘find myself’ again if not for their helpline, reassurances and the publication of ‘My Story’ in their website. I love the wonderful people at the best charity in the world.” – Terry Slade

“So relieved that Headway Helpline has still been operating as they have been my main source of support with regards issues around my disability from head injury. Local group has offered to fetch things for me if needed as I am self-isolating and offered advice and telephone support.” – LS

“My local Headway are amazing. I do an exercise class with them three times a week. I continue to do my course with them and the Ladies event. They have put on special events via Zoom.” – Cathryn James

3.6 Physical exercise

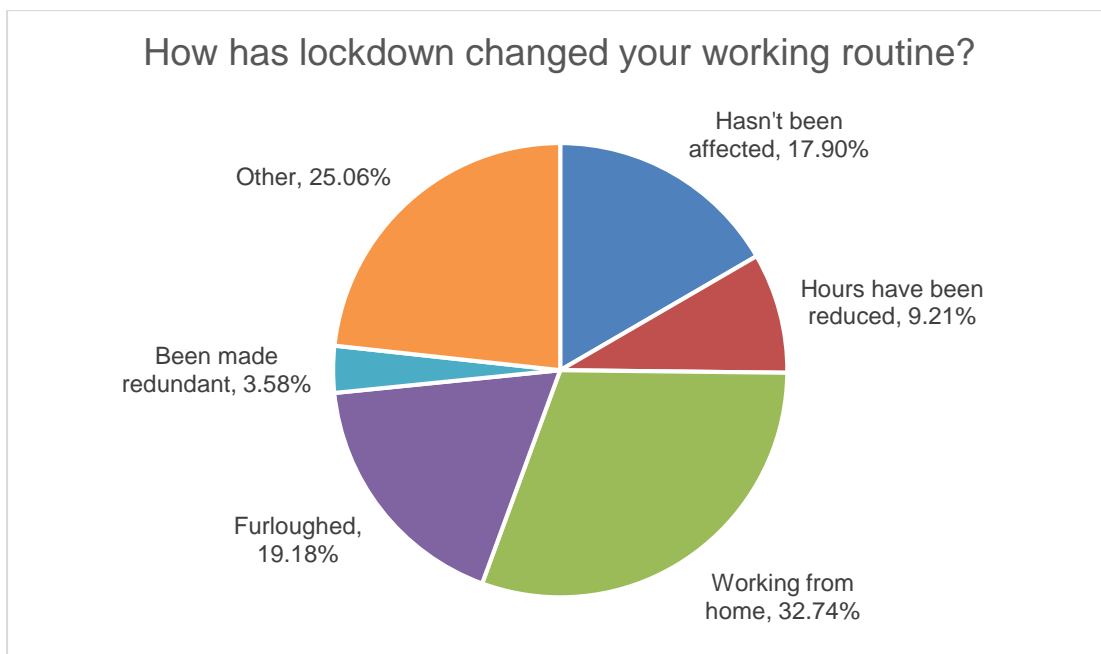
The lockdown has understandably led to a decrease in exercise levels for most people, with 56%, or 634 people reporting a fall and just 18% (206) reporting an increase.

Interestingly, those who have managed to increase their amount of exercise during lockdown have seen fewer issues with some of the mental health effects – 40% of people in this group report a worsening in depression, compared to 56% among those who have seen a decrease or no change in their exercise levels.

3.7 Employment

Of those who were in paid employment prior to the lockdown (396 respondents), only 18% have not seen any effect on their work.

The reported changes include:

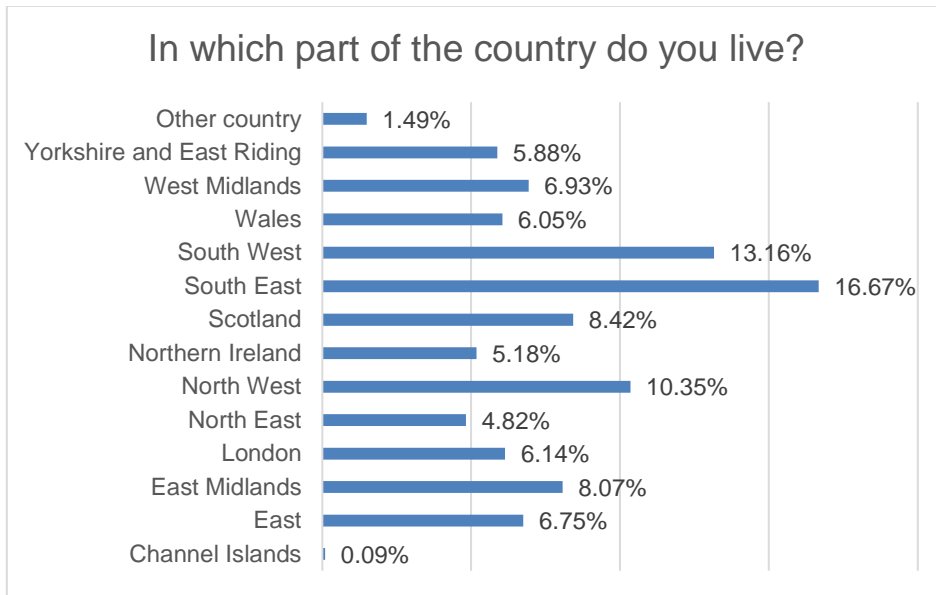


In the 'other' category, many people reported that they had been forced to change their routine due to self-isolation, and other people highlighted that they were self-employed or in contract positions and no work was available.

4. Demographics

1,140 people completed our survey, of which 60.4% are female.

Respondents were from every area of the United Kingdom, with 17 people completing the survey from another country:

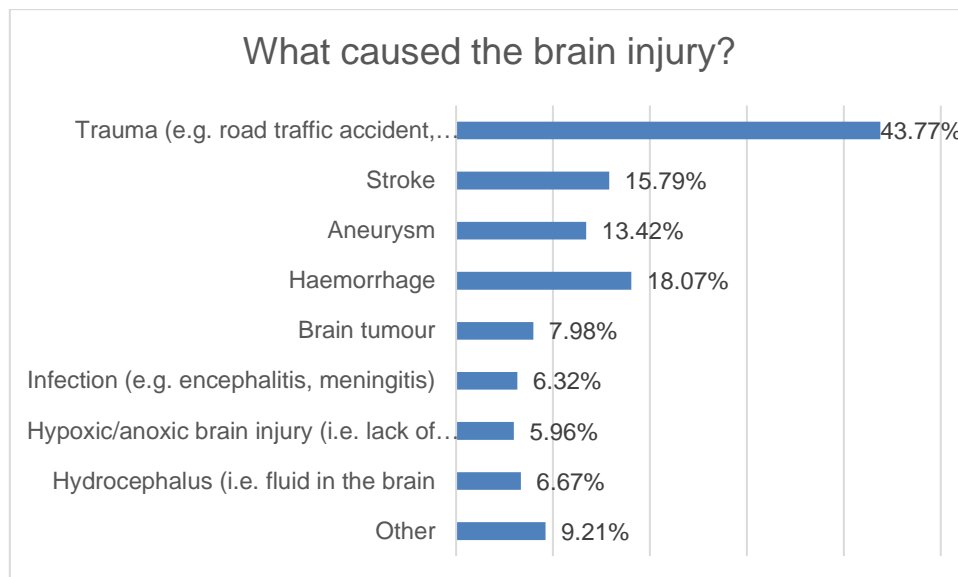


81.8% (933) of respondents have a brain injury themselves, 10.6% (121) are the partner of someone with a brain injury, 4.7% (53) are the parent of someone with a brain injury, and the rest are other family members and carers.

Only 15 survey respondents were under 25 years of age, with the majority (75.4%) being 45 years old and above, and the largest age group of 45-54 accounting for 30.7% of respondents.

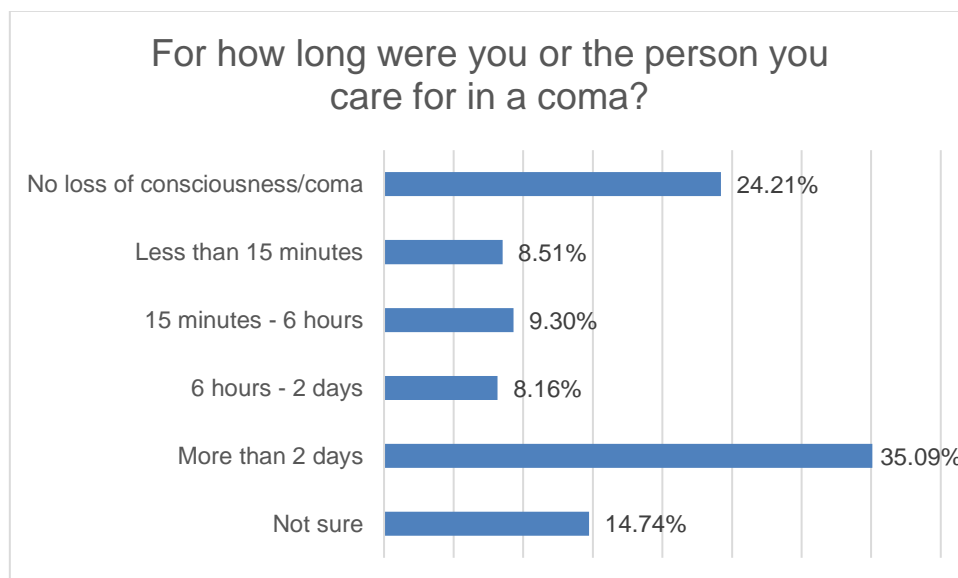
Age group	Frequency
Under 18	1 (0.09%)
18-24	14 (1.23%)
25-34	87 (7.66%)
35-44	178 (15.67%)
45-54	349 (30.72%)
55-64	332 (29.23%)
65+	175 (15.4%)

Traumatic brain injury was the most common cause, with 43.8% of respondents falling into this category, but a wide range of other causes ensured good representation across the acquired brain injury spectrum.



84.4% of respondents told us that they or the person they care for sustained their brain injury over two years ago, with only 19 people (1.7%) sustaining their injury within the last six months.

We asked participants to tell us how long they or the person they care for was in a coma for following their brain injury, in order to estimate the severity of their injury.



We asked people who they are living with during lockdown. A quarter (25%) of respondents are living alone, while 50% are living with a partner and 20% have at least one child in the house.

5. Conclusions

5.1 Loss of rehabilitation may lead to a worsening of the long-term effects of their brain injury

More than half of brain injury survivors have lost access to rehabilitation services as a result of lockdown measures and now fear for their futures.

Early rehabilitation following brain injury can be crucial in helping survivors to regain a degree of independence and relearn lost skills, including walking and talking. But 57% of those who sustained their injuries within the past two years say their access to specialist treatment has been negatively impacted.

Face-to-face rehabilitation is likely to continue to be restricted for some time. This is concerning as the first two years following a brain injury are very important in terms of a patient's long-term prognosis and any delay to receiving specialist rehabilitation can impact their ability to lead an independent life in the future.

These results show that the continuation of rehabilitation services, such as those provided by the NHS and charities like Headway, is more important now than ever.

5.2 Without appropriate support brain injury survivors will be left with lasting damage to their psychological wellbeing

As lockdown measures begin to ease, employment and voluntary work activities are likely to build up gradually and group activities are unlikely to be re-established in the near future. As such, people with brain injury are likely to continue to feel socially isolated, particularly those living alone. People with brain injury were already living with a high rate of many psychological difficulties. Without adequate support for the added impact of lockdown, the risk to psychological wellbeing including suicide risk will likely continue.

5.3 Lockdown has had a major negative impact on brain injury survivors and their families

The lockdown imposed as a result of the COVID-19 pandemic has been a difficult time for most, but even more so for brain injury survivors and their families. The complex physical, cognitive and emotional effects of brain injury that already put tremendous strain on families make it much more difficult to cope with the enormous social and economic changes that have taken place in recent months.

The negative impact includes disruption to daily routine on which many rely, high rates of social isolation, increased concerns about psychological wellbeing for most respondents, often markedly so, and negative net impact on relationships with friends, partners and family as a whole.

5.4 Access to support is vital to ensure that brain injury survivors and their families can cope

In coping with lockdown, people with brain injury have drawn on the support of Headway and from health and/or adult social care services. However, it is of concern that 50% of respondents report loss of access to the vital support that helps them to cope, with 51% struggling with a reduction in contact with their family and friends. Whilst we are now starting to emerge from full lockdown these increased concerns would not be expected to dissipate in the near future.

5.5 The health and social care sector must urgently receive ring-fenced funding

It is imperative that Headway, health, adult social care and other services for people with brain injury and their relatives are supported through this crisis and beyond.

The impact on adult social care in light of this pandemic cannot be underestimated. With long-term structural issues already affecting a social care system creaking at the seams, the additional pressures COVID-19 has brought could be life threatening for some.

Many of the specialist rehabilitation and support services that Headway groups and branches provide are commissioned by local authorities.

But with the impact of COVID-19, some councils are suggesting they meet the criteria to issue a section 114 notice, effectively declaring themselves bankrupt. An investigation conducted by the BBC³ also revealed 148 local authorities across the country predict a budget shortfall this financial year. Put simply, many may not have the funding available to support their services, including adult social care.

Following the outbreak of the pandemic, only 4% of Directors of Adult Social Care from councils across the country are confident that their budgets in 2020/21 are sufficient to meet statutory duties, according to a recent report by the Association of Directors of Adult Social Services (ADASS)⁴.

ADASS also recommends that a two-year ring-fenced funding settlement be provided to local authorities to fund adult social care. Headway supports this recommendation.

This is not just to restore the vital rehabilitation, social and care support delivered previously, on which people with brain injury rely, but also to respond to the increased needs reported as a result of COVID-19 and lockdown. The latter would be expected to include, for example, assisting in both the re-establishment of a revised daily routine post-COVID-19 and in addressing increased psychological and family needs arising as a result of COVID-19 lockdown.

³ <https://www.bbc.co.uk/news/uk-53069772>

⁴ <https://www.adass.org.uk/media/7973/no-embargo-adass-budget-survey-report.pdf>

A two-year ring-fenced settlement would also allow time for a long-anticipated reform of adult social care, to address the intrinsic funding issues which have afflicted the sector for years.

If local authorities are unable to continue to commission the specialist rehabilitation and support services that Headway groups and branches provide, many vulnerable brain injury survivors would be cut off from vital support and seek alternative, more costly services elsewhere.

Action must be taken to ensure local authorities are funded sustainably and are able to maintain service provision. Without support from local authorities, Headway groups and branches will no longer be able to ensure brain injury survivors receive the care and support they so desperately need.