



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. For you to be reading this booklet you must be interested in hearing more about the journey after brain injury and what to expect. Well let me tell you, as someone with who has been living with a brain injury since 1998...



A little bit about my injury and how it started...

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 had a subarachnoid haemorrhage (a bleed between my skull and brain). I was then in a coma for three weeks and in rehabilitation at the RNRU (a specialist rehab ward at Homerton hospital) for six months. I left the unit in a wheelchair and with a big journey ahead of me.

The unknown is scary and I understand, but guess what? We, Headway East London, are here for you! My life has changed from being ugly and bad, to the present which I say is good! I was introduced to Headway East London (HEL) who have been a big part of my achievements to date.

At HEL I have become an example of what you can achieve through having the right support, a sense of determination, and motivation. All these things are hard and I'm a firm believer in the mantra 'you only get out what you put in'. In fact, it helped me in applying for my current job as a Peer Support Worker at the charity.

I still get cognitive fatigue, I still forget things, I 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...

It sounds simple and maybe boring but 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.

What I've just covered above works for ME but remember: no two injuries are identical, as we explain over the page....

We (Headway East London) have written this booklet to cover some of the immediate questions you or a loved one may after brain injury, whilst also sharing some of the different ways you can access support. You can find all of our contact details on the back cover.

The Headway East London Team

The HEL team at the hospital is made up of three Caseworkers: Natalie, Daniela 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 perfectly.

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.

The Casework team will be in the hospital on **Wednesday afternoons (on 12E & F)** so please come and say hello if you see us! Please also 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.



What is brain injury?

An acquired brain injury is an injury caused to the brain post-birth. There are many different causes; road traffic collisions, falls, strokes, assaults.

Traumatic brain injury (which many people also call head injury) is an injury to the brain caused by trauma. 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 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.

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. Just ask the lovely Dean!

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.

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. If you would like more information about either of these please speak to the 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 the Casework team are happy to provide more information regarding these.



Legal advice:

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; and plenty of firms who specialise in brain injury. The Casework team would be happy to explain more about this, and you can also 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; this exists to help 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 and more - please see their website for more information. The Casework team are happy to help you apply for this.

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 also feel free to come up and chat to us. We may also pop along and say hello if we think we can help.

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.

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 Bolt Burdon Kemp for sponsoring this project!

BoltBurdonKemp

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