

Better Together

Headway East London at the Royal London Hospital



Welcome from Dean - Peer Support Worker and brain injury survivor

Hello, my name is Dean. I have been living with a brain injury since 1998 and I am now a Peer Support Worker at Headway East London, a charity supporting people living with brain injury. If you are interested in hearing more about the journey after brain injury and what to expect, **this booklet covers some of the immediate questions you or a loved one may have after brain injury, whilst sharing some of the different ways you can access support.**



The Headway East London Team and Better Together

Better Together is Headway East London's project in partnership with Royal London Hospital to give specialist support to survivors and their families in the early stages following brain injury.

The team is made up of four Caseworkers: Natalie, Penny, Kai and Saul. They can help with advice, advocacy and support whilst you're here. Then you have me (Dean) who brings my personal experience, so we complement one another!

How to contact us: The Casework team will be in the hospital on **Wednesday afternoon (on 12E & F)**. Check in with the clinical team if you think we can be of some help - they can direct us to you. You can also email us: casework@headwayeastlondon.org or call **020 7749 7790**.

A bit about my story: I acquired my injury through an assault, leaving me with a blood clot which needed to be removed immediately to relieve the pressure on my brain. I was in a coma for three weeks and in rehabilitation for six months. I left the hospital still in a wheelchair and with a big journey ahead of me. After a while I was introduced to Headway East London, where I became Peer Support Worker. Over the years, I have become an example of what you can achieve through having the right support, a sense of determination, and motivation. I still get cognitive fatigue, I still forget things, don't sleep properly, I feel lonely and depressed - the list is endless... Unfortunately, that's the nature of the injury but guess what? There are things that can help! "What?" I hear you ask...

In the next pages, I will explain what a brain injury is, what support is available and how to access it.

What is brain injury?

An acquired brain injury (ABI) is an injury caused to the brain post-birth.

There are two types of acquired brain injury:

- a traumatic brain injury is an injury to the brain caused by a trauma, like falls, assaults, motor vehicle accidents or sports injuries
- a non-traumatic brain injury is an injury caused by internal factors, such as strokes, aneurysms or tumours.

The effects of a brain injury can be wide-ranging, and depend on a number of factors such as the type, location and severity of injury.



Effects of brain injury

The more severe the brain injury, the more pronounced effects are likely to be. Survivors of more severe brain injuries are likely to have complex and long-term problems affecting their personality, relationships and their ability to lead an independent life.

Even with good rehabilitation, support and help in the community, survivors and their families are likely to face uncertain and challenging futures.



Common changes and challenges after brain injury

- Headaches and dizziness
- Memory impairment
- Mobility issues
- Extreme fatigue
- Lost sense of self
- Lack of insight and awareness
- Speed of information processing
- Speech and language challenges
- Increased anxiety
- Lack of motivation

This is not a full and extensive list; many effects of brain injury are hidden and can manifest some time after the initial injury.

Headway UK, the national brain injury charity, have published many detailed booklets and factsheets covering a wide range of issues following brain injury. The Casework team are happy to access these for you and print them off.

Medical and clinical questions

If you have any clinical questions regarding your care, or the care of a loved one, we advise you to please seek out a clinician involved in the care. However, we are happy to liaise on your behalf and link you in with the relevant medical team if you find this challenging. Please note, the Casework team are unable to answer specific medical-based queries.

Rehabilitation after brain injury

Rehabilitation means to re-learn. “Inpatient Rehabilitation” is intensive, specialist rehab for people who are not yet ready to return home. Following this intervention, some patients may then transfer to a residential unit to build further independent living skills.

Remember everybody is different

We are all born differently, which makes the world such a wonderful and interesting place to be. This is the same after a brain injury. There are no ‘rule books’ and guarantees. We understand it feels frustrating when clinicians cannot tell you exactly when you’ll feel better. The reality is that recovery takes time, rest, hope and patience.

Outpatient and community rehabilitation

If you are able to go home, the hospital can refer you to receive community rehab. This is time-limited rehab within the home and in your local community; building up the skills you need to be as independent as possible. You may also be invited to outpatient clinics at the Royal London.

Discharge process - what support is out there?

We can support you or your loved one with information, advice and emotional support regarding the next steps following discharge.

We recommend that if being discharged home, you contact your local authority. They have a duty of care to assess you and your family to see whether you would like or need any additional support within the home. They should then generate a care plan to meet these specific needs. We also run **regular support groups in Hackney and Romford** where you can meet other survivors and pass on/receive guidance and support in a safe environment. We also run a meditation group online which gives a space for wellbeing and relaxation as well as learning focused meditation techniques. If you would like more information about either of these please speak to our **Casework team**.



Benefits

There may be benefits you are entitled to following a brain injury and whilst work won't be top of your agenda, if you are losing income there is financial support available. The main two are PIP (Personal Independence Payment) and UC (Universal Credit) and our Casework team are happy to provide more information regarding these.



Headway UK and Legal Advice

At Headway East London we currently only cover 13 boroughs across East London, however if you are out of our catchment we are always happy to signpost to relevant services, and support you in this process. The best way to start is to contact **Headway UK**. On their website you can find brain injury support and services in your area: <https://www.headway.org.uk/supporting-you/in-your-area/>.

You may want to explore whether you or your loved one are entitled to a compensation claim following an injury. There is a wealth of guidance and legal support out there. The Casework team would be happy to explain more, and you can find a full list of approved solicitors on the **Headway UK website** (www.headway.org.uk).

Headway UK Emergency Fund

For immediate financial assistance Headway UK operates an Emergency Fund, which helps with the practical implications of a sudden catastrophic brain injury. Grants up to £500 are available to support with travel costs (visiting relatives), financial hardship, emergency accommodation costs etc.

The Casework team are happy to help you apply for this.

Headway UK phone number: **07585 102987**

Headway UK email: emergencyfund@headway.org.uk

Goodbye from Dean

Well I hope you found this useful. I know there is a lot of information here and it can be overwhelming, but we are happy to explain everything in further detail if we get to meet you!

All of this information can be useful for families as well, so if you are supporting a loved one after brain injury please feel free to come up to chat to us.

Please let us know if you want to chat. You may just need some emotional support, and I am here for you. Honestly, when I had my injury, I had no-one to turn to who understood what I was going through. I would like to leave you with one more advice: try making a ROUTINE. A routine can help in so many different ways. The biggest challenge is adopting one, and there is no blueprint; you need to find what works for YOU. If you want to talk about this more, we can. What can a routine do? It can help you to manage your life better. In fact, I recommend trying it regardless of brain injury!

I look forward to meeting you! Remember, you are not alone and we can help.

It's Better to Be Together

If you would like this booklet translated please do let a member of the Casework team know.

Thank you to brain injury solicitors
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