



First Steps Baseline Report

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Overview

This exploratory report commissioned by Headway East London (HEL) aims to better understand the current state of support available to brain injury survivors, their families and carers. In particular, this study asked brain injury survivors to consider what support has been inadequate or where support was missing in their recovery journey.

This information will feed into the development of Headway's new First Steps Programme, which is designed to provide additional information and advocacy to people affected by brain injuries. These experiences will also serve as a baseline against which to measure the future impact of the First Steps Programme.

Twenty brain injury survivors and/or their carers, who had little or no previous contact with Headway and its support services, were interviewed and asked to consider their experiences from the day of the injury to the present.

The feedback and recommendations made by these survivors and their carers are summarized here and expanded on in the following pages.

Summary of findings and recommendations

Findings

- **The hospital experience:** Survivors and carers described struggling in hospital due to difficulties communicating with the medical staff and understanding medical terminology. Carers and survivors felt they were not provided clear and accessible information about brain injury and its possible implications. The majority of interviewees also felt that medical care and social care were poorly coordinated, and that they left hospital with a limited understanding of their brain injury, what it might mean for them, and what resources are available. All interviewees felt that they would have benefited from an opportunity in hospital to receive information and support from a knowledgeable source.
- **Discharge from hospital:** All survivors and their carers described the first six months to a year after leaving hospital as the most challenging and anxiety-ridden period in their journey. The majority said that having a source of information and support during this period would have been helpful, and many felt that preparations for this transition should ideally start in hospital. One quarter of the interviewees left the hospital with no discharge plan at all, while a further half of all interviewees described scrambling to organise and coordinate different sources of support for themselves or family members. Many carers researched and secured adequate social support, care packages, housing, transportation, and therapies on their own and described this as a very challenging experience.
- **Understanding brain injury:** For most survivors and their carers, educating themselves on brain injury is a key component in coming to terms with the trauma of the injury and its health impacts. Survivors and carers found that seminars, peer support groups, and literature and reading groups on brain injury themes had been invaluable in their recovery journey. Survivors and carers highly recommended these activities as sources of information, but also as opportunities to socialise and network with people who had been through similar experiences.

- **Claiming entitlements:** Carers and survivors described struggling to identify and apply for the benefits and social services to which they were entitled. Two recent survivors were completely unaware that they may be eligible for financial support. Many others described difficulties filling out Disability Living Allowance of Personal Independence Payment forms, and argued that the structure of the forms was not appropriate in describing brain injury and its symptoms. Over a quarter of survivors had experienced welfare reforms, particularly the transition from DLA to PIP, which had left three interviewees with reduced funding. Appealing these decisions brought people a considerable amount of anxiety and stress. Close to a quarter of survivors described being under considerable financial strain due to a drop in their income as a result of cuts to social services.
- **Disappointing experiences with statutory services:** Many survivors and carers spoke about the difficulties and disappointments they had faced in organising and negotiating appropriate support with statutory services. Support was often hard to come by or inaccessible to survivors, and many carers felt that statutory services demonstrated a lack of foresight in failing to anticipate the care needs of survivors. Others were frustrated by poor management and communications between care providers and related organisations, or were disappointed with the type or quality of support they had received.
- **Returning to work, studies and family life:** The majority of survivors described feeling frustrated by their inability to return to their lives before the accident. Considerable trial and error was involved before some survivors had developed sufficient insight to understand their new abilities and limitations. A handful of survivors were able to return to work or studies through a slow phased, and heavily supported return. The majority of survivors, however, struggled to find their place after the injury and many described feeling anxious and depressed by their inability to work, study and in particular to earn a living. Survivors who were considering returning to work in some form found that taking small steps was the best way to build confidence. Survivors described benefitting from activities like volunteering, enrolling in short courses, pursuing hobbies and spending time with other people with brain injuries or other disabilities.
- **Recognising carers:** All twenty interviews highlighted the importance of carers as immeasurable sources of day-to-day care, as well as social, emotional, administrative and financial support. However, carers and survivors acknowledge that providing this support was challenging and emotionally draining work. Carers often spoke about tensions that existed between them and the brain injury survivor, and some survivors felt that their family members were unable to understand them, their symptoms and limitations. All carers spoke of different ways of relieving the pressure they felt. Many found comfort and advice in speaking to other carers or professionals who understood their situation. Several carers found that organising daily or weekly outings for the survivor through befriending services or social workers was helpful. This allowed carers a few hours to recuperate or consider other household tasks.

Recommendations

1. Early intervention: All twenty interviewees felt they would have benefited from early intervention in the hospital by a key contact that could have helped them understand the basics of brain injury and what they might have to consider going forward. Many interviewees felt that they had left the hospital with a poor understanding of brain injury and little or no insight into the kinds of challenges that they would be facing.

2. Supported discharge from hospital: Survivors and their carers also felt that their discharge from hospital could have been overseen or supported by a key contact, who was knowledgeable about the types of support and rehabilitation that may be available. Carers in particular described how it would have been helpful to have more practical information about care packages, social workers, rehabilitation, benefits, mobility vehicles and transportation options, and other helpful services before returning home and having to research and procure these options themselves

3. Central source of information: All survivors and carers felt that having a central source for information and advice on brain injury, and knowing about it early on in their journey, would have made a difference to their recovery. People wondered whether Headway could act as a hub for advice and support, as well as a disseminator of up-to-date information through setting up occasional seminars, support groups, and making available relevant literature.

4. Clarity in what Headway and First Steps can do: Survivors and their carers thought that Headway could provide people with a clearer statement about what it does and how it might be able to support survivors who are currently not members of Headway. Interviewees thought there was some ambiguity about whom Headway supports and what its remit is. Survivors and carers thought that Headway could be better promoted in hospitals and rehabilitation units.

Survivors and their carers also came up with a number of additional **bright ideas** and suggestions for Headway and its First Steps programme to consider and potentially take forward. These bright ideas are listed on **page 26** at the end of this document.

Introduction

This report was commissioned by Headway East London (HEL) to better understand the current support available to people with acquired brain injuries (ABI) and their carers. In particular HEL would like to establish what support is missing in the current recovery journey, and to generate ideas around the types of additional support survivors feel they would benefit from.

The feedback and findings from the report will help guide the development of HEL's First Steps Programme. The First Steps Programme has recently received funding from the Big Lottery and intends to complement existing statutory services by providing additional information and advocacy to people affected by brain injuries. It aims to improve continuity between inpatient care and community support and reduce confusion among survivors and carers by providing them with a single link person who will liaise with other agencies and staff. It will help beneficiaries connect socially, gain support and get the rehabilitation and financial benefits they need. Overall, the First Steps Programme aims to reduce stress and anxiety, prevent crises and help families stay together.

This report is a "baseline report" in that we are collecting experiences and information from survivors who have had very limited or no contact with Headway support services. These experiences will be contrasted in later reports with the experiences of survivors who have received support through the First Steps Programme. It is hoped that this comparison will help identify what kind of impact the First Steps Programme is having on survivors of brain injury and their carers.

The baseline report is based on feedback from twenty in-depth interviews with brain injury survivors and/or their carers.

We would like to thank everyone who gave their time to describe their journey, and to share their experiences and their ideas with HEL.

Terms

An **acquired brain injury** (ABI) is sudden damage caused to the functioning of the brain, occurring due to: traumatic brain injury, brain tumour, haemorrhage, viral infection, or lack of oxygen to the brain. ABI can result in a number of potential impairments, including difficulties with cognition, memory, concentration, or communication, impulse control, emotional regulation, anxiety and withdrawal. There may also be resultant physical difficulties, including headaches, fatigue and chronic pain.

Headway East London (HEL) offers support and services to brain injury survivors and their families and unpaid carers across north and east London. The day service is the most established service, supporting 150 members per week. The day service acts as a hub for the other services, which include the therapy service, young people's group, family support group, case worker team, and support work service. HEL has recently received funding to develop its First Steps Programme, aimed at providing additional information and advocacy for survivors of brain injury regardless of their membership status at HEL. The impact of this programme will be evaluated in a future report.

Data collection

Twenty brain injury survivors and/or their carers were interviewed for this baseline investigation. The interviewees were asked to recount their journey from the day of the injury to today. Interviewees were asked to describe what types of support they had received, and in particular to reflect on the type of support they thought was missing.

All twenty interviewees had little or no previous contact with Headway support services and are not members of the Headway day service.

The aim of these interviews was to better understand what support is typically available to survivors of brain injury, and to establish at what points in the recovery process survivors felt support was missing.

The interviews lasted between 25 minutes to an hour and were conducted over the phone with either the brain injury survivor or their primary carer. On some occasions both the survivor and their carer gave feedback on their experiences and made suggestions.

The interviews were conducted in a semi-structured way so as to allow the interviewee to recount her or his experience freely without interference from the researcher.

Sample

Interviewees were identified by a staff member at HEL who is responsible for outreach and making visits in the community. Through this staff member, people were identified who had little or no previous contact with HEL. They were first contacted by email and later by phone to explain the aims of the report, and to ask if they would like to contribute.

Table 1 provides an overview of the interviewees we spoke to for this report, including their age, the year of their accident, the type of injury they had sustained and how they personally described their symptoms after the injury. All names and identifying characteristics have been changed in this report in order to protect the identity of the contributors.

The table shows how brain injury affects a broad range of people, is acquired through many different types of injury, and manifests itself in unique ways.

For this report we interviewed people living with a range of brain injury - from survivors of brain injury who were still highly functioning to carers of brain injury survivors who had lost a significant amount of cognitive function and physical mobility.

While brain injury survivors at both ends of the spectrum are in need of support, the type of support differs widely depending on the person's unique circumstances.

This highlights how complex it is to provide a support service to such a diverse group of people. While all interviewees had survived similar injuries, they have recovered with markedly different impairments and find themselves in scenarios that often require specific attention and an in-depth understanding of the person's history and personal circumstances.

Table 1. Who was interviewed

Name	Age	Year of accident	Type of brain injury	Described impairments/symptoms
Tom	50s	2015	Haemorrhage	Blurred vision, short term memory loss
Lucy	40s	2015	Aneurysm	Limited mobility, language impairment, short term memory loss, confusion
Charles	30s	2015	Brain abscess	Paralysis down left side, slurred speech, memory, fatigue
Joe	40s	2014	Brain abscess	Seizures, paralysis down one side, language impairment, emotional and cognitive problems
Fahid	40s	2014	Traumatic brain injury	Chronic headache, depression, slurred speech
Beth	60s	2014	Traumatic brain injury	Limited mobility, language impairment, memory loss, anxiety, severe cognitive problems
Tracy	20s	2014	Traumatic brain injury	Restricted movement, language impairment, short term memory loss
Karl	40s	2014	Brain abscess	Seizures, paralysis down one side, language impairment, mild cognitive problems
Emily	20s	2013	Virus	Fatigue, mild cognitive problems
Paul	30s	2013	Traumatic brain injury	Memory loss, anger and anxiety
James	50s	2012	Haemorrhage	Fatigue, memory loss, language impairment, limited mobility
Stewart	30s	2012	Traumatic brain injury	Mild cognitive problems, short term memory loss, fatigue
Mary	50s	2012	Stroke	Short term memory loss, confusion, anxiety
Kate	40s	2012	Haemorrhage	Short term memory loss, language impairment, seizures, anxiety, fatigue
Mark	40s	2011	Aneurysm	Epilepsy, fatigue
Asim	20s	2007	Traumatic brain injury	Loss of sight, short term memory loss, concentration, anxiety
Bo	50s	2007	Stroke	Language impairment, short term memory loss
Ahmed	30s	2000	Blood clot	Epilepsy, fatigue, anxiety
Maria	40s	1991	Aneurysm	Fatigue, short term memory loss, limited concentration, anxiety
John	60s	1990s	Haemorrhage	Language loss, short term memory loss, mild emotional and cognitive problems
Susan	70s	1960s	Traumatic brain injury	Mild language impairment

Findings

All twenty survivors and carers were asked to recount their journey from the day of the injury to the present. In particular, interviewees were prompted to consider the types of support they had received and to reflect on when they felt support had been missing.

The findings presented in this section follow survivors' journeys from their experience in hospital, to their discharge, their rehabilitation, and their reintegration at home, work and into society.

Improving the hospital experience

Communication and language

While the majority of the survivors and carers were positive about the medical care they received in hospital, all twenty interviewees felt that the medical staff generally failed to communicate in an understandable and accessible way how the brain injury had come about, and what it might mean for the survivor.

Some interviewees like Luke described feeling frustrated by the inability of medical staff to communicate in a clear and considerate way with patients and their family members.

Unfortunately doctors, and it seems particularly neurosurgeons, have absolutely no people skills whatsoever...There was one neurosurgeon who wouldn't even look me in the eyes when he was talking to me. I found that very hard, because it was such a traumatic time. I didn't even know at that point what an aneurism was, I'd never heard of one! I had no idea what to prepare for, what to expect. I'd never heard of this. And none of the doctors or medical staff tried to help me understand. – Lucy's husband Luke

The majority of the interviewees described the medical terminology that was used to describe the injury as alienating and incomprehensible. People spoke about feeling frustrated by their inability to understand the meaning of what medical professionals were telling them.

You know medical staff they speak in another language almost and it can be difficult to understand it... It would have been helpful for someone to explain medical terminology to us from the start. My family could have really benefited from that. – James

Many of the interviewees spoke of how it would have been useful to have someone to translate or describe in understandable language what was happening to them or their family member.

I didn't really have anyone who could translate what the doctors were saying to me and as a consequence I felt very out of control of the situation. The language can be so alienating sometimes. What makes people feel better is if they can understand and ask the right questions of the right people. That would make people feel better and like they had more control over the situation – Maria

Lack of clear information

Family members in particular described their frustration over not receiving enough information about brain injury and its repercussions in hospital. Family members described feeling “powerless” and unable to ask the right questions when they met with doctors. Family members wished they had been provided the appropriate information early in the process.

Information is just not forthcoming in hospital. Why did this happen? What are the stages of recovery? Where can we go for help? The answers were so vague. And as someone who is watching someone they love go through this – you feel completely powerless. It would be great if there was someone you could go to who tells you what brain injury is, what will happen, the track to recovery after discharge, what to expect and so on. It's pretty simple information, but it felt like I had to figure it all out myself. – Lucy's husband Luke

All survivors and family members described leaving hospital with either no or a very limited understanding of what brain injury was, how it would affect them and what resources might be available to support them after they had returned home. Family members in particular felt that it would have been useful for someone to help them think ahead, after the discharge from hospital, and to consider what support might be available.

In those initial few days you're in a state of shock, but at some point after the initial shock, I think it would be helpful for someone to sit down with you in hospital and say – this is what's coming towards you, and here's how to prepare. And then certainly as you get into a later stage it would be really helpful for someone to explain to you care packages and things like that. And just to know really, if you need support there are these agencies and groups that you can go to. And especially to know what your loved one is entitled to. Because we left hospital and we didn't even know that our daughter was entitled to benefits, or mobility or care – we didn't know any of that stuff. And all that practical stuff is what gets you through the days, you know. And that's all stuff we had to find out ourselves. – Tracy's mother Grace

Support from a knowledgeable source

All twenty interviewees wished there had been a contract person in the hospital at the beginning of their recovery to explain in clear and understandable terms what had happened, what to expect, and what to consider going forward.

I think the point when I could have really used help was when it first happened. I was completely at sea. I had no idea what was happening. What she was going through. What was going to happen next. So that would have been exactly the time when I could have used someone to go – look this is what it is, this is what you'll have to wait for, but this is coming towards you. And to address all the questions that were going through my mind. As well as the questions that weren't going through my mind at that point, but have come up since. Because at that time you're just so overwhelmed. – Lucy's husband Luke

Struggling to find your way after discharge

A difficult transition

Many interviewees described the first six months to a year after their discharge from hospital or rehabilitation units as the toughest period in their journey.

Survivors described having to come to terms with what had happened to them and their new limitations, while family members and carers spoke of adjusting to a life with a much altered loved one.

Survivors and carers often have to give up work and have to rearrange themselves around a new status quo, and this transition was frequently described as being very challenging and emotional for people.

Many felt that having a contact person or access to a trusted source of support during this time would have eased the transition from hospital to home.

Discharge plan and follow up

Close to a quarter of the interviewees described leaving hospital with no discharge or follow-up plan at all, and spoke of having to navigate life with a brain injury on their own.

Nobody came up with a discharge programme for me after hospital. I had no appointments organised or anything. There was no plan. So I've figured it out myself through the internet and books. I spent hours on the phone trying to organise counselling or physical therapy sessions. When I was discharged I couldn't stand for more than a few minutes at a time. I had to come up with my own ways to live my life with all of these terrible limitations. It was a very difficult time. I don't want that to happen to anyone else. – Kate

Others spoke about leaving rehabilitation units with no follow-up or long-term plans or health objectives to work on at home.

We got the feeling very much that when my husband was discharged from Queensquare that that was it, he was done and dusted. I think his key worker phoned a couple of days after we got home, but that was that. There was no follow up... And you feel like that's the cut-off point, having achieved these short-term goals in rehab. And I mean you are cocooned. You are institutionalised for a long period of time at the end of that, and you're just sent home to deal with it on your own. – Tom's wife Julia

The majority of brain injury survivors spoke about their high levels of anxiety and about feelings of depression in the first months after their discharge. They described grieving for their life before the injury, finding it difficult to come to terms with their new limitations, and scrambling to try to secure the support they needed.

In the first six months I felt I could have used some additional help. I felt like I had no insight into what was going on with myself and what my limitations were. And I have to say that I felt very stressed and panicky when I first left hospital. It was probably my darkest time. – Kate

Organising your own support

Many spoke about organising their own support and the vast amount of time, research and administrative work this required. Carers in particular spoke about their struggles in negotiating care packages, identifying social workers, securing adequate housing and transportation, finding and paying for appropriate therapies and the challenges they faced in communicating with and coordinating these different departments and organisations. People with carers or family members to help them often wondered how survivors without this kind of support managed on their own.

When I first got out of hospital I needed more help. I had to learn how to do everything new...Eventually my brother and I found the right people to get help from, but it took a long long time and I was lucky to find them. There's got to be a lot of people with brain injuries who are not confident to demand what I demanded, or who have family members to support them through this. – Asim

Supporting the initial transition

All twenty interviewees mentioned that it would have been helpful to have access to a connected person who was “in the know” about brain injury at this point in their journey. Survivors and their family members described feeling vulnerable and need of access to understanding and caring support.

I think that it would have been really nice to have someone to follow up with the first month or so. Someone phoning up to ask how it's going, are there any problems? Is there anything we can do? Right after you leave hospital is where more support really could come in. – Tom's wife Julia

Understanding and coming to terms with brain injury

Brain injury education

For most survivors and their carers, educating themselves on brain injury is a key component in coming to terms with the trauma of the injury and better understanding the symptoms that they are experiencing.

All of the interviewees described doing their own research, particularly in the first few months, in an attempt to better understand their conditions.

I think probably through the whole process it would be helpful to have as much information as possible. There are points when you are struggling to understand the impact to yourself and to your family about what you're going through. I want to understand the ins and outs of my brain injury – and that information I've never been given I've had to go out and look for it. And sometimes I've probably drawn the wrong conclusion because I've done it on my own. – James

Interviewees described three sources of information as being particularly helpful - these included seminars they had attended on issues related to brain injury, support groups made up of other brain injury survivors and their carers, and books and literature they had been recommended that explored both the medical and emotional fall out of brain injury.

Seminars

Interviewees had primarily attended seminars on brain injury topics at rehabilitation units. These seminars were often run by doctors, therapists, social workers and benefit advisors who had been invited in to provide information on a variety of topics relating to brain injury, its symptoms and the types of support that are available to people. Seminars gave people an opportunity to ask experts questions that they had been dwelling on and provided a space to meet other survivors of brain injury and their carers.

While I was in rehab we had seminars where we talked about things like how the brain works, and the different kinds of brain injury. And one week they had a doctor come, and another time a physio came, and they explained to us how the body and the brain works and why we were experiencing certain symptoms. It's amazing stuff really to find out how the brain works, and I feel like it really helped me understand myself better. I wish those seminars had gone on for longer really. – Charles

Peer support

Peer support groups were praised by all of the interviewees who had experienced them. Peer support provided insight into how other people struggle and cope with brain injury and through comparison also helped the interviewees develop a better understanding of their own situation. Peer support also helped survivors better understand how their brain injury was affecting their family members and carers.

My husband was embarrassed before to go out and interact with other people. I always had to support him. I could tell that he felt very out of place. We didn't know anyone else with a brain injury. After he started spending time with other people with brain injuries, I could tell that my husband was beginning to reflect

on his own behaviour. And what some of his actions are doing to me. And he's kind of managing to understand that better. – John's wife Lily

Interviewees also described getting tips and picking up strategies from survivors and carers who were more advanced in their journey. Meeting other people with brain injuries also helped to normalize their situation and made survivors feel part of a community.

The most helpful support I received was from other people with brain injuries. When you hear other people talk about how they feel and how they go their injury and the impact it's had – it gives you an opportunity to reflect. And I think you can see through others how your own behaviour might be affecting your family members. Reflecting like that has really led to change for me and I would say that my home life is much better now. – Maria

Literature

Survivors and carers often spoke of books they had been recommended or that they had come across that were especially meaningful to them in understanding life after a brain injury. These books spanned the spectrum from simple medical texts, to the memoirs of carers or experiences of people living with brain injuries. Literature helped people understand both the medical and the emotional outcomes of their injury and provided insight and comfort to people.

A colleague's brother who'd had a brain injury gave me a book which was the memoirs of a neurosurgeon and there was a lot of explanation in that book that was really beneficial to me because he spoke to lots of people who were recovering from brain injury. You know medical staff they speak in another language almost and it can be difficult to understand it. So to read a book that explained that language in basic terms really helped me understand some of it. – James

Someone gave me a novel about someone caring for a son with a brain injury. And that was very helpful I would say. I think it helped me understand my wife more and how it must be to look after me. There should be more books like that about brain injury. – Fahid

All in all, interviewees said that having more information and a better understanding of brain injury reduced their anxiety and made their journey more manageable. Survivors and carers emphasized how important knowledge was in more confidently managing a brain injury on a daily basis.

What really helped me was when someone clearly explained to me how my brain injury was connected to my seizures. When the neurophysicist explained that to me - the mechanics of a seizure, the reasons for having a seizure - he made me realise that if I take my medication and avoid stress and getting too tired I am much less likely to have a seizure. Being given that information and that knowledge gave me much greater confidence and enabled me to live my life in much more understanding way. – Karl

Claiming entitlements

Eligibility for benefits

Twelve out of the twenty interviewees were claiming benefits, four interviewees either didn't claim benefits or received support from their employer, two were in the process of claiming, and a further two said they were not aware that they might be eligible to claim.

I haven't applied for PIP because I didn't know about it. Nobody ever told me about it. I didn't know there was such a thing and that I could qualify for it.
– James

The majority of the interviewees described how they had to figure out what benefits they were eligible for themselves after they left hospital, and that they often had to fight for benefits they were sure they deserved.

Eventually I got the help that I was entitled to and that's only because I fought for them and looked around and researched what was available to me and that was a lot of work on my part. I had to take it to extreme levels to get the kind of help that I needed...It was amazing how much I had to fight for my benefits. I was just out of a coma, I was blind and I was being questioned about why I thought I should deserve DLA. And they questioned me over and over again about why I should deserve DLA – that's how they put it! And I couldn't believe it! – Asim

Filling out forms

More than half of the interviewees claiming benefits spoke about how difficult it was for them to fill out the forms. Many felt that especially the Disability Living Allowance and Personal Independence Payment forms were not conducive to describing the symptoms normally associated with brain injury.

We got some help from the social worker in the Homerton to fill out the forms and that was very helpful for us because the forms are so complicated. I don't think we could have managed them on our own. It's hard to see on those forms where my brain injury comes in. It's all about whether you can walk, and dress yourself and make your dinner, which doesn't really include what my problems are about. – Charles

Many interviewees described brain injury as an “invisible disability” that often manifested itself through cognitive impairments, and weren't always visible in the way that a physical disability might be. This made claiming disability benefit especially difficult.

I never received benefits for my problem, no never. I tried once to get it, but they said you are not disabled! You can walk! You can talk! Why do you want to call yourself disabled? And I thought – why are you judging me? You don't know what's going on with me? If you see me I don't have any physical problems. I can walk properly so you'd never know what going on inside me. – Maria

When we first applied and he went for his interview and the report came back that my son had no cognitive impairment whatsoever, which is ridiculous. But this is the thing with a brain injury – is that it's a hidden disability that isn't obvious to people. So we went to appeal and eventually we got the PIP. – Stewart's mother Anne

Welfare Reform

Several survivors had experienced welfare reforms and the resulting cuts in their benefits. Particularly common was the transition from Disability Living Allowance to Personal Independence Payments, which in two cases left the interviewee with reduced funding, or no funding what so ever. Both interviewees were in process of appealing these decisions.

Mark's experience below shows how survivors of brain injury are struggling with cuts in their benefits and how these cuts often spill over into other aspects of their recovery process.

Recently I've needed support due to all the changes in to my benefits. And it would be helpful to get support with that, because I think someone who knows brain injury could help me explain better what I'm going through on the forms. You really need support from someone who is up to date with all the reforms and knows what's going on.

The reasons they gave me for not transferring me from DLA to PIP were that I could wash, dress and feed myself. And that's meant to be the definition of living independently – anyone who can do these basic things doesn't seem to qualify for help anymore. And this is pushing people over the edge – it's pushing me over the edge because I'm not getting the support I need. And it's giving me anxiety and I know that I should avoid stress because it triggers my epilepsy. I would say this whole process has not been good for me in terms of my health.

I received DLA up to October, and when it stopped I appealed that decision. But I don't really understand the answers I'm getting back after sending in the forms. They're quite complicated the forms and they seem to be going against all of the evidence from my doctors. And I don't understand the comments I'm getting back from them.

Not getting DLA anymore means I've lost £180 from my benefits, and I'm just finding out now really what that means for me. It's going to make things really tight. I've got to be honest that I was only just making things work as they were. Electricity in this flat is really expensive. So now my electricity bill has really run up, and I've got that huge bill to sort out and I've gone into debt on my credit card just trying to stay afloat. So to lose £180 a month on my benefit is really going to push me over the edge. – Mark

Mark's experience shows how benefit changes are particularly difficult for survivors of brain injury to navigate and understand. It also shows how benefit changes are causing survivors to feel significant stress, which may potentially exasperate their symptoms and stall their recovery.

Close to a quarter of survivors and their carers described being under considerable financial strain due to a drop in their income as a result of cuts in benefits and social services.

Need for support

Half of the interviewees claiming benefits said that it would help them to know someone who is up to date with benefits changes and who could support them in filling out forms, preparing for assessments and, when necessary, organising appeals. Several interviewees wondered if a drop-in centre could be set up at Headway to provide this kind of support.

Disappointing experiences with statutory services

Many survivors and carers spoke about the difficulties and disappointments they had faced in organising and negotiating appropriate support with statutory services. Support was often hard to come by or inaccessible to survivors. Others felt frustrated by poor communications between care providers and departments, or were disappointed with the level or quality of support they had received.

Securing appropriate housing

Several survivors and carers described difficulties in securing and affording appropriate housing after the injury.

Stewart needs someone to live with him and I have moved over to do that. But when we applied for rent allowance for Stewart it was a huge battle, and we only got rent allowance for one bedroom even though he needs to live with a carer. So when we appealed this we were asked – well does Stewart need the spare room for any equipment? Does he have a wheel chair? And I said no - he needs it because he needs someone living with him! But we still didn't qualify for two bedrooms. – Stewart's mother Anne

Poor management

Poor management by statutory services was also repeatedly reported. Several carers in particular lamented the lack of foresight by social workers and communication between departments in anticipating and coordinating the eventual needs of the brain injury survivor.

During those six months back at the Royal London the care home she was in had gone into liquidation and they only gave us a few weeks notice! So they couldn't take her back, and I didn't get the help I needed to find an alternative arrangement. So it took me a long time to try to find a suitable alternative. All in all, I looked at over 20 care homes. But lots of homes wouldn't take her because they couldn't provide the one to one care that she needed. – Beth's partner Tony

Unresponsive social workers

Several carers reported receiving little or no attention from their designated social worker, or felt that their social worker was not trained in understanding and supporting brain injury survivors. Survivors and their carers worry that they're missing out on important information and available support.

We've had no help from our social worker here. And the social worker at the rehab centre was never there, she worked part time. On one occasion we were given a booklet to have a leaf through, but even now we don't know what the care package is and what our daughter should be getting. Nobody around us or at the council seems to know anything brain injury, about what support is available, where it is, if she could qualify for more support... you know. – Tracy's mother Grace

Difficulties negotiating support

Disagreements were also frequently reported between statutory services and the survivor regarding the appropriate type or level of support. Many carers felt that more could be done for the survivor, or that the limitations caused by brain injury were not

appropriately understood and supported. People found these negotiations with statutory services frustrating and several survivors had given up trying to secure the support they felt they needed.

Social services feel that once someone can shop and dress and cook, people can just be left alone. Like there's nothing else that should be done or can be done for people. So my son doesn't have a social worker or anything like that...That's a big worry for me, because Stewart needs support with so many other things. – Stewart's mother Anne

When I came out of hospital the council only gave me support with my blindness, and that's all of the support that I ever got. For my brain injury - I've suffered memory loss, concentration problems - but I've had no support with my head...What I find frustrating with the council is that they only give you what they want to give you. I have other problems beyond my sight loss, but the people there don't seem to want to hear about that. – Asim

Returning to work, studies and family life

Time, insight and communication

Many survivors spoke about their attempts to return to their occupation before their injury. Whether this was work, studies or home life, interviewees described their struggles in trying to slot back into their previous roles.

For some survivors it was possible to return to their previous occupation with slight modifications, others described it as a great struggle, and for many it was simply not possible.

In retrospect, many survivors spoke of needing time to identify and understand their limitations, and then finding ways of communicating these limitations to their family members and employers. However, most survivors admitted that developing this kind of insight was challenging, due to the fact that their cognitive functions had been affected by the injury.

After the accident I went back to work for three days a week, but I had some big issues and I just couldn't fit back in. So I started to Google my symptoms and I saw that my issues were part of my brain injury. It sounds strange, but it took me a long time to understand that my anger and anxiety and my memory problems had to do with the injury. And I found it very hard to speak to other people about what I was experiencing. – Fahid

I don't think I'm quite ready yet to return to work. I think I'd like to work again in the next year. But my brain injury makes me feel confused. I forget things a lot. I would say that I'm recovering really well but I definitely suffer from fatigue. And when I get fatigued I suffer from fits. And when I'm fatigued my ability to be productive really deteriorates. So that's something I'm learning how to manage at the moment. I'm doing very well but I'm really not fully fit. I still have a lot of issues that I have to deal with in my daily life. I still don't know how that will come together with work. – Mark

Many survivors found communicating their injury and their limitations to their employers particularly difficult. Survivors who had returned to work said that they had to go through a lot of trial and error, and many felt that a slow phased return was the best way to find out if work was manageable for them.

I went back to work a year later and I pushed one of my managers because I was frustrated. And I was shocked because that's really not me, I don't push people! So I realised then that I would need help with this. So thankfully I have medical insurance and I received help in the form of counselling and I would say that that has been a great help. I'm still going to work, but I'm on a phased return. And work has been very good with me because since the incident of the outburst and the pushing, I think they understand what I'm going through more. They are supporting me with the return and not giving me so much work and helping me avoid situations of tension. I was worried about returning to work. – Joe

Anxiety and frustration

Survivors returning to work felt anxious about their abilities, their reliability, and their employers' and co-workers' level of understanding of their limitations. Survivors recognised that they needed flexible employment, but that this kind of work was not easy to find.

It's difficult to work because sometimes you can't show up because you've had a seizure, and you worry that people won't understand it. That they won't accept your absence. Or you worry that people think you're making it up. I worry that people will say that I'm sick too often and that they can't accept that. That they think I'm not a reliable person. – Ahmed

Many survivors were unable to return to work at all and they described their frustration at not having an occupation, earning an income, or being recognised as a productive member of society. The financial strain caused by lost income was a particular source of worry and anxiety for survivors.

I started going back to work, but that's proved very problematic and my employer really struggled to find me suitable levels of work. So my employer told me to go home and continue with the recovery process. So now I'm stuck at home not doing any work. I'm worried they're going to make me redundant and I'm feeling really frustrated about that. I want to work. And I need to make money. I'm not really sure how I'll manage. – James

The majority of the survivors spoke about suffering from anxiety, depression or social isolation. They recognised that having contact with people beyond their primary carers was important to their recovery, their sense of confidence and their ability to return to a social life. Spending time with others outside of the home was acknowledged to be a meaningful step in the recovery process.

Returning to college or university

These experiences also held true for survivors who returned to college or university. The two survivors who returned to their studies found that communicating their symptoms and their limitations to their institutions was difficult, and that appropriate support and response was often not forthcoming.

I managed to go back to college, but I wasn't supported in college because the organisation didn't know how to handle people with epilepsy and they didn't really try to understand my situation. So for example, when it came to computer work – I just couldn't do it because my epilepsy would be activated. – Ahmed

Everyone thinks it's brilliant he's back at university, but it's not really good because he struggles a lot. He's not able to learn independently. And the university doesn't seem to know how to deal with a student like him. His situation is quite different from someone with dyslexia or depression or something like that. I don't think the University has tried to understand what problems my son faces. – Stewart's mother Anne

Managing expectations

Out of six people attempting to return to work, only two had received any support or counselling to help them through the process.

All six survivors who had returned or were in the process of returning to work or to their studies felt that it would have been helpful to receive advice along the way. Survivors spoke in retrospect about needing to manage expectations, and having to develop a better understanding of what they could and could not do before returning to work.

Several found that activities such as volunteering, taking short courses, pursuing hobbies, or spending time with other people with brain injuries or disabilities gave them insights and the confidence they needed before contemplating a return to an occupation.

I meet with someone twice a week and she helps me get back into basic things like typing and that kind of thing. I get very tired so I have to consider that. She's really good – learning typing and maths. I can't do simple calculations now. I have to learn not to get too stressed out, and frustrated that I can't do simple things anymore. I have to find some balance. – Emily

After a year or so I went out and volunteered with other people who have disabilities, but disabilities that are worse than mine. And that was good for me, because I see myself in them – you know? I think it helped me understand myself better and eventually it led me to my new job. – Maria

Recognising carers and their need for support

Providing immeasurable support

Carers and family members are essential to survivors of brain injury. Carers and family members provide day-to-day care, emotional, administrative and financial support and much more. They are described as providing immeasurable support to survivors, and many have made great sacrifices to become carers.

At the moment my husband and I both work, but obviously we've had to drastically adapt our working schedules. So my husband sits with my daughter from 9-3pm, and then I go back at 3pm and stay with her until 11pm and we just do that every day. I haven't had any support at all... it's something that would be helpful, but I can't prioritise the time for it. Because when I'm not with my daughter, I'm at work or I'm asleep. We're just trying to hold it all together really – Tracy's mother Grace

Challenges and tensions

Providing care to someone with a brain injury is inevitably a difficult and emotionally challenging job. Carers said that survivors of brain injury are often unable to acknowledge their support, or appreciate how their own lives have been changed due to the injury. This lack of recognition often put carers under pressure.

A partner of someone with a brain injury also goes through emotional turmoil. Although the person with the brain injury is aware, and can move and make certain actions, they're not always sensitive to you or sensitive to you emotionally. And although you as the carer keep quiet, you can only keep quiet to a certain extent. There are times when you feel like I've been struggling with this for quite some time, and I think it's time to make my partner understand how it affects me. Otherwise we'll just basically be two people with brain injuries! I have to look after my own health as well. – John's wife Lily

Survivors and carers both spoke of tensions existing between them, which sometimes escalated and became hurtful or unmanageable. Carers speak about their struggle between understanding that the survivor's actions are due to the injury and are often not controllable, and their feelings of frustration and exasperation with the survivor. This conflict often leads to feelings of guilt for the carer.

I'm on my own with my son, he doesn't want to be with me. He wants to live by himself, but he doesn't understand that he can't do that. When he's with me by himself in the apartment – he won't have me in with him...he can get very angry with me. And sometimes I get really agitated with him. And I get annoyed...There's friction between us a lot of the time. And I often just have to walk away from it. – Stewart's mother Anne

Two survivors spoke about how their family members and carers either didn't understand their injury or had never come to terms with it. This inability to understand the survivors' actions and limitations had in both cases lead to resentment and family breakdown.

I live with my family, but they didn't know how to handle my diagnosis. My two sisters and brother and father aren't very cooperative and don't understand what's wrong with me. My mum is the only person I can turn to for support when I suffer from seizures and nausea and migraines. But my family has really broken apart over my illness. And since then I've really had no moral or practical support from anyone but my mum. – Ahmed

Relieving the pressure

All carers spoke about ways of reliving some of the pressure they felt. Many carers found that the help and comfort they received when they met other carers in similar situations was invaluable. Advice and guidance from peers was often described as being more productive than individual counselling, especially because people felt they were part of a community.

As a family member there are ups and downs and highs and lows and everybody told me that it would be two steps forward and one step back, but it's when you take that one step back that you realise that things aren't happening as quickly as you'd like. And it's at that point that having access to other carers who had been through similar situations to chat to is excellent really. It's just being with other people who have partners in a similar situation, who had been through the same thing of coming out of hospital and trying desperately to pick up the pieces. You can learn so much from other people and figure out where you might go from here. – Tom's wife Julia

Carers also found that organising social workers and befriending services for the survivor was a big help. This relieved them of their caring duties for a few hours a week. Carers were the most positive about support workers who organised social experiences for their family member, such as going to the cinema, the swimming pool or the park or a café. Carers felt good about getting their family member out of the house to enjoy a social experience, and it gave them a small break from their caring responsibilities.

What would really help is if a social worker could just take my son out of the house and do something fun with him. Send somebody over for a few hours a week to go swimming with him, or take him to see a film, or even just sit with him and study. That would make him feel better, and it would be such a great relief for me. – Stewart's mother Anne

Recommendations

Survivors of brain injury and their carers came up with four recommendations that they felt would significantly improve people's recovery going forward.

Early intervention

All twenty interviewees felt they would have benefited from early intervention in the hospital by a key contact that could have helped them understand the basics of brain injury and what they might have to consider going forward. Many interviewees felt that they had left the hospital with a poor understanding of brain injury and no insight into the kinds of challenges that they would be facing.

I wish I had had more knowledge and more understanding of my problem from the beginning in hospital. I think it would have reduced all of my anxiety. If someone had been with me at the beginning to explain what I might feel, what I might experience, it would have been so much better. It would have helped me understand my injury and my new limits more quickly. – Maria

Supporting the discharge from hospital

Survivors and their carers also felt that their discharge from hospital could have been overseen or supported by a key contact who was knowledgeable about the types of support and rehabilitation that may be available. Carers in particular described how it would have been helpful to have more practical information about care packages, social workers, rehabilitation, benefits, mobility vehicles and transportation options and other helpful services before returning home and having to research and procure these options themselves.

I think that somebody being able to help guide me through where I needed to go and what I needed to do would have been most helpful. I was really fighting to find out these basic things. And I felt that wherever I went I hit a brick wall. And I kept being passed on from person to person. So every turn I took I came up against a brick wall. And it felt like the more brick walls I hit the more my son was sinking. It would be good to have more helplines, because that is hard to find at the moment. – Paul's mother Leila

All interviewees described being discharged from hospital and returning home or moving to supported living as the most challenging time in their recovery. All felt that having access to a knowledgeable contact during this time would have eased some of their concerns and made them more aware of the support that was available.

Central source of information

All survivors and carers felt that having a central source of information and advice on brain injury and knowing about it early on in their journey would have made a difference to their recovery. People wondered whether Headway could act as a hub for advice and support, as well as a disseminator of up-to-date information through setting up occasional seminars, support groups, and making available relevant literature.

What would be really nice is to have a central source of information, somebody or some place that knows all the resources that are out there, and all the facilities that are available. Rather than me trying to find out about these things second and third hand. Somebody who knows what they're doing and have done it before. But at the moment that doesn't seem to exist. You are discharged from hospital and feel that there is nobody you can get in touch with if you need help or more information about something. You feel like there's nobody there to look after you. They just say off you go and we'll see you in 6 months time. And you're pushed into the realm of people saying that your GP should sort it out. – Beth's partner Toby

Clarity in what Headway and First Steps can do

Finally, interviewees thought that Headway could provide people with a clearer statement about what it does and how it might be able to support survivors who are currently not members of Headway. Interviewees thought there was some ambiguity about whom Headway supports and what its remit is. Survivors and carers thought that Headway could be promoted more in hospitals and rehabilitation units.

There is a vagueness about what Headway can do for you if you're not a member. Even when I went into the Headway centre, there was no guide anywhere about what Headway can do for you. It's almost like if I knew that they did a particular thing, or they fitted into the pathway in some particular way that would help. Then I think I would approach them and try to lean on them a bit. But at the moment it's not clear to me what I can ask them for. – Lucy's husband Luke

Bright ideas

Beyond the four main recommendations, survivors of brain injury and their carers came up with a variety of ideas for actions they felt would have better supported their recovery.

These bright ideas are listed and described below and may serve as useful stimulus during the development of the First Steps programme.

Table 2. Bright ideas from survivors and carers

- An introduction to brain injury booklet made available in key hospitals providing basic information on brain injury, its causes, and possible symptoms.
- A glossary of brain injury terms defined.
- Regular drop-in and advice sessions in key hospitals around London.
- Regular drop-in and advice sessions at Headway East London.
- Regular seminars at Headway East London run by experts on brain injury themes.
- Setting up a lending library at Headway East London with books on brain injury themes.
- Organising a regular book group / reading group on brain injury themes.
- Spreading the word more about Saturday Socials, pop-up dinners, and other open days and events for non-members.
- Facilitating a peer support network for survivors and carers – making connections, introductions, and sharing phone numbers.
- Organising a carer “speed dating” event.
- Setting up a carer telephone support group.
- Suggesting projects for survivors to work on at home – including art projects or photography projects to do with brain injury and recovery.
- Encouraging families to take photos of survivors in hospital to help document the journey and aid in the recovery process.
- Promoting Headway more effectively in key places – hospitals, rehabilitation units etc.
- Setting up a webpage that clearly outlines all the information and support that Headway offers to people who have recently acquired a brain injury.