Evaluation of the Headway East London Casework Service
June 2017

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Submitted to: Big Lottery Fund
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1. Introduction and Summary of Main Findings

Introduction

This is the external evaluation of the Headway East London (HEL) Casework Service, which received funding from the Big Lottery in 2015 in order to fill existing gaps in the support available to survivors of brain injury and their family members and carers.

This evaluation builds on an exploratory report produced in 2015 (see Annex 1), which identified gaps in the existing provision for brain injury survivors in the London area. This information fed into the development of an enhanced HEL Casework Service, funded by the National Lottery, which has been developed over the past two years to provide additional support, information and advocacy to people affected by brain injury.

This evaluation traces the development of HEL’s Casework Service, and draws on interviews with and surveys of a total of 86 stakeholders in order to assess the quality and reach of the HEL Casework Service.

Summary of main findings

Overview of Headway East London’s Casework Service


The HEL Casework Service has developed over the past two years to focus on the following five interventions:

• Early intervention in Hospitals: survivors of brain injury and their family members make early contact with HEL and receive information and emotional support as well as support organising their discharge from hospital.
  → Number of people supported between April 2015- April 2016: 90
  → Number of people supported between April 2016- April 2017: 193

• General casework: the casework team provides advocacy, information and advice to anyone getting in touch with this free service. Support ranges from signposting people to the correct support in their area, to helping organise care needs assessments, applying for benefits, helping secure housing or connecting them with legal support.
  → Number of people supported between April 2015- April 2016: 152
  → Number of people supported between April 2016- April 2017: 187
• **Support groups:** survivors of brain injury and their family members are invited to attend monthly meetings with other people who have been affected by brain injury to share their experiences.
  → Number of people supported between April 2015- April 2016: 50
  → Number of people supported between April 2016-April 2017: 60

• **Peer support:** peer support workers carry out specific pieces of casework, spend time in the hospitals and at support groups sharing their lived experience of brain injury.
  → Since funding began: two peer support workers have been trained and employed as part of the Casework Service

• **Saturday socials and family days:** social events intended to provide a fun day out to survivors and their family members and friends and to provide an opportunity to meet other people who have been affected by brain injury and access peer support.
  → Total attendance between April 2015- April 2016: 121
  → Total attendance between April 2016- April 2017: 113

**Feedback from Key Stakeholders**

Big Lottery funding has enabled the HEL Casework Team to establish a weekly presence in the Royal London Hospital and the Homerton Regional Neurological Rehabilitation Unit (RNRU) over the past two years. The casework team along with HEL’s peer support workers spend one day a week in neurotrauma and neurorehab wards to provide social, emotional and practical support to survivors of traumatic brain injury and their family members.

Eight key stakeholders were interviewed for this evaluation to provide a professional, external evaluation of the casework service. The majority of these stakeholders are NHS employees (such as doctors, nurses, social workers, speech therapists) working alongside the HEL Casework Service in both hospitals.

The eight stakeholders were unanimously enthusiastic about the service HEL was providing in their hospitals. NHS staff described how the HEL Casework Service provided a range of support, not just to survivors and family members, but also to doctors, nurses and other members of staff. Four out of eight stakeholders described the integration of the HEL Casework Service into the hospital setting as “Gold Standard Care”. NHS staff argued that the inclusion of Headway in their hospital ensured that survivors were treated holistically and were supported to manage their new physical, social, emotional and practical limitations. All eight stakeholders strongly recommended that the Big Lottery continue funding this service.
Feedback from survivors and carers

Seventy-three survivors and carers were consulted for this evaluation to help assess the HEL Casework Service and gauge how satisfied brain injury survivors and their family members were with support they were receiving.

A survey conducted of 50 survivors and carers found that the majority of respondents reported feeling more informed, more independent, and having better access to appropriate brain injury resources and support services as a result of their contact with Headway East London. The majority of respondents also reported an improved sense of wellbeing as a result of support from the HEL Casework Service. In their written responses people identified help with benefits and other practical support, as well as support with the transition from hospital into the community, and the opportunity to meet other people affected by brain injury as key ways in which they had benefited from the Casework Service.

Interviews conducted with 23 survivors and carers in 2017 helped to expand on the experiences people were reporting in the survey feedback. Interviewees described how they had benefited from the HEL Casework Service in a variety of ways, the most significantly from:
- Early intervention in the hospital setting
- Preventing isolation through a sense of belonging to a community
- Providing opportunities for beneficial peer exchange
- Helping with basic necessities such as benefits, finances, care and housing
- Providing brain injury information
- Building confidence through regular activities
- Acknowledging the significance of carers and their need for support
- Filling a gap in existing brain injury services

Survivors and family members felt that HEL filled a significant gap in the current statutory support that is available to brain injury survivors and worried that the removal of funding from this service would spell disaster for the vulnerable survivors and carers who have come to depend on the HEL Casework Service. Survivors felt that the Casework Service enabled brain injury survivors to lay the foundations for a positive recovery and reintegration into society, and hoped that this service would continue.

Ideas for further development

The vast majority of the people surveyed for this evaluation were content with the HEL Casework Service and did not have any suggestions for improvement. However, feedback from staff, key stakeholders, survivors and carers did generate a number of suggestions and ideas including:
- Extending the Casework Service by securing more funding, hiring more staff, extending the time spent at the Royal London Hospital and
the Homerton RNRU, and possibly expanding the early intervention service to other hospitals.
- Identifying ways in which survivors with more minor head injuries could be contacted in the early stages of their recovery process.
- Providing more brain injury education.
- Developing an advocacy branch of the Casework Service, which would work to promote better understanding of brain injury within statutory services and wider society.
- Providing support at the earliest stages of the hospital experience, such as making first contact in intensive care units.
- Developing a “back to work” programme for survivors to help build confidence and provide ideas for and pathways to future employment.
2. Overview of the Casework Service and Caseworker Feedback

Overview


The HEL Casework Services has developed over the past two years to focus on the following key interventions:

- **Early intervention in hospitals**: survivors of brain injury and their family members make early contact with HEL and receive information and emotional support as well as support through their discharge from hospital and back into the community.
- **General casework**: the casework team provides advocacy, information and advice to anyone getting in touch with the service. Support ranges from signposting people to the correct support in their area, to helping organise care needs assessments, applying for benefits, helping secure housing or connecting them with legal support.
- **Support groups**: survivors of brain injury and their family members are invited to attend monthly meetings with other people who have been affected by brain injury to share their experiences.
- **Peer support**: two peer support workers carry out specific pieces of case work, spend time in hospitals and at support groups sharing their experience of brain injury.
- **Saturday Socials and Family Days**: social activities intended to provide a fun day out to survivors and their family members and friends and to provide an opportunity to meet other people who have been affected by brain injury and engage in peer support.

How many people has the Casework Service reached?

The data below provides an overview of the number of people reached by the casework team’s activities in 2015-2016 and in 2016-2017.
Early hospital intervention:

<table>
<thead>
<tr>
<th>Early Intervention at the Royal London Hospital</th>
<th>2015-2016</th>
<th>2016-2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of contacts</td>
<td>188</td>
<td>323</td>
</tr>
<tr>
<td>Total number of people supported</td>
<td>90</td>
<td>153</td>
</tr>
<tr>
<td>Monthly average</td>
<td>30</td>
<td>40</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Early Intervention at the Homerton RNRU</th>
<th>2015-2016*</th>
<th>2016-2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of contacts</td>
<td>0</td>
<td>80</td>
</tr>
<tr>
<td>Total number of people supported</td>
<td>0</td>
<td>40</td>
</tr>
<tr>
<td>Monthly average</td>
<td>0</td>
<td>20</td>
</tr>
</tbody>
</table>

* The Early Intervention Service was first established at Homerton Hospital in 2016-2017

General casework:

<table>
<thead>
<tr>
<th>Casework reach since</th>
<th>2015-2016</th>
<th>2016-2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of contacts</td>
<td>213</td>
<td>237</td>
</tr>
<tr>
<td>Total number of people supported</td>
<td>152</td>
<td>187</td>
</tr>
<tr>
<td>Breakdown:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Member</td>
<td>65</td>
<td>61</td>
</tr>
<tr>
<td>External</td>
<td>148</td>
<td>176</td>
</tr>
<tr>
<td>Monthly average</td>
<td>17</td>
<td>20</td>
</tr>
</tbody>
</table>

Legal advice clinic reach since April 2016

<table>
<thead>
<tr>
<th>Total clinics</th>
<th>2015-2016</th>
<th>2016-2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total attendance</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Total attendance</td>
<td>31</td>
<td>26</td>
</tr>
</tbody>
</table>

Support groups:

<table>
<thead>
<tr>
<th>Support group reach</th>
<th>2015-2016</th>
<th>2016-2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Romford</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total attendance</td>
<td>126</td>
<td>131</td>
</tr>
<tr>
<td>Hackney</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total attendance</td>
<td>61</td>
<td>111</td>
</tr>
<tr>
<td>Whipps Cross</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total attendance</td>
<td>20</td>
<td>10*</td>
</tr>
</tbody>
</table>

* Numbers have decreased because attendees have migrated to the Hackney group
Saturday socials and family days:

<table>
<thead>
<tr>
<th>Social events reach</th>
<th>2015-2016</th>
<th>2015-2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Saturday Socials</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Total attendance:</td>
<td>149</td>
<td>170</td>
</tr>
<tr>
<td>Total number family days</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Total attendance:</td>
<td>121</td>
<td>113</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Total number of people reached by the HEL Casework Service</th>
<th>2015-2016</th>
<th>2016-2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Through Early Intervention at RLH and RNRU</td>
<td>90</td>
<td>193</td>
</tr>
<tr>
<td>Through the Casework Service</td>
<td>152</td>
<td>187</td>
</tr>
<tr>
<td>Through the Support Group</td>
<td>50</td>
<td>60</td>
</tr>
<tr>
<td>Total unique contacts</td>
<td>292</td>
<td>440</td>
</tr>
</tbody>
</table>

The casework team estimate that they work intensively on twenty individual cases across the casework service every week. On top of this they provide rolling support to people who are getting in touch asking for basic information, or who are in need of signposting to local services. The focused cases often demand a lot of time, especially at the beginning when the team need to newly assess a persons needs.

_I imagine we work on about 20 cases a week across the service. And some might be more intense than others. But all cases that are new to us are intense at the start. There’s a lot of input needed to get a person assessed. Or even to just get a date to be assessed. And you always know you’re going to be in a battle with a local authority to get this right. And people with brain injuries often can’t understand the process, or can’t retain the information they need. So we follow up with people to make sure that councils are following the guidance._

- Caseworker 1

All three caseworkers and both peer support workers described the casework service as being in high demand. Everyone on the casework team expressed a desire to expand the service in an effort to reach more people.

_We’re doing what we can with what we have. But if we had ten more people on the team we’d be just as busy as we are now. It’s that kind of scale of demand. And you can easily get swamped with stuff if you wanted to._

- Caseworker 3

_There’s so much crisis and need for emotional support so at the moment it feels like a drop in the bucket only having one day a week at the hospital. Because the level the communication people want face to face when you’re there, plus the work that you have after one day in hospital. That can be 4 or 5 brand new cases that you need to start_
from scratch. People who have never received any support. So it would be good to have more time allocated to focus purely on the hospital and the people there.

- Casewoer 2

<table>
<thead>
<tr>
<th>Caseworker experience 1 – Brain injury survivor Laura</th>
</tr>
</thead>
</table>
| I met Laura in the hospital just over one year ago when the early intervention service just started. She was sitting there with no covering on her head. She was a lovely lady but also a little erratic in some ways too. And she was getting quite depressed, because she had some other difficulties. Her skin wasn’t covering over the craniotomy. So she had an infection and was feeling extremely frustrated and eventually even discharged herself early. She just left the hospital against everyone’s advice and went out into the community as an extremely vulnerable person. But because we made that link with her at the start I was able to call and keep in contact with her. So I checked in on her and made sure she was allocated a social worker, and referred her for a care needs assessment. And we found out the care needs assessment hadn’t been done right, so we followed up with the council and made sure it was done correctly.

What Laura needed was somebody to just support her with these kinds of things. And to encourage her to stay in the hospital, to take her medication, to watch her diet and make sure she was eating – because she wasn’t eating. So we did that and she’s really benefited from our services. Laura’s house wasn’t suitable, so the Headway support worker helped her and the social worker around the practical elements of getting more appropriate housing. And now she’s like a changed woman. Physically she’s still a bit vulnerable, her scalp is not healed properly. But she’s getting proper nutrition because her support worker is helping her cook at home. And she comes into Headway and meets other people and can relate to them. Her wellbeing has increased immensely since our first engagement. And again we’ve just been this voice in the background saying – why don’t you do this, this is going wrong let’s do it again. And I think that’s a big part of our role.

The following sections break down the five elements of the HEL Casework Service, and further illustrate their role in supporting survivors of brain injury and their families.
What does HEL’s Casework Service do?

Early intervention

HEL caseworkers have a physical presence in the Royal London Hospital and the Homerton RN RU at least one day a week.

Patients at the Royal London have recently undergone brain trauma and caseworkers provide emotional support, and information about brain injury primarily to family members and friends of brain injury survivors. Caseworkers support people to more effectively communicate with hospital staff, understand medical language and come to terms with the effects of the injury. As the patient recovers from surgery the casework team helps families look ahead to life outside of the hospital and feeds into the discharge process and requests care needs assessments in order to support patients during the next stage of their recovery.

At the Homerton RN RU patients may be further along in their recovery and are receiving rehabilitation. Here caseworkers are more likely to offer practical support to patients and their families including applying for benefits and linking in with social care, or dealing with housing problems and financial or legal issues.

The casework team works to establish a relationship with the patient and their family before they return to the community so that HEL is recognised early on as a trusted organisation that can be relied upon when support is needed in the months and years following a brain injury.

At the Royal London Hospital, where most people have only very recently sustained a brain injury, the casework team primarily provide information and emotional support to survivors and their family members. The team visit people at their bedside, distribute general brain injury information and meet with people during drop in sessions.

When people are in such a crisis moment, when a loved one has a brain injury, I think it can be difficult to understand the ins and out of brain injury. So having someone there who can say – you may experience this, this may be something that your loved one goes through and to normalise it a bit and say – when this happens come and talk to us. And there are other people who have gone through this who you can talk to about it as well. So making that link early is important. If we weren’t there people would be going through these things not understanding what’s happening and maybe thinking they’re going mad and maybe not using the right language or being aware of what’s going on with them. Not understanding why they’ve changed emotionally and not linking it to brain injury. So that’s the big thing, is to create that initial link. And the hope is that by being there and having a presence and advertising our service people will be aware that the support is there.

- Caseworker 2
The casework team also spends a considerable amount of time explaining and clarifying medical terminology to survivors and facilitating communication between hospital staff and patients. The complexity of brain injury and the time constraints on hospital staff can lead to situations in which patients struggle to understand and process diagnosis and medical information. HEL helps to clarify and manage the accurate transfer of medical information to survivors and their family members.

**A lot of the people we work with don’t understand the medical language, or might not have insight into what’s happened to them and then might go down the wrong road, where it’s not picked up what their difficulties are and what causes them. We do come across people who didn’t understand or were not able to communicate their brain injury and were consequently misdiagnosed and gone into mental health services, such as someone being diagnosed as having manic depression when the person really has a brain injury. And that kind of diagnosis can really worsen someone’s condition.**

- Caseworker 1

The early intervention service dedicates a lot of time to preparing survivors and their family members for their discharge from hospital and their life back at home, in their job and in the communities. The transition from hospital into the community had often previously gone unsupported and the casework team has worked over the past two years to address this gap in brain injury support.

The casework team work to make sure that survivors and their family members have a clear understanding of the diagnosis, and that they are aware of what support is available and who they can rely on for help when they leave hospital. The casework team organises care needs assessments, benefits advice and many other forms of support, which link directly in to the casework service. The aim is to empower survivors and their family members to take up local services and entitlements through greater knowledge and support.

**With the early intervention you develop a relationship with that person several weeks before the time that they are discharged, so you’re getting to know that person and developing trust. So that’s been really helpful to have that relationship prior, as opposed to going into the community cold. And going in fire fighting. This way of working with the early intervention is much more seamless.**

- Caseworker 2

I think a lot of the time if we didn’t catch people early they would go home without acknowledging the term brain injury and that it’s their diagnosis. And people might try to go back to work or re-join their own life and then potentially fail at that. And what’s more likely is that people with brain injuries will just be put under the umbrella of mental
health. Someone will go back to work and they might get frustrated and depressed and then be signed off because of mental health difficulties, without understanding that this is an implication of the brain injury. So we bridge the gap between nursing staff, consultants and specialists and the community. And that’s absolutely what we do at Headway. Ensuring that people when they go home are aware of what support is out there and what they are entitled to. And having open communications with someone who can help. So they have access to a resource of information and support.

- Caseworker 2

The benefits of having a Headway presence in the hospital is that people are making contact with us much earlier. We’re meeting families at the earliest stages of the injury. It’s when the person is getting back into the community without having the correct support in place that things usually really go wrong. So people being discharged with no package of care, no knowledge of what benefits are out there, who to contact, not knowing what potentially the constraints are. We’ve had occasions where people have really gone through periods without essential care, without money. And for a lot of people moving out of hospital people need the emotional support. What we find is that a lot of family members, through no fault of their own, are simply unable to manage the changes when the person has been discharged home. But what we’re seeing now is that family members are a little bit more empowered. And we have so many people in the support groups saying – gosh I wish I’d known this stuff in hospital. No one told me that I was eligible for these benefits, or I didn’t know I was entitled to making a criminal injuries compensations claim. I didn’t know there were brain injury specialist solicitors out there! So the outcomes that I’ve seen is that there feels to be almost like a wider uptake in terms of people knowing who to go to for help with claiming benefits.

- Caseworker 3

Casework

The casework team receive daily requests for information and support from survivors of brain injury and their family members and friends and supported 152 people in 2015-2016 and a further 187 people in the past year. Often HEL is able to signpost people to appropriate services in their local authority, other times the casework team steps in to provide more in-depth support with more complex processes such as care needs assessments, benefit applications or appeals, safeguarding alerts, or housing and legal support. Given many people’s limitations as a result of brain injury, caseworkers often play an important advocacy role in securing a person’s entitlements. The casework team will often follow up with survivors on the phone after they leave hospital to make sure they’re receiving the support they need. One caseworker summarised the many different elements of the job and the support the HEL Casework Service provides in the following words:
The job is advocacy, information and advice. And generally that will involve things like referring people on to further services that can support them in the long term. It also includes helping people to fill in forms, to physically get to appointments, to represent people at meetings – so anything from community care reviews or care needs assessments – we help challenge DWP decisions like PIP and DLA decisions. We help people with applications for general needs housing or sheltered housing. In terms of advocacy we do a lot of work trying to get people specialist services. So I do a lot of care needs assessments. So I help demonstrate that a person is struggling for instance with finances or that a carer needs respite. So we work closely with social services to advocate that that person get’s the right kind of specialist support. We also provide support and clarity where local authorities have withdrawn someone’s care, either when the person has or has not been given formal notice. And in some of those cases we may have to refer people on to solicitors for public law guidance.
- Caseworker 1

All three caseworkers stated that one of the main aspects of their work was helping people though care needs assessments, which identify the survivor’s needs and help them access their statutory rights. Caseworkers spend a lot of time advocating on behalf of survivors in order to secure their claims for support.

Supporting care needs assessments and helping people access support from their local authority and using the Care Act to do that I would say is number one. Because in my experience if it’s just left to the authorities it just doesn’t happen. So I see us as an organisation that works in the background and makes sure that people are accessing what they’re entitled to, and makes sure they’re being assessed and their supports are being put into place. And then there’s the benefits side, especially when they’ve maybe lost their benefits. I realise that councils are facing a lot of cuts, but they also have duties to their residents. And that’s something that we push for.
- Caseworker 1

The HEL casework team spends a substantial amount of time supporting people in the filling out of benefit forms such as Personal Independence Payment (PIP) and Employment Support Allowance (ESA) claims. Years of experience in filling out these forms for survivors of brain injury has led the casework team to develop strategies for filling out theses forms correctly and efficiently. These strategies are regularly shared with survivors and their family members in both the one to one casework setting and in support groups. The casework team has also found that these forms can act as an effective insight tool, which can encourage survivors to be more aware of their disability. Caseworkers also say that filling out these forms has flagged previously unacknowledged problems that the casework team can subsequently set about addressing.
PIP forms people can feel awkward filling out. Because it might address things that they don’t have insight into, or they’re feeling awkward about or they’re in denial or very defensive about it. So we can use the PIP form as a tool, actually, and break down the survivors thought process about themselves and to help develop insight. And figure out ways to fill it out without the person getting frustrated and angry. Or we tell carers to keep diaries and make a note of how many times the person has seizures, if they have difficulty going to the toilet, how often they have to ask for assistance with cooking – write all that down because you can be the person who provides the insight. And that record can be put into the PIP form and so those are tips that we can give people.
- Caseworker 2

Support groups

Three support groups are held once a month at three locations around London – Hackney, Whips Cross and Romford and reached 50 people in 2015-2016 and a further 60 people in the past year. Support groups are run by a caseworker and a peer support worker and offer survivors of brain injury and their family members and friends a space to discuss brain injury and its consequences with other people who have been affected by brain injury. Support groups are often organised around themes such as the emotional response to brain injury, anger management, or benefit advice. The support groups allow survivors and their family members and carers to be exposed to others who have similar experiences or who may be further along in their recovery. The support groups were described by a caseworker in the following way:

We generally have a specific theme for each support group that is a fall back. But we begin by asking how people are doing. So we’ve spoken about things like emotions after brain injury or anger management and also benefits. So we’ve spoken a lot about those things. With the benefits session we talked about what everyone had experienced, what hints or tips they had. So that was really good and went on for an hour and a half. And generally it’s just a good, safe place for people to meet and share how they’re feeling, or what they’re struggling with.
- Caseworker 2

The support groups provide a space for people to share their brain injury experiences, and are an opportunity for people to recognise their own experiences and difficulties in others. The support groups allow people affected by brain injury to air any problems they may be struggling with in an understanding and supportive space. The information shared in the support group can help to identify symptoms and problem areas that caseworkers were previously unaware of and caseworkers will work to address and hopefully solve these issues.

The support groups have been so successful. In the support group people are getting to hear from other people with lived experience talking about their stories and you see that there are these eureka moments where people recognise that they’ve had similar symptoms. They say that’s
happened to me! Or I didn’t know that! And people can ask specific questions about what they should do. So we’ve set it up as being one of our main points of contact. Obviously we continue to talk to people on the phone and meet with people one to one, but equally we try to channel people through the support group in the initial stages so they have that connection and exposure to other people. And the support groups have their own life now. There are people meeting up outside of the support groups and there’s a social thing going on. So those connections are happening.

- Caseworker 3

The support groups have grown in popularity since the Big Lottery started funding the casework service. Caseworkers put the success of the support groups down to their presence in both hospitals, where they meet and are able to invite survivors and their family members at an early stage in the recovery. The caseworkers have said that the support groups can be an important insight into brain injury, as people who are early in the recovery process meet and speak to other survivors and family member who have years of brain injury experience.

The support group meets once a month and we have around 17 people attending. I think it’s grown so much because we have quite a lot of people from the hospitals coming along now. People and their families. And because there are limited time and resources at the hospital I normally tell people to come along to the support group, because there’s more time there but it’s also such a good insight tool. I find the support group is incredible especially for people who are very new on their journey of brain injury. Because they come along and can relate to people.

- Caseworker 3

Peer support workers

The peer support service is a separately funded element of the casework service that has been running for the past year. The casework team has trained and now manages two peer support workers who are survivors of brain injury to go to hospitals, support groups and social events and share their experiences of brain injury. Peer support workers introduce themselves to survivors and their families and give people a sense of the impact of brain injury and how they themselves have experienced it. The peer support workers try to give people at the early stages of their recovery an understanding of what life after a brain injury might look like. The casework team believe that, due to their personal experience of brain injury, peer support workers can help gain trust with survivors and their family members in a way that medical or support staff may not be able to.

A peer support worker described his role in the following words:

I got a job at Headway as a peer support worker. As part of my work I help organise the Support Groups and the Saturday Socials and we’ve got other staff to support us. And a lot of people who come to these events maybe
can’t get into the day centre or their injury isn’t that bad, so they come to the Support Group and the Saturday Social instead. And people share experiences there and people ask questions and they just want to know how things are, and what having a brain injury is going to be like. And I think people like to hear others talk about the problems they’re going to be facing. They’ve never spoke about this to someone who understands before. And I understand because I have the experience and can talk about these things.

My other role is to be at the hospital with the early intervention project. When I go out there the staff signpost me to who needs to be seen and then I meet people’s families and they just can’t believe it. I met a family there recently and after I spoke to them they said – we’re so glad that we met someone like you! And they said that I’d put it all in perspective for them. So I offer my experiences to the person who’s had the injury, but also to their family and loved ones and carers and I even talk about my experiences with the hospital staff.

The way I see it is that the casework team can help with the practical stuff like what support you need, what’s out there, what benefits you can claim, but they can’t tell you what I can tell people. We peer support workers have the experience of brain injury. I think we are the experts on brain injury. I’ve had a head injury – I can tell people what it’s like to live with cognitive fatigue. What it’s like to get angry. Do you know what I mean? So what we do is peer-to-peer support and I think that’s really crucial.

- Peer support worker 1

The peer support workers both reflected on their own experience after brain injury and spoke about how they had not received immediate support or made contact with organisations like HEL. They lamented the lack of support they had received in the early stages of their injury, and felt that they had recovered more slowly as a result.

When I had my injury they didn’t have support like this at all. And that’s why I think that this service that Headway offers now is key to people improving more readily and not being left out there with no help or support. I’m really keen on helping people in that way because I never had this help at the beginning and I think if I’d had I would have gotten a lot better more quickly.

- Peer support worker 2

Both peer support workers wanted to help to counter the loneliness people often feel after a brain injury. They acknowledged that new physical and cognitive difficulties can often led to confusion and depression in brain injury survivors and spoke about wanting to help people out of the “deep hole” they might find themselves in after head trauma. Peer support workers also spoke about the practical advice and useful tips they could give to survivors and family members, as well as advice they had given to healthcare professionals to make brain injury information more accessible to survivors and their family.
I think the casework service in invaluable. Not just to brain injury survivors, but to everyone affected by brain injury. And we make sure that people aren’t just shoved off. You’re not just pushed aside. All them years ago when I had the injury I wish I would have had this kind of service in place, because it would have helped me so much. Without this kind of support you feel lonely and lost. You feel like you haven’t got anything. I don’t want people to feel lonely. I want them to know that I’m there for them. And I want to share my experience and get people out of that deep hole. Because I’ve been there, I’m not joking.
- Peer support worker 1

One thing I find quite important, because I’ve been through the injury to the brain, I find that I have a lot of empathy for the people there. I am able to relate to them and what they’re going through. When people know that you’ve been through that, they’re more willing to communicate with you. They are keen on hearing your story and what brought you to this point in life. And that’s what’s so good about the peer support workers. And I can also suggest simple things that I have found make my life easier. So for example, it helped me to have pictures of my family around my bed while I was recovering. It reminded me of the past, and I think it helped my brain identify the important people in my life. So little things like that I can suggest to people. And I also help by giving people handouts and information that might be helpful to them. I’ve also told the casework team how to design leaflets and handouts in a way that makes it easier for people to understand –so by making words bold or simplifying sentences or using larger fonts.
- Peer support worker 2

Peer support workers described that they felt very supported by the casework team who acknowledged their difficulties, such as cognitive fatigue or memory loss, and had together found ways to work around them. Peer support workers had received training from the casework team on how to interact with survivors and their family members, and were having regular supervisions to discuss their progress and any amendments that needed to be made to their working environment. The casework team had come up with adaptations such as asking peer support workers to take breaks every thirty minutes, and changing their working hours in order to avoid rush hour traffic.

The casework team they support me 100%. Because I get tired and get confused and then I start getting agitated. And when they see me like that they tell me to take a break. And I’ve now got a timer in the office and every half an hour it goes off and I take a break. On bad days I’ve lost my way on the way home because tiredness is a killer for me. But the casework team are there for me and helping me manage it. They’ve given me headphones to use in the office so I can focus. And they’ve tried to adapt my working hours around times that aren’t so busy for public transport.
- Peer support worker 1
The casework team they really understand my issues and my limitations so I know that there is always someone for me to talk to who has lots of professional skills about how to manage someone with a brain injury. So it’s been good to have my own mentors on the team who support me. I’m definitely well supported. And I know I can reach out to people around me anytime.
- Peer support worker 2

Not only does the peer support service provide comfort and emotional support to survivors and their family members, but it also gives the support workers themselves a great sense of purpose. They have survived severe brain injuries to ultimately work at HEL and provide support and encouragement to people who have found themselves in similar situations. This provides both peer support workers with great satisfaction and purpose in life, as well as providing the income and the dignity of paid employment.

This role has provided me with great purpose in life, and I’m using skills that I’ve developed since my injury not just for the benefit of myself but for the benefit of other people. It gives great purpose in life to get paid for a job that you enjoy doing and to also help other people at the same time.
- Peer support worker 1

Doing this work makes me feel like I can give something back to my brain injury peers. I talk about my experiences and I know that everyone with an injury has got potential. So I just hope that they can achieve things.
- Peer support worker 2

Saturday socials and family days

The casework team together with the peer support workers organise a number of free social events throughout the year to which they invite survivors of brain injury and their family members. These events are organised around fun activities, music and food and are an enjoyable day out for the family. The events are especially important because they are open to people who are not members of HEL’s day service and may not qualify for funding to receive regular support from HEL or other organisations. These events provide unfunded people with a rare opportunity to meet and socialise with other people affected by brain injury and benefit from peer support.

The Saturday Social is a big part of our work and the peer support workers work. These events link people in who maybe aren’t eligible for the level of support that other people are. The idea is to give people access to Headway who don’t have funding to attend the centre regularly maybe. And they come to the centre, meet others, share food. But what comes out of that is that we connect with people and identify
who needs what kind of support. I think it’s an important part of the service we offer.
- Caseworker 3

The Saturday Socials started off with only five people coming, now we’ve usually got 20 people and sometimes we even have a waiting list. It’s grown so well and people really enjoy it. It gives people an opportunity to unwind and have fun with their family members in a place where they feel understood and accepted.
- Caseworker 2

Help navigating cuts to welfare, social services and social care funding

Caseworkers explained how an additional aspect of their work involved dealing with funding cuts to social security entitlements, local social services, and reductions to funding for social care. In the hospital setting, NHS staff report that increasing pressure on their time and resources reduce the level for meaningful one-on-one interactions with survivors and their family members. Local councils are strapped for income and struggle to follow good practice with regards to potentially vulnerable people in their areas, and welfare reform has led to the reduction of many people’s benefit entitlements. These cuts, which often lead to a reduction in people’s access to and the quality of statutory support, are frequently being navigated and mitigated by the casework team.

Cut’s are massive. We see that a lot in the people we’re seeing. And you sometimes see people treated by the council in a way that’s almost less than human. And we come across a lot of bad practice in councils so we’re there to highlight this and complain about this. And we’ve had to take things to a legal level on some occasions. And it seems like that’s how local authorities seem to work, where they expect that there will be fatigue and people who are complaining will go away after a time. And I think the appeals that should be happening aren’t really happening. So that’s where we often step in.
- Caseworker 3

We’ve seen cuts to benefits, cuts to services, limited exit strategies from hospitals when it comes to discharge – people are just kind of sent home. Where families have to take on huge responsibilities, and there are other people who need a continuous health check list before they go or a care needs assessment or an allocated social worker. But I’ve never seen that happen. So that’s when we step in, and we make sure those things are in place. So there’s a big practical element to my position in the hospital.
- Caseworker 1
Casework experience 2 – Brain Injury Survivor Rob

I helped a young man who was referred to us by someone at a London hospital. He’d been encouraged to come to our support group, but when he came he couldn’t stop crying. He was very anxious and depressed, and it eventually turned out he was homeless. He was a shadow of a young man. But after he came to that support group I met up with him and we completed a PIP and the ESA forms, we got him appointments and inputs with local healthcare professionals, and secured housing for him. He eventually went back to college and is now pursuing a claim for compensation for his accident. And we facilitated all of that. So I was unofficially his case manager, and followed up on everything.

Before he came into contact with Headway he was really on his own - he’d discharged himself from hospital, his friends didn’t understand what was wrong, and he had very little insight into his brain injury. But now he’s out in the community, living in secure housing, he’s pursuing a degree, his social network has come back, and he continues to come to our support groups and is quite motivational there.

The significance of HEL’s Casework Service

All five members of the casework team described their work as being essential in preventing survivors of brain injury from “slipping through” the system and becoming isolated once they returned to the community. The casework team felt that their efforts were preventing survivors from struggling with loneliness, depression, and sometimes even suicidal thoughts by providing readily available emotional and practical support, and by helping the survivor gain insight into his/her brain injury. Three members of the casework team emphasised the importance of the positive message that HEL promotes within the brain injury community, which emphasises that people are able to have a meaningful and productive life after brain injury. The casework team felt that they were “empowering” people with the information and support they need to take control of their situation.

I think in a lot of cases people just wouldn’t bother if we weren’t around. Lots of people feel very low after brain injury and say – what’s the point? And there have been cases where we’ve had to initiate safeguarding precautions because the person has concluded that no one is helping them, or no one cares. We genuinely do fear for people that we’re not working with. We have a concern for people who do slip through, who have a severe brain injury and don’t understand what they’re going through and who don’t have a caring local authority who tries to seek them out and assist them. And especially if people don’t have family members or don’t understand themselves. These situations are very sad.

- Caseworker 3
The casework service has allowed people to take ownership of their condition and brain injury. And it helps people realise that life doesn’t stop after brain injury and that there are supports out there that will allow people to take control of their situation and get back into the community. We have a positive message and we do something about it, we’re a really proactive team. Without that people would be left on their own, maybe misdiagnosed as having mental health. We can help with people’s insight, their work, their social network, the support they have access to. So it’s important to get in there at an early stage so we can get these things set up. We now manage to provide support to people at every step of their journey. And I think that’s alleviated a lot of problems and stress.

- Caseworker 2
3. Feedback from Key Stakeholders

Overview

The early intervention service in the Royal London Hospital (and later in the Homerton’s RNRU) came to fruition after a series of conversations between the Clinical Director of Neuroscience Stroke and Trauma at the Royal London Hospital and Headway East London staff in response to a perceived gap in early support to survivors of brain injury.

Big Lottery funding has enabled the HEL Casework Team to establish a weekly presence in these two London hospitals over the past two years. The casework team along with HEL’s peer support workers spend at least one day a week in neurotrauma and neurorehab wards to provide social, emotional and practical support to survivors of traumatic brain injury and their family members.

Eight key stakeholders were interviewed for this evaluation to provide a professional, external evaluation of the casework service. The majority of these stakeholders are NHS employees (such as doctors, nurses, social workers, speech therapists) working alongside the HEL Casework Services in both hospitals.

The eight stakeholders were unanimously enthusiastic about the service HEL was providing in their hospitals. Four out of eight stakeholders described the integration of the HEL Casework team into their ward as “Gold Standard Care”, in which survivors were treated holistically to manage their new physical, social, emotional and practical limitations. All eight stakeholders strongly recommended that the Big Lottery continue funding this service.
<table>
<thead>
<tr>
<th>Key stakeholders interviewed</th>
<th>Positive experience of Casework Service?</th>
<th>Recommend that funding continue?</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant Neurosurgeon</td>
<td>✓</td>
<td>✓</td>
<td>I would absolutely recommend the lottery continue funding this project. If they don’t, the NHS does not have the resource to fund this. The place where the funding would have come from would have been social care money, but there is no social care money anymore. So if this funding stops, then the social and economic burden of not funding this is going to be huge… The Headway service has been set up by people who have had head injuries because they know that there is a wilderness out there. If this service wasn’t continued we’d go back to a skeleton service where we were only able to help a significantly smaller number of people.</td>
</tr>
<tr>
<td>Consultant Neurologist #1</td>
<td>✓</td>
<td>✓</td>
<td>I would 100% recommend that funding for this service continue. Unfortunately, the NHS does not have funds for this, so any type of support we can get to continue this important service is essential.</td>
</tr>
<tr>
<td>Consultant Neurologist #2</td>
<td>✓</td>
<td>✓</td>
<td>I would definitively recommend that funding for this service continue in both the Royal London and the Homerton RNRU because their presence in both places strongly support the patients brain injury recovery. And not only that, but they also support the professionals that work with people with brain injuries – both in the hospital and in social services.</td>
</tr>
<tr>
<td>Senior Social Worker</td>
<td>✓</td>
<td>✓</td>
<td>I would absolutely recommend that funding for Headway continue. Absolutely no</td>
</tr>
</tbody>
</table>
question about it. They are a hugely valuable service and I know that their work in both hospitals has been highly regarded. I would hate to lose that service for people on this unit.

<table>
<thead>
<tr>
<th>Clinical Nurse in Neurology and Trauma</th>
<th>✓</th>
<th>✓</th>
<th>I would recommend that the funding for this service continue, yes, 100%. This kind of service is what people are calling “gold standard” in the hospital. There’s a real demand for Headway now. People know that they’re around and will ask for them. So having them here has become part of the norm and part of good practice.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senior Nurse for Neurology and Trauma</td>
<td>✓</td>
<td>✓</td>
<td>I think Headway in the hospital has enhanced what we do. We are so time poor. We know what needs to be done, but having something like Headway let’s us really deliver holistic care and meet people’s needs. So I definitely want Headway to continue, and the feedback from patients and relatives has been overwhelmingly positive.</td>
</tr>
<tr>
<td>Speech and Language Therapist</td>
<td>✓</td>
<td>✓</td>
<td>Definitely this service needs to continue. I absolutely support what they do.</td>
</tr>
<tr>
<td>Clinical Negligence Lawyer</td>
<td>✓</td>
<td>✓</td>
<td>I most certainly and emphatically recommend that this service continue.</td>
</tr>
</tbody>
</table>
NHS staff experience prior to Headway East London’s presence in hospital

Before Headway East London’s involvement at the Royal London Hospital and the Homerton RNRU, NHS staff reported facing three key obstacles in providing high quality care to survivors of brain injury.

NHS staff reported:

- not having the resources to give patients and their family members the appropriate focused attention that they deserved.
- feeling strapped for time and resources which weakened their ability to provide satisfactory one-on-one time with patients in order to make sure that important information and advice was being taken on.
- that the time spent supporting patients in their understanding of brain injury had been inconsistent over the years and that this gap in provision had led to dissatisfaction and complaints from patients and their family members.

Before Headway was at our hospital we had a lot of dissatisfaction. We had a lot of complaints from relatives particularly that they found it difficult to access information. The nurses and staff didn’t have enough time to talk to them. They left hospital with very little information about what was going to happen next and what the future was going to hold. Having Headway has reduced these complaints significantly, in fact I can’t remember the last time we had a complaint of this nature.
- Clinical neurologist

NHS Staff also reported their dissatisfaction with their ability to communicate effectively with patients and their family members. This was again due to lack of time and resources which prevented them from adequately explaining medical terms and diagnosis, and repeating important information to patients and family members. NHS staff were aware that the shock of a physical trauma can prevent patients and family members from taking on information and worried that people left the hospital without having fully understood their medical diagnosis.

Before Headway was around it was quite chaotic really. It was just so busy on the wards, the patients are very sick and family members had very little information. Medical information can be difficult to understand, and often the information is just about acute care, and not what’s going to happen to their loved ones down the line. And often we realised that relatives were leaving the hospital and didn’t have a clue about what was going on. And a lot of people with brain injuries have hidden disabilities that need to be watched for. So we know that it was important for relatives to have a better understanding of brain injury from early on, but the problem is always resources and time.
- Consultant neurologist 1

The main gap that NHS staff identified in their service was the mostly unsupported patient transition from the hospital back into the community.
Doctors and nurses spoke of seeing discharged patients again in follow-up visits and discovering that they were not taking up the appropriate support services and benefits, and often described feeling isolated and depressed. One neurologist interviewed for this evaluation admitted that the discharge and transition advice given to patients prior to HEL’s presence was inappropriate and a “cop out”. Staff worried that patients were being released without the appropriate insight into their condition and without knowledge of and access to community support and care.

We’ve invested in hyper-acute care at this hospital, so we get patients to surgery very quickly and look after them in the acute phase. But the things that wasn’t so good, was that there was basically no support for these patients after the acute phase whatsoever. The advice used to be – take time off work and go and see you GP if you have trouble. Which was basically a cop out. We knew perfectly well that the GP could do very little. The other thing we would say to people is to check the Headway website, but that was also a cop out because very few people got around to doing that. So there was very little engagement with patients to prepare them for the transition out of hospital before Headway has it’s presence here.
- Consultant neurosurgeon

NHS staff experience since Headway East London’s presence in hospital

Supporting survivors of brain injury

Since the Big Lottery enabled Headway East London to have a presence in the Royal London and the Homerton RNRU, NHS staff report that their patients have access to a wide variety of support, which previously did not exist on their wards. NHS staff identified four key areas in which HEL has provided support over the past year such as:

- **Bedside support** including brain injury information and facilitating better communication with hospital staff.
- **Practical support** including supporting patients in accessing the appropriate services and benefits.
- **Peer support** that provides opportunities for patients and family members to be exposed to other people who have experienced brain injury.
- **Managing the transition out of hospital** and into the community.

**Bedside support**

NHS staff explained that HEL plays a big role in simply listening to patients and their family members and in helping them to understand and assess their situation during the early stages of recovery. Through listening, the casework team is able to identify whether the family needs more information or if medical terminology needs further explanation. A large part of HEL’s role,
particularly at the Royal London Hospital where people are at a very early stage of their brain injury, is to provide support and information to the patient’s family members. This early contact provides comfort to family members and also helps them prepare for the recovery ahead.

Headway will meet with family members or with patients and at first they’re often a sounding post where they let the relative explain what’s happening. They help explain clinical information to the patients and their family and they work with medical staff to obtain information and summarise it and make it more accessible to the patient and their families.
- Clinical neurologist 2

Now someone will come around the bedside and say – look you’ve had a bad head injury, let’s have a chat with you and your family. Let’s explain what’s likely to happen when you go home. We can tell you what’s going to happen with your relationships, your work, how to cope with not being able to smell, how to cope with your personality issues, and maybe even put you in touch with someone who’s been through it themselves. And I think that has been a game changer in our management of the non-devastating brain injuries.
- Consultant neurosurgeon

Supporting people’s family members and relatives is particularly important. Many of our patients are very ill and they’re unable to interact on their own terms. But supporting the family means that by the time the patient has recovered or even if they don’t recover very well the family is in a better position to cope with that.
- Clinical nurse specialist

Practical support
One clinical neurologist described the HEL Casework Service as a “surrogate Citizens Advice Bureau specifically for patients with head injury”. While in hospital, HEL caseworker speak to and identifies if the survivors are in need of any additional social and practical support and works to secure this support for the survivor. Caseworkers signpost survivors and their family’s to appropriate local services, and in some cases gets directly involved in the securing of social support and benefits. HEL has provided financial advice to families and acts as an advocate on behalf of survivors if they are struggling to claim their entitlements. NHS staff described Headway East London as being a very competent organisation with local knowledge and a reputation for effectively advocating on behalf of their patients.

Headway have got a large amount of information they can give out on request and they’ve got specific information on benefits and social support, which we know many of our patients find difficult to access. So they operate as a type of surrogate citizens advice bureau specifically for patients with head injury. Headway are almost unique in the respect
that they are trained in how to interact and communicate with patients with brain injury.
- Consultant neurologist 2

Headway helps with the practical issues. So people are struggling with their finances – how to pay for their rent or the mortgage – and I’ve tried to do some of that, but there’s a real area of expertise at Headway about how to deal with that. Same with applying for benefits and giving advise and support. And these are things that as healthcare professionals we don’t know much about.
- Clinical nurse specialist

Headway will help patients with their employment situation, help them liaise with housing officers, liaising with local social services and obviously those patients who are unable to advocate for themselves, often their carers and families will need support as well. And with all the different local authorities and all the changes and cut backs there’s a lot of things to navigate. So Headway helps people navigate out of the hospital system and into the community.
- Consultant neurosurgeon

We have some very, very distressed family members here. It’s a trauma and they’ve been through a roller coaster of emotions. And I think because of the nature of the disabilities people are left with often, their lives are torn apart. And people face benefit issues, housing issues, people dealing with debt. And family members are often overwhelmed by that. So I work together with Headway to try to sort that out. Headway have a lot of contact and resources in the communities that we’re working in. So there’s been real value in being able to refer to a competent organisation that are known in the local area and are listened to.
- Social worker

Peer support
NHS staff described how HEL provides survivors and their family members with peer support by introducing people to their peer support workers who regularly visit the hospitals, as well as hosting monthly support groups for survivors and family members. These two services give survivors access to other people who have had a direct experience of brain injury. Patients have praised the peer support element of the HEL Casework Service to NHS staff, describing how these meetings make them feel that there’s “a light at the end of the tunnel” and help to provide insight into what life with a brain injury might entail.

I think there’s a huge value in getting people to meet people who’ve had similar injuries. And we’ve had huge positive feedback from families about the peer support workers. Because it shows that there’s light at the end of the tunnel and can give a positive spin on what it might mean
to live with a brain injury. So that peer support has also been hugely valuable. - Clinical nurse specialist

The peer support workers have had brain injuries in the past and have direct experience of that. It works well and I’m glad Headway do that. We would never be able to support the peer support service the way they supervise it. Again, it’s particularly helpful for relatives because it gives them a real on the ground idea of what’s coming. They can see how patients recover, and they can get insight into the injury. And that a person with a brain injury can continue to be part of society and be useful.
- Senior nurse for neurology and trauma

Managing the transition out of hospital and into the community
Finally, NHS staff identified HEL as key to helping manage patients’ transition out of the hospital and into the community. Staff described how HEL is able to build on the trust and personal connections it develops in the early stages of the injury while the survivor is still in hospital, to develop a support relationship that extends out of the hospital into the community. Many NHS staff described the HEL Casework Service as a “safety net” for survivors as they return to their old lives often considerably altered. To smooth the transition, HEL organise and support people with care needs assessments, and liaise with social workers and local authorities to secure the appropriate support for the patient. NHS staff described how they’d heard that many patients were pleased to receive a phone call from Headway a few days after discharge. Staff felt that it was important for patients to not feel forgotten and to be encouraged to re-join society once they’d left the hospital.

We can give people support in the hospital, but when patients leave the hospital that’s when Headway really kicks in. And so having Headway in the hospital is a huge advantage in bridging the gap between suddenly going home and finding you’ve got nothing. Or going home and getting a phone call from someone you’ve already met in the hospital, then that’s a big advantage. A lot of people will have lost a lot of self-confidence and will need people they trust to approach them.
- Consultant neurosurgeon

Headway absolutely supports the work we do. In taking someone who has a bad head injury we save their life and stop them from physically dying, but that’s only the start of it. Trying to get them back to normal. They are far more likely to be part of society if they have the support to get them through. We know that many of our patients previously would go home and literally do nothing. They were just sitting at home. But we started feeding them into the Headway service and with Headway they start getting their lives back.
- Consultant neurologist 1
Supporting NHS staff

Not only was the HEL Casework Team described as providing support to survivors of brain injury and their family members, but HEL was also acknowledged as an important ally to staff within the NHS. The HEL Casework Service was described as being a big resource to hospital staff, as they helped them to communicate more effectively with survivors, provided staff with additional information on patients, and jointly worked on cases to deliver care that covered physical, emotional and social needs. NHS staff acknowledged that they were not experts on issues such as benefit advice and social care and found it a relief to be able to refer their patients on to Headway East London.

They’re a huge resource. I meet with the casework team and we talk through cases and it almost becomes like a supervision where we support each other. And I can pick up the phone if I’m unsure about something. And also there’s lots of stuff that comes up with the casework team that they can feedback to us and makes a difference medically. And that can sometimes give us the answers as to why people are acting in a certain way.
- Clinical nurse specialist

I think empowering the patient’s relatives with information and understanding makes it easier for the doctors and hospital staff. Because it’s easier to communicate with people when they’re informed properly. If they haven’t a clue they ask the wrong questions and need a lot of follow up support. Or they get unrealistic expectations. So that’s a useful thing for communication. So Headway definitely helps the staff.
- Consultant neurologist 2

Headway completely supports the work we do at the hospital. It’s transformed the care that we give to our patients. Headway works together with our nurses to reach as many patients as possible. We can rely on Headway to provide a resource and information and support that we would be completely unable to do because we are busy and under resourced ourselves.
- Consultant neurologist 1

NHS staff frequently spoke about their large workload and their inability to dedicate time and resources to the social and emotional aspect of care. Staff felt that having the Casework Service in the hospital provided patients with a more “holistic service”. NHS staff described feeling more confident in the service they were providing to patients, knowing that HEL was there to meet a variety of previously unmet patient needs. One NHS staff member described Headway East London as, “Taking what I do and what I offer, and enhancing it and bringing it forward.”
With Headway, patients have access to more time, to more resources then we’re able to provide in the NHS. Headway is integrated in local communities, they can signpost people on to particular services and support groups, and I know Headway run groups of their own. These are all things that we’ve been unable to provide in the past due to the great demands on our time and resources. It’s a relief to many of the staff that Headway can fill this gap.

- Consultant neurologist 1

Several NHS staff also spoke of what they saw as HEL’s brain injury advocacy role within professional settings. Staff described how caseworkers often helped to educate professionals – either in hospitals, councils or in social services – in terms of what to look for and what to expect with brain injury survivors. Several staff described how they had been witness to caseworkers helping professionals develop a better understanding of how to handle brain injury survivors and the difficulties they might be facing. Supporting statutory services by providing guidance and insight into head injury was seen as an important aspect of Headway East London’s work.

Headway helps professionals identify and understand how to work with people with brain injuries. So Headway actually educates professionals too. So for example take social services with a disability assessor - Headway can help educate these people in terms of what they should look out for with brain injury. So they’re educating not just the staff in hospital but also outside agencies. Because a lot of professional people don’t pick up on brain injury because of the hidden nature of the disabilities. So you do need the professionals in social services to be educated about that and Headway is very important in that regard.

- Consultant neurologist 2

The final verdict from key stakeholders: “Gold Standard Care”

In my opinion, the addition of Headway in this hospital provides patients with a gold standard of care.

- Consultant neurosurgeon

All eight stakeholders interviewed for this evaluation agreed that Headway East London’s presence in both the Royal London and the Homerton hospitals was a positive addition to their brain injury service and should be continued. Four out of eight stakeholders described the combination of NHS and Headway support as “gold standard care” to survivors of brain injury, which allowed for a more seamless transition from the hospital to reintegration into society. One doctor said,

We save their life, but that’s only the start of it. Headway gets them back to normal again. We don’t do that, Headway do.

- Consultant neurologist 1
NHS staff also argued that the addition of HEL to their service meant that not only the physical, but also emotional, practical and social needs of survivors were being acknowledged and cared for in the hospital setting. One nurse commented on this by stating,

_We look after them physically, but brain injury is so life changing emotionally, socially, practically. Now Headway looks after that side of things._

- Clinical nurse specialist

All NHS staff argued that Headway East London’s presence in the hospital complimented and enhanced the care they provided and set patients up on a well-supported path to recovery.

_Having a really reputable, competent voluntary partner agency working collaboratively with the NHS in a way that is actually in the best interest of everyone – the patient, the family and the staff. We know that people leave the hospital and go out into the world with the right support that everyone can trust._

- Social worker

All eight stakeholders recommended that funding for the HEL Casework Service continue and five out of eight stakeholders argued that NHS staff and patients would benefit from an extended casework service in both hospitals.

_I think the massive gap in the service is the four days a week when Headway is not at the hospital. If there was somebody there more then once a week, that would be ideal. It would make a significant difference._

- Consultant neurologist 2

Several key stakeholders said that a loss of funding to HEL would be devastating to the support now available to brain injury survivors. Doctors and nurses described how losing the Casework Service would mean going back to a “skeleton service” in which vulnerable survivors of brain injury were left to identify and claim support and care on their own. NHS staff thought that, similar to their experience before HEL’s early intervention service, survivors would fall through cracks in the system and become isolated. Stakeholders argued that the social and economic costs of failing to adequately support survivors of brain injury in their recovery and rehabilitation would be significant.
4. Feedback from Survivors and Carers

Overview
Seventy-three survivors and carers were consulted for this evaluation to help assess the development of the Headway East London’s Casework Service and gauge how satisfied brain injury survivors and their family members were with support they were receiving.

Before the HEL Casework Team set up its new services, twenty brain injury survivors and carers were interviewed in 2015 to identify what gaps existed in the support available to survivors of brain injury at the time (See Annex 1). These interviews identified the following problems survivors and family members were facing during their recovery:

- A difficult hospital experience
- A challenging transition out of hospital
- A limited understanding brain injury
- Struggling to claim entitlements
- Disappointing experiences with statutory services
- Low confidence and isolation after the injury
- Feeling unsupported as a carer

Since the Big Lottery started funding the HEL Casework Service in 2015, a number of new services and systems have been put in place to address these gaps. A survey conducted in 2017 of 50 survivors and carers found that the majority of respondents reported feeling more informed, more independent, and having better access to appropriate brain injury resources and support services as a result of their contact with HEL. The majority of respondents also reported an improved sense of wellbeing as a result of support from the HEL Casework Service. In their written responses people identified help with benefits and other practical support, as well as support with the transition from hospital into the community, and the opportunity to meet other people affected by brain injury as key ways in which they had benefited from the Casework Service.

Interviews conducted with 23 survivors and carers in 2017 helped to expand on the experience people were reporting in the survey feedback. Interviewees described how they had benefited from the HEL Casework Service in a variety of ways, the most significantly from:

- Early intervention in the hospital setting
- Preventing isolation through a sense of belonging to a community
- Providing opportunities for beneficial peer exchange
- Helping secure basic necessities such as benefits, finances, care and housing
- Providing brain injury information
- Building confidence through regular activities
- Acknowledging the significance of carers and their need for support
• Filling a gap in existing brain injury services

Survivors and family members felt that HEL filled a significant gap in the current statutory support that is available to brain injury survivors and worried that the removal of funding from this service would spell disaster for the vulnerable survivors and carers who have come to depend on the HEL Casework Service. Survivors felt that the HEL Casework Service enabled brain injury survivors to lay the foundations for a positive recovery and reintegration into society, and hoped that this service would continue.

Experiences of brain injury recovery without support from HEL’s Casework Service

In 2015, before the HEL Casework Service was funded by the Big Lottery, twenty survivors of brain injury and their carers were interviewed to investigate the current state of brain injury support and what interventions might be most needed in better facilitating a person’s recovery. This report made up a baseline investigation, which fed into the development of the HEL Casework Service. Two years later, these interviews can now be used as a control group against which to compare survivors and family members who have received support from HEL against survivors and family members who had not received support.

The twenty survivors and carers interviewed in 2015 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 were missing.

In 2015, survivors and their carers described struggling with brain injury recovery in the following ways:

• **A difficult 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.

• **A challenging transition out of 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.

- **A limited understanding of 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.

- **Struggling to claim 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 or 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.

- **Struggling to return to “normal”**: 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.

• **Feeling unsupported as a carer:** 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.

**Experiences of brain injury recovery with support from HEL’s Casework Service**

Two years later, with the Headway East London Casework Service funded and running, survivors and carers were once again consulted about their experience of the brain injury recovery and asked to consider what support they had received and what intervention might be missing.

Fifty survivors and carers completed surveys of the HEL Casework Service, while twenty-three survivors and carers were interviewed about their experiences.

The following two sections present the feedback survivors and their carers gave in the survey and interviews.

**Survey of the HEL Casework Service**

*Who completed the survey?*
Fifty people who had come in contact with the Casework Service at some point over the past two years completed a survey for this evaluation. The majority (28) were survivors, 14 identified themselves as carers, and a further 8 described themselves as family members or friends.

Seventeen people had first heard of HEL during their stay in the hospital, which suggests that the casework team is reaching brain injury survivors at the earliest stages of their recovery. Ten people had come in contact with the
casework team through the HEL day service, nine people had been referred on to HEL by a professional, and the rest had heard about HEL from a friend or had come across the casework service while researching online.

The majority of the fifty people contributing to this evaluation were in regular monthly contact with HEL (27 people). Sixteen people received support from HEL once or twice a year and only six people had minimal interaction with HEL (once or twice in total).

_Feedback from fifty survivors and carers_
The survey began by asking survivors and carers to identify what kind of support they had received from the Casework Service in the past two years. The four most common responses included receiving brain injury information, making contact and speaking with other brain injury survivors and carers, joining a support group and receiving advice about relevant brain injury services. People had also received support with practical matters such as claiming benefits, receiving housing and legal support and so forth. Table 1 provides an overview of people’s responses.

<table>
<thead>
<tr>
<th>Table 1. What kind of support have you received from Headway East London?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received brain injury information</td>
</tr>
<tr>
<td>Spoken to other brain injury survivors and carers</td>
</tr>
<tr>
<td>Joined a support group</td>
</tr>
<tr>
<td>Given advice about relevant services</td>
</tr>
<tr>
<td>Helped me with benefits</td>
</tr>
<tr>
<td>Helped me communicate with others</td>
</tr>
<tr>
<td>Introduced me to peer support workers</td>
</tr>
<tr>
<td>Helped me with housing</td>
</tr>
<tr>
<td>Supported during discharge</td>
</tr>
<tr>
<td>Helped me with legal support</td>
</tr>
<tr>
<td>Supported during hospital stay</td>
</tr>
<tr>
<td>Helped me get back to work</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Specify</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Supported me during hard times</td>
</tr>
<tr>
<td>• Helped appeal fit for work decision</td>
</tr>
<tr>
<td>• Helped me when I couldn’t work</td>
</tr>
<tr>
<td>• Helped me understand the effects of my injury on my personality</td>
</tr>
<tr>
<td>• Helped me find volunteer work</td>
</tr>
<tr>
<td>• Helped me communicate with the council and social services</td>
</tr>
<tr>
<td>• Helped me build confidence</td>
</tr>
<tr>
<td>• Helped me with language barriers</td>
</tr>
<tr>
<td>• Helped me organise funding for transport</td>
</tr>
</tbody>
</table>
The survey went on to probe whether survivors and carers felt that HEL had played a part in identifying and organising the appropriate support they needed. Table 2, 3, and 4 show that a majority of people surveyed felt that HEL had helped them identify and access services, and encouraged professionals to communicate and work together.

**Table 2. Headway has helped me/the person I care for access and organise better support and services.**

<table>
<thead>
<tr>
<th>Agree</th>
<th>36</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>1</td>
</tr>
<tr>
<td>Neither agree or disagree</td>
<td>12</td>
</tr>
</tbody>
</table>

**Table 3. As a result of support from Headway I know where to go and what to do if difficulties arise.**

<table>
<thead>
<tr>
<th>Agree</th>
<th>35</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>1</td>
</tr>
<tr>
<td>Neither agree or disagree</td>
<td>14</td>
</tr>
</tbody>
</table>

**Table 4. Headway has helped the professionals (eg. doctors, support workers etc.) that are supporting me to work together better.**

<table>
<thead>
<tr>
<th>Agree</th>
<th>27</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>3</td>
</tr>
<tr>
<td>Neither agree or disagree</td>
<td>20</td>
</tr>
</tbody>
</table>

The survey went on to ask whether survivors and their carers felt better informed and more independent as a result of support they’d received from the Casework Service. Forty-five out of the fifty people surveyed said they were better informed about brain injury thanks to HEL. Twenty-one people felt that they had to rely less on family members, and twenty-seven said they felt more independent as a result of support from HEL. See table 5, 6 and 7.

**Table 5. I am better informed about brain injury as a result of the support I received from Headway.**

<table>
<thead>
<tr>
<th>Agree</th>
<th>45</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>0</td>
</tr>
<tr>
<td>Neither agree or disagree</td>
<td>4</td>
</tr>
</tbody>
</table>

**Table 6. The support from Headway has meant I have to rely less on family or unpaid carers.**

<table>
<thead>
<tr>
<th>Agree</th>
<th>21</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>4</td>
</tr>
<tr>
<td>Neither agree or disagree</td>
<td>24</td>
</tr>
</tbody>
</table>
Table 7. I am more independent as a result of support I have received from Headway.

<table>
<thead>
<tr>
<th>Agree</th>
<th>27</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>3</td>
</tr>
<tr>
<td>Neither agree or disagree</td>
<td>19</td>
</tr>
</tbody>
</table>

Finally, the survey asked whether the survivors and/or carers sense of well being had been improved as a result of support from the Casework Service. A large majority of people responded positively to these questions, agreeing that they felt more able to manage difficulties, had greater contact with other people affected by brain injury and felt less isolated due to the support they’d received from HEL. See Table 8, 9 and 10.

Table 8. I feel more able to manage difficulties as a result of support from Headway.

<table>
<thead>
<tr>
<th>Agree</th>
<th>35</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>1</td>
</tr>
<tr>
<td>Neither agree or disagree</td>
<td>14</td>
</tr>
</tbody>
</table>

Table 9. I have had more contact with other people affected by brain injury and/or carers of people with brain injury due to support from Headway.

<table>
<thead>
<tr>
<th>Agree</th>
<th>45</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>3</td>
</tr>
<tr>
<td>Neither agree or disagree</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 10. I feel less isolated as a result of support from Headway.

<table>
<thead>
<tr>
<th>Agree</th>
<th>40</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>4</td>
</tr>
<tr>
<td>Neither agree or disagree</td>
<td>6</td>
</tr>
</tbody>
</table>

The survey concluded by asking survivors and carers to state what they thought was good about the HEL Casework Service, and what they thought was bad or in need of improving. Table 11 and 12 provide the verbatim responses survivors and carers left for this survey. People were very positive about HEI’s Casework Service and apart from general praise about support they had received and the kindness of the casework staff, they identified six key areas in which they felt the casework team had been particularly helpful. These were:

- Receiving practical support such as help with benefits, legal advice, discharge plans etc.
- A feeling of belonging and security
- Receiving support from caring and friendly staff
- Information about brain injury
- Gratitude for relationships with other survivors of brain injury
- Support through the transition out of hospital
The vast majority of respondents said they were satisfied with the HEL Casework Service and didn’t have any suggestions for improvement. Those who did comment on ways the Casework team could improve suggested:

- Securing more funding in order to offer more support to a wider group of people
- To develop existing services particularly in terms of time spent at the hospitals
- Develop ways to facilitate more one-on-one contact between the casework team and survivors and carers.

Tables 11 and 12 explore these points in more detail.

| Table 11. |
| What are the good things about the Headway East London Casework Service? (verbatim responses) |

**Practical support**
- Helped me put pressure on the council for support - support with housing - support in hospital - Headway gives people a reason to be around.
- Help is priceless with benefits and legal advice.
- It's great to have someone to contact when you need help and they are very knowledgeable about completing forms etc.
- Helped me through my hard times. Helped me with my housing, benefits. Supported me with my condition, given useful information about support groups. Very caring and never felt isolated. Thank you!
- The caseworkers have helped me through the assessments. I feel they are on my side.
- Headway’s Casework Service has helped me claim my benefits and get legal support for free. I think it provides an excellent service.

**Sense of belonging and security**
- Headway have given my son access to feeling secure in a safe environment. It's his sanctuary from the outside. They help him with everything he needs
- [My husband] is a different person since coming to Headway. I couldn't have wished for more support and help.
- That my husband has a routine with regular Wednesday slots and that he does lots of voluntary work now.
- It has made our brain-injured relative feel valued. She loves her day-sessions there. It provides much-needed stimulus outside her home.

**Caring and friendly support**
- Open, welcoming, friendly
- Lovely people, very nice, lots of information, they get in touch with me to check in
- Polite, supportive, understanding.
- Friendly, approachable, kind, go out of their way for you.
• Always at hand to listen and advise. Caring and empathetic.
• Headway East London Caseworker service is very supportive, reliable and caring.
• Compassion and true caring.
• They are very helpful and understandable.

Information
• Headway and other head injury organizations provide useful sources of information about brain injuries. Peer support groups help survivors steer around and overcome barriers set by society.
• Take the pressure of family members, find out the correct information, explain more about the hidden disabilities which are common with brain injuries.
• I know Headway is a resource I can go to when I have a problem regarding my brain injury. If they can't help me directly they will point me to somewhere else that can.

Meeting other survivors and peer support
• Talking to other people with brain injuries
• Support group - help each other. The art, day centre, training for speech with therapists
• Meeting others affected by brain injury for support.
• Access to people in similar situations and learn from their experiences.
• It provides knowledgeable support to brain injury survivors and carers. The support groups provide an environment where people feel understood and accepted - often for the first time - and can express how difficult things are after a brain injury, even if they look and present 'as normal'. It provides a community to which they can return for further support, guidance and signposting as often as they need to.
• I personally have appreciated the conversations on topical issues, as well as contact with other people.
• It helps to know that you are not alone. There are others experiencing the same difficulties as carers. Always being accessible.

Supporting the transition out of hospital
• Just having someone at the end of a phone when you come out of hospital is very important and you don't feel so alone.
• It is excellent. Headway has been so very helpful every step of the way since I was assaulted, they helped me get my life back after I left hospital.

General praise for Headway
• They are very polite and understanding! Non-judgmental and always helpful. I am not judged when I talk about something I am finding challenging.
• The day center and services are excellent. I especially like the opportunities to take part in member led training.
• Headway EATS [bi-monthly dinner] are very well organised and an enjoyable evening. It must be very rewarding for those who run it.
• It is a free service so many people who don't have the funds for other
services can feel supported in some way. The service deals also with helping and supporting the families of survivors. The team is greatly committed.

- Very open, accessible and understanding staff providing advice, information and a forum in which to meet and hear from other victims and carers.
- They are supportive for family and help us in every way they can. They are amazing.
- You know you can rely on people who understand your difficulties.
- There seems to be very few other organisations in this field.
- Brilliant service. Understanding of my needs and supportive.
- That they were there when I needed to talk to someone.
- This is only my second meeting but I enjoyed the first and will definitely be back.

### Table 12.
What could the Headway East London Casework Service do better?
(verbatim responses)

<table>
<thead>
<tr>
<th>Secure more funding to offer more support</th>
</tr>
</thead>
<tbody>
<tr>
<td>• They're doing what they can for me. It would be good to have more money for Headway!</td>
</tr>
<tr>
<td>• They could do with more funding. If I ever come into money I would like so much to repay the help and support I have received.</td>
</tr>
<tr>
<td>• At the moment what they do for my son is just right. But of course with funding they would know themselves what they need to help those who are brain injured.</td>
</tr>
<tr>
<td>• Have more Headway staff and more centres</td>
</tr>
<tr>
<td>• There is lots of stuff available for people attending Headway, however there is currently a very long waiting list for the day service.</td>
</tr>
<tr>
<td>• More employees to run the service. So more funding for them to do this.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Develop existing services</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Could connect carers to each other by internet or phone. Maybe reach out more to carers so more can benefit.</td>
</tr>
<tr>
<td>• It would be helpful for carers to have more opportunity to meet on their own and share experiences without their family member being present. In particular, from my point-of-view, to be able to discuss with other ‘ageing’ carers the steps that need to be put in place to create an alternative support system.</td>
</tr>
<tr>
<td>• More support with therapy would be helpful.</td>
</tr>
<tr>
<td>• More help with benefits i.e filling out forms, making phone calls to DWP, attending interviews etc.</td>
</tr>
<tr>
<td>• Doing more to raise awareness for brain injury within social services and public.</td>
</tr>
</tbody>
</table>
| • Perhaps to know a little more of what is happening by email and Facebook would be useful. However we think Headway are doing a brilliant job and without it we're sure [my son] would not have achieved what he has achieved.
- More thought about how to accommodate people with physical disabilities would be useful.

**More one-on-one contact**
- It would be good to have more contact with my husband's keyworker.
- Sometimes you don't know what help you need. Maybe an assessment could be done when you first approach Headway for help.
- I'd like Headway to stay in touch with us more.
- I was looking for help for my partner who has the serious brain injury, but the help available in our area seems limited to a monthly group rather than individual personal intervention.

**Satisfied with existing service**
- I'm not sure that Headway can do anything better given their resources.
- Nothing, I am satisfied with the service I received.
- Personally, I am still very satisfied and pleased with Headway Casework Service.
- I don't think they could do more than they do already.
- I feel they are doing a very good job.
- I think they were excellent. They were there when I needed to contact someone and ask questions.
- I cannot think of anything Headway could do better. They have made a huge positive difference in my life.
Interviews with survivors and carers supported by the Headway East London Casework Service

As the survey was limited to mostly closed questions that had to be asked simply and concisely in order to accommodate all survivors of brain injury, this evaluation also drew on twenty three interviews conducted with survivors and their carers in order to explore more in-depth experiences of their recovery and the support they have received from the HEL Casework Team. These interviews were conducted in 2017 and lasted between 20 minutes and an hour.

Similar to the baseline interviews, respondents were asked to recount their journey from the day of their brain injury to today and to describe the kind of support they had received and whether the HEL Casework Service had played a role in their recovery.

The people interviewed described a variety of experiences after their brain injury and required different levels of support. Survivors and carers most frequently spoke of HEL supporting them in the following ways:

- Early intervention in the hospital setting
- Preventing isolation through a sense of belonging to a community
- Providing opportunities for beneficial peer exchange
- Helping with basic necessities such as benefits, finances, care and housing
- Providing brain injury information
- Building confidence through regular activities
- Acknowledging the significance of carers and their need for support
- Filling a gap in brain injury services, support and education

These themes are further illustrated in the section that follows.

On the whole everyone consulted was satisfied and grateful for the support they received from the Casework Service which ranged from helping them with practical issues such as avoiding homelessness and applying for benefits, to providing an understanding community and peer support that helped them gain insight into many of their brain injury related experiences. The HEL Casework Service was described as preventing isolation and facilitating a positive, supported recovery after brain injury.
Who was interviewed?
Table 13 below gives an overview of the twenty-three people who were interviewed for this evaluation. The table shows how varied people’s experience of brain injury is, and the array of symptoms survivors deal with on a daily basis.

Table 13. Characteristics of participating survivors and carers

<table>
<thead>
<tr>
<th>Carer or survivor</th>
<th>Brain injury</th>
<th>Contact with Headway</th>
<th>Type of brain injury</th>
<th>Described symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer for son</td>
<td>2011</td>
<td>2013</td>
<td>Virus</td>
<td>Paralysis left side of body, and difficulties with thought processing.</td>
</tr>
<tr>
<td>Survivor</td>
<td>2012</td>
<td>2015</td>
<td>Traumatic brain injury</td>
<td>Two types of amnesia, seizures, anxiety, language impairment.</td>
</tr>
<tr>
<td>Carer for partner</td>
<td>2014</td>
<td>2015</td>
<td>Traumatic brain injury</td>
<td>Memory impairment, language impairment, anger</td>
</tr>
<tr>
<td>Survivor</td>
<td>2014</td>
<td>2015</td>
<td>Aneurysm</td>
<td>Memory impairment, extreme fatigue, limited concentration</td>
</tr>
<tr>
<td>Survivor</td>
<td>?</td>
<td>?</td>
<td>Haemorrhage</td>
<td>Almost fully recovered.</td>
</tr>
<tr>
<td>Survivor</td>
<td>2015</td>
<td>2016</td>
<td>Traumatic brain injury</td>
<td>Headaches, neck pain, memory impairment, dizziness, fatigue.</td>
</tr>
<tr>
<td>Survivor</td>
<td>2014</td>
<td>2015</td>
<td>Traumatic brain injury</td>
<td>Memory, limited concentration, depression, anxiety, anger.</td>
</tr>
<tr>
<td>Carer for husband</td>
<td>2015</td>
<td>2016</td>
<td>Traumatic brain injury</td>
<td>Memory impairment, cognitive fatigue, loss of empathy</td>
</tr>
<tr>
<td>Survivor</td>
<td>2016</td>
<td>2016</td>
<td>Traumatic brain injury</td>
<td>Memory impairment, anger, more impulsive, language impairment.</td>
</tr>
<tr>
<td>Survivor</td>
<td>2012</td>
<td>2014</td>
<td>Aneurysm</td>
<td>Memory impairment, headaches, limited concentration.</td>
</tr>
<tr>
<td>Survivor</td>
<td>2014</td>
<td>?</td>
<td>Unsure of exact cause</td>
<td>Memory impairment, can’t walk in straight line, blurry vision.</td>
</tr>
<tr>
<td>Carer for son</td>
<td>2015</td>
<td>2015</td>
<td>Hypoxic brain injury</td>
<td>Cognitive fatigue, noise fatigue, spatial problems, memory impairment, behaviour, being around lots of people difficult, anxiety.</td>
</tr>
<tr>
<td>Carer for husband</td>
<td>2007</td>
<td>2011</td>
<td>Stroke</td>
<td>Paralysis left side of body, memory impairment, anger, confusion.</td>
</tr>
<tr>
<td>Survivor</td>
<td>1977</td>
<td>2016</td>
<td>Hydrocephalus</td>
<td>Fatigue, difficulty processing information, sensitive to noise.</td>
</tr>
<tr>
<td>Survivor</td>
<td>1987</td>
<td>2015</td>
<td>Haemorrhage</td>
<td>Not many symptoms now.</td>
</tr>
<tr>
<td>Survivor</td>
<td>2015</td>
<td></td>
<td>Traumatic brain injury</td>
<td>Headaches, memory impairment, fatigue, lethargy, communication.</td>
</tr>
<tr>
<td>Survivor</td>
<td>2012</td>
<td>2013</td>
<td>Stroke</td>
<td>Limited concentration, problems with initiation, affected executive</td>
</tr>
</tbody>
</table>
function – any form of planning, reduced sense of passage of time, left sided hemiparesis, reduced sensation on left side, reduced balance.

<table>
<thead>
<tr>
<th>Carer for husband</th>
<th>As above</th>
<th>As above</th>
<th>As above</th>
<th>As above</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survivor</td>
<td>2016</td>
<td>2016</td>
<td>Traumatic brain injury</td>
<td>Memory loss, headaches, communication, fatigue, anger</td>
</tr>
<tr>
<td>Survivor</td>
<td>2016</td>
<td>2016</td>
<td>Haemorrhage</td>
<td>Limited concentration, memory loss, confusion, depression, anger</td>
</tr>
<tr>
<td>Survivor</td>
<td>2013</td>
<td>2015</td>
<td>Traumatic brain injury</td>
<td>Memory impairment, cognitive fatigue, loss of empathy</td>
</tr>
<tr>
<td>Carer for partner</td>
<td>2012</td>
<td>2015</td>
<td>Stroke</td>
<td>Paralysis, memory impairment, anger, confusion.</td>
</tr>
</tbody>
</table>

Feedback from 23 survivors and carers

Early intervention in hospital

HEL’s early intervention in hospital was highly praised by survivors and carers for providing early in-hospital support and attention to patients and family members and continuing this support after a person’s discharge and during their reintegration into the community. The following three case studies, presented in the survivor or family member’s own words, best illustrate the variety of ways in which early interventions by the HEL Casework Team can have positive effects on a patient’s recovery and reintegration into society. Each of the following case studies is followed by a summary of the ways in which the Casework Service has provided support in these cases over the past two years.
Early Intervention Case Study 1 – Nina's experience

I first came in contact with Headway the day I was discharged from hospital. I’d been there for about a month, and [name of caseworker] from Headway came around and introduced himself and told me about Headway. He gave me a leaflet and a business card and told me to get in touch if I ever needed any help. So I kept the business card and actually I found that when I got home I really did need help. I started opening post and couldn’t understand anything that I was reading. I didn’t know what to do. And that’s when I remember meeting Headway at the hospital. So I phoned them and since then they’ve been there for me. Headway has been an absolute god send. They sent someone round to my house soon after I called and they interviewed me and found out what kinds of disabilities I had and that sort of thing. They explained social services and the forms I had to fill out. They helped me with absolutely everything.

I reckon that from the moment I realised I couldn’t read anymore I probably would have just hid myself away and become severely depressed without Headway. Depression is a side effect of the brain injury and I had it pretty bad. And I think if I hadn’t had Headway to rely on I probably would have done away with myself if I’m totally honest with you.

Headway have helped me with my PIP and they’re still doing that for me now because some of my money has been cut, so they’re helping me reclaim that. But Headway have not only helped me, they’ve helped my family as well. I’ve got a couple of boys – one’s an adult and one’s a child. And the one that’s a child is at home. And he’s struggled a lot with how different I am from what I used to be. So what Headway did was send him literature. So he felt that he was part of everything and important in the whole process. Throughout all of this I know that my family have been pushed aside because all the attention is on me all the time. And so I thought it was good that Headway sent just my son something. I could see that Headway understood that he was going through stuff as well. I think that meant a lot to him.

And I would say that Headway saved my life twice, actually. The first time when I just left hospital, and again now because I’ve finally got a place at the day centre. I was very isolated before. I was at home all day everyday. I only saw my family and that was about it. And I really worried about leaving the house and how I’d manage. But Headway has helped me so much and I’ve not looked back since. And I’d say I’m making a lot of steps towards a normal life again, and that’s all thanks to Headway supporting me and building my confidence. I think Headway know that people who go there have lost themselves. What I used to do for a living before I can’t do anymore, so they’re helping me find a new and different path.

It’s only now that I can see how hard it was for me at the start of my injury. Because my brain is clearing now. I spent all of last year in a fog, I had really bad depression. I’d even thought about killing myself because it was just… it was so weird to have a brain injury, to collapse and wake up a completely different person. And I’m only half way through my recovery really. But I’ve
already made so much progress.

Meeting Headway in the hospital was probably one of the most important encounters of my life. When I got home and found out I couldn’t read, I wouldn’t have known where to turn to. I would never have got anywhere without them.

But now I’ve got a key worker at Headway. He’s a lovely man and he kind of is my first port of call for anything that I have any problems with. He’ll call me once a week to hear how I am and that makes me feel good, because for a long time I only had my immediate family to rely on and that can get very lonely. I think you can just shut yourself away because everything feels too difficult. But to have people out there who understand me and who I can talk to makes it all bearable.

I think Headway is invaluable, it’s saved me. And not only me, but my family as well. They really did.

Support provided by the HEL Casework Service:
• Early contact in hospital
• Available as a source of support after discharge
• Providing information and understanding of brain injury
• Filling out forms and claim entitlements
• Combating isolation and depression
• Providing support and information to family members
• Facilitated introductions to other survivors of brain injury
• Helping build self-confidence after the injury
Early Intervention Case Study 2 – Pat’s experience

I first met Headway at the hospital. I saw big signs on the notice boards about Headway there. And then I met [name of case worker]. He came to see me. And he told me to come to his drop-in session when I was feeling better and that's how we met. And I'd say I've got a really good relationship with him now.

I don’t know how I ended up in hospital. I don’t remember anything about the accident or anything. I was at home and I tripped over a chair and then landed on the floor and lay there for eight hours I think before a friend turned up. That was a year ago. I was at the Royal London for four months. It meant a lot to me to meet Headway at that time, I thought my days were numbered. I was feeling hopeless, and I was feeling down and feeling very depressed. And it was a good thing for me to meet [name of case worker] and meet people at Headway with head injuries.

I have a few family members, but not many really. So that’s why it’s really helpful to have [name of support worker] from Headway to help me. If it wasn’t for her coming around every week, I don’t know... Because my depression is still high. If it wasn’t for her coming around that would be it. I think I would have done something stupid. I can’t concentrate, sometimes I stop eating. But when she comes I start eating again because she cooks with me. And so that’s made a big difference to me. She comes twice a week. If it wasn’t for her I probably wouldn’t be around now, because I get these ups and downs and so she helps with the depression. We go shopping together, she helps me cook. Without her I would stay in. I wouldn’t go nowhere. But she cooks with me and then we both sit down and have a meal. She does all of my bills for me, makes sure my bills are paid and my rents paid – everything. Headway saw that I needed that sort of person and so they went to work to help me get that support at just the right time.

They’ve done so much for me. Even with my housing, my housing is all sorted finally with the council because of Headway. They got me a council flat. And now they’re helping me get a shower in that is accessible, and they’ve been talking to the council about that because no one was listening to me. And so they’ve made me feel secure and happy, I guess. I mean happy although I can’t do what I want anymore. And I’m trying to get away from this depression and get back to normality. Put some weight back on and get back to myself.

I’ve been to support groups at Headway. That’s been an eye opener really. You see how other people are affected and how no one is giving up that easily. It gives you some hope. Because I was just ready to give up for a while. I couldn’t do simple things anymore, and I felt like I was just ready to go. So it was good to meet other people who’ve been through it.

I can’t imagine what the last two years would have been like without Headway. If Headway wasn’t around I would have been lost, I think it would have been easy to do harm to yourself. Because depression can be so high with head injury. But I know that I have this group of people supporting me, if I
feel bad I can ring Headway. There’s a lot of support there. And if you didn’t have that support, oh my, you could just be lying on the floor all day and no one would find you. People who don’t have family, I don’t know what they’d do. Imagine a person with a head injury who didn’t have family and didn’t have Headway. I think that person would be lost. And there’s a lot of people out there with no family and no Headway.

The lottery have to keep funding the Headway Casework Service. They need to. It’s very important. This is saving lives. Doctors save lives, but it’s the aftercare too that saves lives. It’s the aftercare that is needed. It’s not just your head that goes wrong, it’s everything that goes wrong after the injury. And we need the help and support of Headway. If Headway didn’t exist there’d be a lot of people committing suicide or something. Headway deals with everything, your housing, your money, your well-being. They introduce you to others. The support group is good. Being around people and getting into normality again. Imagine coming out of hospital and all you’ve got is your family and that’s it.

I think what Headway gives especially is professionalism. That’s something that a family member couldn’t give you. They know how get you rehoused, they fill out the forms, they know how to talk to people and what resources are out there. that’s why people with head injuries need Headway. A lot of people would be facing really bad news without them.

Support provided by the HEL Casework Service:

- Early contact in hospital
- Helping to combat isolation and depression
- Organising weekly care after discharge
- Support with finances, and claiming entitlements
- Securing appropriate housing
- Attending Headway support groups and made contact with other survivors of brain injury
- Access to professional knowledge of brain injury and related services
Early Intervention Case Study 3 – Cora’s experience

My mother had the brain haemorrhage in the early hours in February. She was in bed, it was after midnight, and had the haemorrhage. And my father called me and said she was going blue and making strange noises. She couldn’t breathe. So my dad called the ambulance immediately and the medics talked him through CPR and somehow he got my mum on the ground and saved her life. And then the ambulance came.

The surgery at the hospital was successful and she was unconscious for about two weeks. During this time she suffered a seizure but we didn’t know about this because the communication in the NHS wasn’t very good. And that’s when Headway stepped in.

We saw signs in the hospital for Headway and that they had a drop-in session every Thursday. So we went to that, but it was too busy that week so I arranged with the caseworker to meet at the following session. And while we waited Headway sent me lots of information by email and asked me questions. And then we met in person and talked to her for about an hour and a half. And she gave us lots of information and leaflets and things like that.

And from then on Headway helped us communicate with the hospital. At many points they got information from doctors and nurses for us that I don’t think we would have heard without them. So that was really very helpful. There was a time when we weren’t getting any news from doctors at all even though we were there everyday and Headway changed that. They gave emotional support as well, and talked us through what would happen now, and what would happen once she woke up and how the recovery might go. Because none of us knew anything about brain injury or anything like that. So Headway sort of charted a path for us from the start and were always extremely helpful and reassuring.

Two months after my mum had the aneurism she was transferred suddenly to another hospital. That was a big surprise and a big panic for everyone because we didn’t know why she was moving. And I guess that part of the problem might be that my dad’s first language isn’t English. So there was maybe some confusion there. But we spoke to [name of caseworker] right away and she made calls to figure out for us what was going on. So these are the kinds of things in hospital that it’s good to have Headway around for.

Once we left hospital Headway helped us out with applications to different rehab centres. This took a lot of research and form filling and Headway led us through all that and we’re now really happy with the rehab centre she’s in. She’s got good care there, good therapists, she has a key worker. And Headway have been in touch the whole way through.

We’ve also been attending the Headway support group meetings since the beginning. I think we’ve only missed one of them. They’ve also helped us with paper work there. And they organised a brain injury card for my mum, which she can wear and it lists her main impairments and says “I have a brain injury”
with a photo on it. So if my mum ever gets into trouble people can see that and use the information on the card.

My mum was in charge of everything to do with the house. She was in charge of all the finances and all the household stuff and now she can’t do any of that. So it falls to my dad now. So having Headway and the support group meetings where he can get advice and talk to other people has been incredibly valuable to him. It’s given him new confidence and he’ll come back and tell us about how he needs to apply for Personal Independence Payments for my mum, whereas before that would have gone completely over his head. So Headway has helped with that, but it’s also enabled him to form friendships in the group. And that’s been a huge help to my husband and I, because that takes some of the burden off of us.

I think one of the ways Headway helps is by repeating important information over and over. There is so much paper work and bureaucracy to deal with. Everything from power of attorney, to PIP and ESA forms, DWP stuff just everything. There is so much of it. And Headway just continues to re-provide this information. It can be hard to take it all in, and Headway are patient when I ask the same question again. They give good advice and explain it in a different way. They’ll sit down with you and do the forms.

It was very comforting speaking to someone in the hospital. To find out how the brain injury might effect my mum and us, and to look ahead to the future. You’re bombarded with all this medical information and you feel overwhelmed and hopeless and helpless. And you’re surrounded by wires and tubes and beeping and we didn’t know what was going to happen. So to speak to someone who could understand what that was like and chart a way forward for us when we couldn’t even think was very valuable. And the Headway staff are kind and generous spirits and that helped a lot.

Support provided by the HEL Casework Service:
- Early contact in hospital
- Facilitating communication between patients family and hospital staff
- Providing information on brain injury
- Emotional support
- Organising discharge from hospital and access to rehabilitation
- Support with finances and claiming entitlements
- Attending Headway support groups and made contact with other survivors of brain injury and carers

Preventing isolation

Interviewees described how contact with the HEL Casework Team has prevented them from feeling isolated. Many survivors spoke about how depression had followed their brain injury as they were coming to terms with
their new limitations. Survivors and carers spoke about brain injury as an isolating experience that can be hard to communicate to others and is difficult to make sense of.

Interviewees described how the HEL Casework Team not only provided professional support, but also facilitated access to a sense of community and a feeling of being normal and surrounded by peers. Whether through the Peer Support Service, the Peer Support Groups, Saturday Socials, Family Days or eventual access to the HEL day centre, the HEL Casework Team enabled survivors and carers to become part of a community of people who have been through similar experiences and to feel normal, understood and supported.

*It's a community, it's a family, they welcome people with brain injuries, they make them feel at home, they listen to them, they listen to your problems and they help you to solve your problems and it is like one big family and community and they're all there to help you...they're just so supportive in any way and every way.*
- Sarah (mother of Sean)

*Mainly I come in just to chat to people and get myself out of my house, because normally I almost never leave my house, it's very common that I will go through an entire calendar month and the only time I leave the house, aside from going to the corner store...is when I come here. So it's mainly to get myself out of the house 'cos...since the head injury I am uncomfortable going out of the house.*
- Craig (survivor)

*Going to the support group is brilliant because it brings together people with the same kind of issues and I've made lots of good friends , just to share that you're not alone, you're not on your own and you're all going through the same kind of thing. The support group has been really great I think it's probably been the best thing I've enjoyed.*
- Claire (survivor)

**The benefits of peer exchange**

Survivors of brain injury described the peer exchange facilitated by HEL on topics and experiences related to brain injury as being very helpful to them. Interviewees described that it was a relief to discuss the many challenges of having invisible disabilities often associated with brain injury with people who were undergoing similar experiences. Having access to an organisation where people have a unique understanding of your injury, and where you potentially have the ability to help and support others through the sharing of your own experiences was seen as being very satisfying and fulfilling.

*There are other people going through similar situations and you are able to benefit them from your experience as well as calling on their*
experience, that was what I found in the early stages to be enormously helpful, to know that there are other people experiencing this as well and having the same problems...so being able to get advice but also to share and help other people.
- Karen (carer)

Interacting with other people who have sustained brain injury, so it's a case of us as groups sometimes having conversations on how we got our brain injury and how we're dealing with it and coping with challenges...how to deal with various other struggles like dealing with political structures like health and Government on dealing with our issues.
- Ben (survivor)

Basically that’s helped me a lot because you find out information there from talking to other people that have actually gone through the same situations and talking about it, because you can talk to your friends and family, but unless they’ve had this experience, they are caring and they do help but they don’t really understand, like everything unless you’ve gone through it yourself you don’t really understand. And talking to the support group is really vital because these parents, these brother or sisters, whoever’s there they’ve all been through it…and it gives you hope as well seeing other brain survivors, further down the line when you see how they’re doing, you think wow it is achievable, because you sometimes can’t see the light at the end of the tunnel.
- Hattie (mother of Steve)
Help securing basic necessities - benefits, finances, care and housing

A significant way in which the HEL Casework Service had helped many of the interviewees was by supporting them in securing basic necessities after brain injury such as care, an income, and housing. Often this support involved filling out forms for Personal Independence Payments (PIP) or Employment Support Forms (ESA). Sometimes these benefits had been reduced or cut and HEL supported survivors in appealing these decisions. The casework team often advocated on behalf of the survivor by attending meetings and helping them articulate their difficulties and care needs. Survivors described how caseworkers had helped them navigate complicated systems with local authorities and with medical care, to ensure they got the support they needed. Understanding how the system works and having a knowledgeable professional supporting you through the processes, empowered many survivors and carers to take up their entitlements and strengthen their security.

One of the main things [Headway] have supported me in is a lot of the form filling. Also at one stage, [my son] lost his benefit...they had put him in the wrong category...we had to appeal everything, certain things they’d said in the interview wasn’t actually correct, and Headway came along to my home and for 4 hours they spent with me we did an appeal, wrote it all down and then he got all his benefits reinstated. They’ve got solicitors. The legal side of things they understand, because again it’s not all about the physical disabilities, it’s about the mental hidden disabilities and for a lot of the benefits that’s not recognised enough.
- Hattie (mother of Steve)

I had help appealing because I didn’t get PIP and [name of caseworker] helped me appeal and now I have been retrospectively awarded PIP for the previous year. They haven’t confirmed any payments going forward though, so we still have to appeal again and it’s likely we will go to court.
- Craig (survivor)

I’ve received a lot of support, I’ve received financial support, a one-off voucher because I didn’t have any food at the time to eat, and Headway also gave me a small grant because I didn’t have a bed or furniture and also a social worker came by from Headway, called [name of caseworker], and she helped me with everything like filling out applications, speaking to the local council, local authority, she did everything on behalf of me and without them I’d be homeless, literally.
- Laura (survivor)

Four people described that they were living in inappropriate housing or were homeless before the Casework Team stepped in to help them, and another described being able to stay in their home after a caseworker secured additional funding to cover the rent.
What’s been particularly important to me is the caseworker. For example I wouldn’t be able to afford my rent, I was receiving discretionary housing payment because the local housing allowance doesn’t even cover half my rent and so the discretionary housing payment is meant to be a short term thing...they basically expect people to move and find cheaper accommodation so that the local housing allowance will cover it, but because my unique situation with the housemates being so helpful and me not even having the money to pay a removal company, the borough has been renewing it twelve months at a time...so the caseworker help in filling out the application has been very important.
- Craig (survivor)

When I was homeless, a case worker helped me...I was in a hostel for nearly three years and they asked me if I wanted help and I said yes and since then they have helped. I would recommend anyone to go there honestly...I was struggling with debt and PIP I couldn’t do it on my own but there I was helped.
- Maria (survivor and volunteer)

Providing brain injury information
Many people described HEL as a valuable source of information for anything they needed or had questions on as a result of their brain injury. Most of the interviewees and their family members had received information about brain injury, including a better medical understanding of the injury, what to expect as a result and how to cope with many of their new limitations. Survivors and carers also received information on available local services and entitlements they would be eligible for. The HEL Casework Team was seen as a respected source of brain injury information that could be tapped if any questions arose.

They explained, because we had a lot of questions about what is it about the brain, and how is it affected...they told us lots of information and training, it’s very good.
- Margaret (survivor)

From early on I got information from Headway...When I got home (from hospital) they rang me and made an appointment to come round and see me and assist me which they did...they saw what I needed, helped me with hospital appointments, helped me with anything that I needed until I could really stand on my own two feet really, because when you have a brain injury you feel completely alone and it’s nice to be able to just pick up the phone and have someone on the end of a phone just to advise you on certain things.
- Kitty (survivor)
Building confidence through activities
The HEL Casework Service was described as supporting people in building up their confidence after brain injury by inviting them to regular social events held in a safe and understanding environment. The Peer Support Groups, Saturday Socials, Family Days, HEL’s bi-monthly supper club and other regular activities run at the HEL daycentre were all hailed as positive social experiences that got people out of the house and socialising. Being regularly exposed to opportunities to interact with others helped survivors test their limits within a safe environment and thereby build their confidence.

Going to Headway has done wonders for his confidence, he really has improved. He still has memory problems, but he’s learned strategies for getting around it, making lists, planning journeys.
- Karen (carer)

Sometimes they have the family fun day. It’s really good. I bring my little one, he really enjoyed it before. Christmas and summer - two days of family days, its really good, bring the family together and helps you socialise with other people.
- Virginia (wife of Joe)

Headway is like getting the golden ticket from Willy Wonka’s chocolate factory! (laughs)... Headway is helping him to be a better person, a different person and more confident. It helps him to go there, as he says the outside world isn’t normal to him anymore - when he goes to Headway he feels normal.
- Sarah (mother of Sean)

They have lovely art and a lovely kitchen, you can learn to cook...We went bowling and did the things I hadn't done in a lot of years because of my disability… whenever I go there I always feel safe and like it’s like home, honestly.
- Maria (survivor and volunteer)

I recently attended a life skills course which covers areas like building up self-confidence which is a major issue that I've got - got very low confidence in myself...dealing with money management, time management - it's given me more awareness on how to deal with such issues.
- Ben (survivor)

Acknowledging carers and their need for support
Survivors and carers both spoke about the important support HEL provides to family members and carers of brain injury survivors. Interviewees described how at the early intervention stage of recovery it is normally family members that directly benefit from the emotional support and information that the HEL casework team provide. After discharge the HEL Casework Service is available for family members to ask questions and receive advice, and the
monthly support groups and regular socials are open to carers and family members.

The HEL Casework Service was described as providing much needed professional advice and support, but also as a service that helped take pressure off the carer by stepping in to fill out forms or advocate on behalf of the survivor, as well as giving carers much needed relief by occupying survivors with activities at Headway East London.

Several carers also spoke about the important peer support they had received. Support groups not only serve as spaces for survivors to meet, but also family members and carers. Carers described how they had benefited from hearing other carers describe their experiences and struggles, and several had developed close and supportive friendships as a result of meeting at HEL.

"The more I go there and listen to others the more I realise there is such a crying need for support for carers. Headway offers help and services to the carers looking after people who are quite often in appalling situations, so it's a great organisation."
- Paul (survivor)

"My challenges are his paperwork and phone calls and dealing with his hospital appointments...with the bigger things it gets to the point where it's like I can't cope with this and that's when I get in touch with Headway, and they're there for me straight away which is good."
- Sarah (mother of Sean)

"Obviously I faced the challenge of when I wanted to apply for things, getting [my son] what he is entitled to, sometimes you hit barriers. And then I know I've always got somebody at the end of the phone. If I tell them what's happened they can say to me 'this is what you need to do, this is who you need to phone, you can have that', obviously with the cut backs you will get told no first of all. And they help you. 'cos sometimes you do feel like giving up and if they see you are struggling then they'll come on board and help you and guide you through it... So they're taking the pressure off the family, basically, and that enabled us then to all move forward."
- Hattie (mother of Steve)

"If I have a problem I can get in touch with them and they can guide me, when we had a tribunal they were very, very good in dealing with all my paperwork for me...and helping us at the tribunal I don't think I could have done it all without them because I'd been doing so much. I needed someone to help me and bolster me, but yes if ever I have a problem I can always phone and get some help and guidance from them, so in that sort of caring capacity they are a useful font of information for me."
- Sarah (mother of Sean)
You find out information there from talking to other people that have actually gone through the same situations and talking about it, because you can talk to your friends and family, but unless they’ve had this experience, they are caring and they do help but they don’t really understand, like everything unless you’ve gone through it yourself you don’t really understand. And talking to the support group is really vital because these parents, these brother or sisters, whoever’s there they’ve all been through it…and it gives you hope as well seeing other brain survivors, further down the line when you see how they’re doing, you think wow it is achievable, because you sometimes can’t see the light at the end of the tunnel.
- Gillian (survivor)

**Filling a gap in brain injury services**

A theme that emerged frequently during these interviews was that survivors and carers felt that the Casework Service was filling a large gap that existed in the statutory support currently available to brain injury survivors. Many people described being discharged from hospital without any formal support arrangement, and feeling that there was no other point of contact in the community with a person or service who understood brain injury. Survivors described GPs as not really understanding their difficulties and often misdiagnosing survivors with mental health problems. Local authorities were described as lacking insight into brain injury and its affects, and as a consequence often failed to acknowledge the needs of survivors.

In all of these cases the HEL Casework Service was seen as a vital bridging organisation between the survivor and the hospital and statutory services. The HEL Casework Team helped to advocate and communicate on behalf of the survivor and provided the support people needed in order to access the appropriate services. Particularly during a time in which many services are facing funding cuts, HEL was seen as an important ally in securing and defending people’s rights to entitlements.

Furthermore, HEL was seen as providing an important brain injury education function. The Casework Service was described as educating not only survivors and family members, but also professionals within statutory services and the wider public about brain injury and its effects.

I do feel that if I need to tap any of those resources I'd go to Headway. I wouldn't go to my GP or hospital…I'd go to Headway…It seems to me they have a variety of options available for you, they have a lot on offer.
- Paul (survivor)

There was quite a lot of contact first of all, they were the only people I could connect to and there wasn't anyone else that I could really ring or any other contact, because when you’ve had a head injury like that there's no one that you know that's been through the same sort of thing...
- Kitty (survivor)
Communication's been very good and they can give advice about what you're going through because even the GP doesn't seem to know about head injuries. It's just someone that's knowledgeable about the process you're going through, how it affects you and the difficulties you have on a day-to-day basis. They are understanding, good listeners and empathetic towards you as well and professional.
- Grace (survivor)

The local council were just passing me onto every single other officer and then someone from Headway stepped in and stopped it straight away. If it wasn't for them I would be homeless because they [local authority] basically ignored me, they ignored my condition. But when Headway supported me, they backed me up with a specialist report themselves, they contacted my hospital, they did everything on behalf of me so I don't have to go through that stress again.
- Laura (survivor)

Conclusions

Feedback from 73 brain injury survivors and carers shows there is universal support and gratitude for the information, advice and advocacy a Big Lottery funded HEL Casework Service has provided brain injury survivors since funding began.

The twenty survivors and carers who were interviewed in 2015 and who had not received support from an equivalent service described a range of difficulties that they had faced. The HEL Casework Service has created systems to address all of these difficulties and gaps in provision in the past two years, and survivors and carers have confirmed the success of these interventions in their feedback. Table 14 lists the gaps in brain injury provision identified two years ago and whether survivors and carers feel they have been addressed by the HEL Casework Service.
Table 14. Comparing brain injury provision before and after intervention by the HEL Casework Service

<table>
<thead>
<tr>
<th>Gaps in brain injury provision identified by survivors and carers in 2015</th>
<th>Gaps addressed by the Big Lottery funded HEL Casework Service by 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>A difficult hospital experience</td>
<td>✓</td>
</tr>
<tr>
<td>A challenging transition out of hospital</td>
<td>✓</td>
</tr>
<tr>
<td>A limited understanding brain injury</td>
<td>✓</td>
</tr>
<tr>
<td>Struggling to claim entitlements</td>
<td>✓</td>
</tr>
<tr>
<td>Disappointing experiences with statutory services</td>
<td>✓</td>
</tr>
<tr>
<td>Low confidence and isolation after the injury</td>
<td>✓</td>
</tr>
<tr>
<td>Feeling unsupported as a carer</td>
<td>✓</td>
</tr>
</tbody>
</table>

In conclusion, recipients of HEL support were adamant that the HEL Casework Service should continue. They felt that the Casework Service filled a significant gap in the current statutory support that is available to brain injury survivors and worried that the removal of funding from this service would spell disaster for the vulnerable survivors and carers who have come to depend on the HEL Casework Service. Survivors felt that the HEL Casework Service enabled brain injury survivors to lay the foundations for a positive recovery and reintegration into society, and hoped that this service would continue.

While recipients of support were universally positive about the service provided by the HEL Casework Team, survivors and family members did have a number of suggestions for how the service could be developed over the coming years. These suggestions are listed in the concluding section, along with the ideas presented by casework staff and key stakeholders for future development of the HEL Casework Service.
Table 14. Overall support for the Headway East London Casework Service

<table>
<thead>
<tr>
<th>Statement</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>It puts out there that you’re not alone and that most things are achievable in a certain way, or if something’s not achievable they’ll give you an alternative — they always keep things positive, there is never any negativity from Headway.</td>
<td>– Hattie (mother of Sean)</td>
</tr>
<tr>
<td>I would say that the people here are wonderful and they’ve been super helpful and it’s just a wonderful place. I love Headway and I am so grateful.</td>
<td>- Craig (survivor)</td>
</tr>
<tr>
<td>I really couldn’t have done without them…they were always really approachable, if I called and they weren’t there they would always call back, just everything about them was really, really good.</td>
<td>- Kitty (survivor)</td>
</tr>
<tr>
<td>They’re very nice people, very friendly and I feel very supported there. It’s nice it’s like my place I can go, that feels good. People around you forget you’ve had a brain injury and just kind of ignore you but you go there (Headway) and they’re so nice, especially (key workers name) she’s so positive and everything, she’s really, really nice.</td>
<td>- Margaret (survivor)</td>
</tr>
<tr>
<td>The staff are very lovely, they’re very friendly, I never expected to find anyone that would just help…with happiness, without any complaining, they are willing to help you, they are very friendly, I just always feel happy when I go there.</td>
<td>- Gillian (survivor)</td>
</tr>
</tbody>
</table>
5. Improving and Developing the Headway East London Casework Service

Overview
The great majority of the people surveyed for this evaluation were content with the HEL Casework Service and did not have any suggestions for improvement. However, feedback from staff, key stakeholders and survivors and carers did generate a number of suggestions and ideas on how the service could be developed. The main suggestion that was repeated frequently by staff, key stakeholders and survivors and carers was to extend the Casework Service by securing more funding, hiring more staff, extending the time spent at the Royal London Hospital and the Homerton RNRU, and possibly expanding the early intervention service to other hospitals. Further suggestions are listed below.

Staff suggestions
The three HEL caseworkers interviewed for this evaluation suggested the following improvements to the Casework Service:

- To secure further funding to maintain and grow the existing service. This might include offering more services, hiring more staff, and expanding HEL’s presence in the Royal London and Homerton hospitals beyond one day a week.
- Extending the HEL’s early intervention service into other hospitals in the London area.
- Identifying ways in which survivors with more minor head injuries could be contacted in the early stages of their recovery process.
- Providing more brain injury education. This might include organising events around speakers with a specific expertise on brain injury, developing more targeted information for family members specifically children of brain injury survivors, and creating a programme of brain injury education session in the Royal London Hospital.
- Developing an advocacy branch of the Casework Service which would work to promote better understanding of brain injury within statutory services and in wider society. The Casework Service could document and highlight cases of bad practice within local authorities and advocate for a better processes.
- Extending brain injury support to the prison population. Studies suggest that a significant portion of the prison population may have a brain injury. HEL could provide services in prisons to help identify needs and provide support to inmates with head injuries.
- More support could be provided to elderly survivors of brain injury in helping them set up their organise their pensions and set up their wills.

One of the main ways we could expand and improve the service is just by having a presence in other hospitals. We don’t currently have the capacity to go to other hospitals, but with more resources it’d be great to have a presence in other hospitals in the area and to try to capture
I think we could develop in terms of advocacy. We work within 13 boroughs in London and we’ve seen a lot of bad practice in these boroughs and we could really have a unique opportunity to capture how things are happening with regards to the Care Act. And how things should be happening. So we’ve seen one borough do something wrong for three different people. And it makes you think that there must be a policy in this borough that needs to be changed so that this no longer happens to people. And I think maybe that’s a big area that we could think about developing.

- Caseworker 3

What we can keep working on is education, I think. Education on brain injury, the brain, the impact for friends family and children. And thinking more carefully about how do we get these message across to them. How do we communicate to children that mummy or daddy is different? It’s hard enough with and adult, let alone with children. We could have educational groups at the hospital. Maybe carers educational sessions and brain injury survivor educational sessions. Maybe even hosting events with speakers.

- Caseworker 2

Peer support worker suggestions
Two peer support workers interviewed for this evaluation suggested the following improvements to the HEL Casework Service:

- To secure further funding to maintain and grow the existing service, including offering more services, hiring more staff, and expanding HEL’s presence in the Royal London and Homerton hospitals beyond one day a week.
- Extending HEL’s early intervention services into other hospitals in the London area.
- Developing the peer support service to include the training and eventual hiring of more peer support workers. This might include developing peer-to-peer training sessions.
- Extending brain injury support to the prison population. HEL could have a presence in London prisons to help identify and provide support to inmates with head injuries.

One idea I’ve had is that I think we need to expand. I think we need more. As we’re getting more popular and getting in the hospitals more, then more work is coming out of it. What definitely needs to happen is that funding should continue, without funding we’re not able to work. So if they can carry on supporting the casework team, we can then in turn support more people. You’ve got to bare in mind the amount of people who’ve had a head injury and who are suffering. We’re just...
touching a little bit of it with our work. If we get more funding we can develop and grow and reach more people.
- Peer support worker 1

It would be good if more people from Headway could work towards being a peer support worker. We could develop a training programme to do that. I know that takes a lot of support, but if the money was there that would be good. Because it's a good goal for survivors to work towards and it's so rewarding. I also think it would be beneficial if Headway could be in more hospitals. The consultant doctors I've spoken to in the past all think that peer support is key to the patient's recovery. And I think it helps save money in the NHS as well. Because if you leave people out there without support it means that they have to ask for more help from elsewhere and rely on other services. Maybe they get ill or confused and it builds up.
- Peer support worker 2

I'd like to expand into prisons. I think there is a high percentage of people in prison with a head injury. So what support is in place for those people? As we do in hospital with early intervention, I think it would be good to do something similar with prisons. And again I thought that peer support workers could be helpful in prison. But that's the big picture. We're not really there yet at the moment. But that's my out of the box thinking.
- Peer support worker 1

**Key Stakeholder suggestions**
The eight key stakeholders interviewed for this evaluation suggested the following improvements to the HEL Casework Service:

- Extending the HEL’s presence at the Royal London and Homerton Hospital beyond one day a week.
- Extending the early intervention service HEL provides to other hospitals and trauma and rehabilitation wards in London to avoid a postcode lottery in terms of the support available to survivors.
- Identifying ways in which survivors with minor head injuries could be captured and contacted in the early stages of their recovery process.
- Providing support at the earliest stages of the hospital experience, such as having a presence and making first contact in intensive care units when survivors and family members can be at their most vulnerable.

_I think the massive gap in the service is the four days a week when Headway is not at the hospital. If there was somebody here more then once a week, that would be good. I’d also like to have someone who was able to identify patients in the trauma ward who sometimes don’t get referred to neurosurgery, but they’ve had a head injury. Many people with more minor injuries go home and find out that they’re not_
OK. Same in the emergency department. But most of all I’d like double or triple the amount of time Headway is in the hospital. That would make a significant difference.
- Consultant neurosurgeon

The only other thing that strikes me is that there’s an opportunity for developing this service beyond the Royal London hospital. There are many major trauma centres around the country where a similar service should be provided. So there isn’t this postcode lottery. I think we should consider the generalizability of this service and whether it can be expanded to other centres.
- Consultant neurologist 2

Survivor and carer suggestions

The 73 survivors and carers who contributed to this evaluation suggested the following improvements to the HEL Casework Service:

- To secure further funding to maintain and grow the existing service, including offering more services, hiring more staff, and expanding HEL’s presence in the Royal London and Homerton hospitals beyond one day a week.
- A handful of people felt that support for survivors and carers could be separated more. This would allow people to discuss and explore areas that they might feel uncomfortable or guilty discussing around family members.
- Extend the popular peer support group meetings to weekly rather than monthly sessions.
- Several survivors and carers felt there could be more clarity in terms of the different kinds of support that the HEL Casework Service provides. Several respondents said they were unsure when it was appropriate to contact HEL and ask for support. They felt that HEL could be clearer online or in their promotional material about the different services it provides.
- Several survivors and carers wondered if it would be possible to develop a “back to work” programme for survivors. This might include workshops, training sessions and volunteering opportunities that would help build confidence and provide ideas for and pathways to future employment.
- Several survivors and carers thought they would benefit from evening events organised around presentations given by experts in the field of brain injury. People thought that they could benefit from information and question and answer sessions.

It would be really great if they did something to try and get you back into work in some way, either a volunteering programme or maybe some training sessions. Maybe Headway could hook up with local
employers willing to hire people with brain injuries part time? You know ideas like that. To get back into work would be lovely.

- Craig (survivor)

I think Headway could do events with speakers. Like if they could get a doctor in or something to talk about brain injury and we could all ask questions...I often forget what I want to ask you know when you go to the doctors and it’s quite quick and they rush you a little bit, so it’d be brilliant to have an opportunity to someone who is knowledgeable questions.

- Gillian (survivor)

Initially the support group was for carers only, then it opened up to everyone and I’ve felt that’s a bit difficult. If you had a problem as a carer you might not want to open up to survivors about that, especially to the person you care for. I wonder if Headway could separate these groups again?

- Karen (carer)

I know Headway can help signpost, but I never know if it’s appropriate to ask them to help me fill out forms, or attend appointments or argue our case. Maybe Headway could be clearer about the different kinds of support they provide.

- Virginia (wife of Joe)

I think maybe they don’t have enough caseworkers. They can seem very busy. They need more resources, the monthly group sessions could be weekly. The service is there, and it’s good, but they could provide more of everything in my opinion.

- Paul (survivor)
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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 HEL’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 East London 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 HEL 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 East London and First Steps can do: Survivors and their carers thought that HEL 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 HEL. Interviewees thought there was some ambiguity about whom HEL supports and what its remits are. Survivors and carers thought that HEL could be better promoted in London hospitals and rehabilitation units.

Survivors and their carers also came up with a number of additional bright ideas and suggestions for HEL 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 HEL 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 HEL 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>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Year of accident</th>
<th>Type of brain injury</th>
<th>Described impairments/symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tom</td>
<td>50s</td>
<td>2015</td>
<td>Haemorrhage</td>
<td>Blurred vision, short term memory loss</td>
</tr>
<tr>
<td>Lucy</td>
<td>40s</td>
<td>2015</td>
<td>Aneurysm</td>
<td>Limited mobility, language impairment, short term memory loss, confusion</td>
</tr>
<tr>
<td>Charles</td>
<td>30s</td>
<td>2015</td>
<td>Brain abscess</td>
<td>Paralysis down left side, slurred speech, memory, fatigue</td>
</tr>
<tr>
<td>Joe</td>
<td>40s</td>
<td>2014</td>
<td>Brain abscess</td>
<td>Seizures, paralysis down one side, language impairment, emotional and cognitive problems</td>
</tr>
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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 of 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 were 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
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.

Five survivors and their carers described being under financial strain due to cuts or changes to their benefits.

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 East London 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 wheelchair? 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 fatigues 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 East London 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 East London and First Steps can do

Finally, interviewees thought that HEL 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 HEL. Interviewees thought there was some ambiguity about whom Headway supports and what its remits are. Survivors and carers thought that Headway East London 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 in Hackney, 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**

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