

Headway East London – Early Intervention Project

Headway East London is a charity supporting people affected by brain injury. Working across 13 London boroughs we offer specialist support and services for survivors and their family. We offer therapies, advocacy, family support and community support work alongside our day service: a community venue where people can make the most of their abilities and interests. Our vision is to build a community where people with brain injury are valued, respected and able to fulfil their potential.

The Headway East London Royal London Hospital Early Intervention Project supports families of brain injury survivors in the first stages of care and rehabilitation.

An experienced Headway staff member has been holding weekly drop-in sessions at the hospital since late November 2015, providing advice and information to families with loved ones in the early stages of care and rehabilitation.

These sessions also act as a peer support network for those experiencing similar issues.

The project offers assistance navigating the health & social care system, exploring benefits & entitlements and signposting to other specialist services

The project aims to improve beneficiaries' stability and wellbeing and to help reduce the psychological, financial and personal crises that so commonly affect families and patients as they return to the community.

The project is the result of a four year Reaching Communities grant from the Big Lottery Fund, and includes the appointment of 2 Peer Support Workers, roles which (among other things) offers survivors and their families a personal insight into the issues they may be experiencing.

**Headway East London's Early Intervention Drop-In at the Royal London Hospital runs every
Thursday from 2 - 4pm**

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Early Intervention Project Overview

Aim: The Project provides Information, Advice and Support (including emotional and practical support) to families of patients who have endured a TBI/ ABI in the Royal London Hospital.

Overview of Project: The project complements existing statutory services by providing information and advocacy to people affected by BI. It strives to improve continuity between inpatient care and community support and reduce confusion among beneficiaries by providing them with a link person who can liaise with other agencies and staff. The project helps people connect socially, gain peer support and access the rehabilitation and financial benefits they need. It will strive to reduce stress, prevent crises, and ultimately aim to help families develop resilience and stay together. The project can provide this level of support to any family that has a Traumatic /Acquired Brain injury diagnosis within the RLH.

The project does all this by providing opportunities for families to come, on a regular basis, to a set location, which is a space for them to discuss issues resulting from a BI.

This may involve all or some of the following as appropriate:

- Creating a welcoming space for people to come for a tea/coffee, a chat/ seek emotional support
- Providing Information, Advice, Support & Advocacy relating to accessing health and social care services, entitlements, benefits, rights etc.
- Signposting to appropriate specialist services regarding finances, employment issues, legal support, victim support, Housing concerns etc.
- Signposting to other Headway East London services as appropriate
- Linking families in with Family support service & others who are/have experienced BI
- Assisting with planning for discharge & being a support through the discharge process
- Assisting with creating links to appropriate community supports & neuro-rehab
- Signposting/linking families in with other Headways nationally
- Exploring the potential to offer Peer support to TBI patients and/or Family Members

Referring: The main source of referrals comes through hospital staff directing families towards the project and a secure referral procedure is in place for this.

Advisory Group: An Advisory group is in place to provide guidance and practical solutions to assist the project. This group meets when necessary and consists of key staff including the Headway Casework Manager, the RLH Consultant Neurologist, the RLH Senior Nurse for Neuroscience & Trauma and the RLH Clinical Nurse Specialist for Neurotrauma. The main point of contact regarding the project is the Headway Casework Manager

Evaluation/Monitoring: An external evaluator from the London School of Economics has completed a baseline study in mid-February 2016 and will be developing a detailed evaluation to measure the progress and outcomes.

London School of Economics - Baseline study Overview (Feb 2016):

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

This information will feed into the development of Headway's new Early Intervention 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 Early Intervention Programme.

Twenty brain injury survivors and/or their carers, who had little or no previous contact with Headway, and its support services, were interviewed and asked to consider their experiences from the day of the injury to the present. The feedback and recommendations (relevant to the Royal London Early Intervention Project) made by these survivors and their carers are summarized below:

Findings

- **The hospital experience:** Survivors and carers described struggling in hospital due to difficulties communicating with the medical staff and understanding medical language. 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.

Recommendations from the LSE Exploratory Report

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 challenges that they would be facing.

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

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

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