

## Harbour Map

We are a group of people with an Acquired Brain Injury. In this document we want to:

- Communicate what it is like to have an Acquired Brain Injury
- Indicate what we need to participate in society and show where existing services fail to support us in meeting those needs
- Propose some practical solutions and ways forward

### About Acquired Brain Injury (ABI)

There is very little general understanding of Acquired Brain Injury both in the general population and within the medical profession.

Acquired Brain Injury is a “silent” condition. Damage to the brain is not necessarily visible. Because of this we often feel that our condition is not recognised and that we are not taken seriously enough. Some of us have found that because of the lack of signs of visible damage many service providers say there is nothing wrong with us. Also, because of our injuries, many of us have difficulty explaining what our problems are. This leaves us sometimes feeling under-served and misunderstood.

It is easy to overlook the “walking wounded”.

### Some symptoms of Acquired Brain Injury

Every brain injury is unique and effects can vary greatly in severity and type. Symptoms can also vary over the course of time. Some of the common effects of an acquired brain injury are:

- fatigue, which can be chronic
- the lack of ability to concentrate
- difficulty with language and with finding the right words or explaining things involving numbers, dates and times
- difficulty dealing with distractions in social situations
- difficulty processing information such as reading or taking in detailed instructions
- forgetfulness to the point where it can be dangerous
- inability to tolerate bright lights or sunshine

### What it is like to live with the consequences of Acquired Brain Injury

We find that having to deal with chronic fatigue severely restricts our family and social life. We need far more time to rest than we did before our injuries, some times up to sixteen hours a day. This leaves us with much less free time to spend with family and friends. During our active time we can tire easily and be less productive in performing even simple tasks.

Because of our difficulties with language and memory, everyday activities such as having a conversation, answering the phone, watching TV etc, can be very frustrating for us. Some of us can think very clearly but can't articulate our thoughts. Some of us mix up our words a lot and even fail to recognize people who seem to know us very well.

Many of us have to manage our time very tightly and stick to routines to maximise our limited energy. Deviation from these routines can leave us exhausted and sometimes physically sick. Physical afflictions resulting from our low energy can include itchiness, nausea and dizziness. For those of us coping with epilepsy or chronic pain, deviation from routine can be utterly debilitating.

Engaging in recreational and leisure activities necessitates a major effort and many of us find holidays abroad impossible.

Many of us have restricted opportunities to work, even voluntarily and for those of us who do, promotion opportunities or career development are often out of the question.

One member of our group has experienced homelessness as a direct consequence of an ABI injury.

## **Our experience with ABI**

We acknowledge that imagining what it is like to have an Acquired Brain Injury is impossible for most non-injured people, regardless of their desire to be sympathetic and regardless of how medically or psychologically qualified or how vast their expertise. Because some of us can function "normally" for short periods of time, others can fail to understand the severity of our injury or the extent of our fatigue.

We are adversely affected by the limited nature of the neurological and rehabilitation services in Ireland. In hospital, most of us were given little or no appropriate information or literature from social workers about any specialist medical or rehabilitation services. We suffer from the lack of information about Acquired Brain Injury and services compared to what we know to be available in other countries.

We have had some difficult experiences with specialist health professionals, some of whom display a lack of knowledge, interest, understanding or empathy with our situation. On occasions, we have experienced this as a distinct antipathy, which we find hard to understand. Some of us have also experienced a lack of confidentiality in dealing with our personal stories. Some of us have also experienced a lack of sympathy when encountering civil servants.

In the early stages of our condition, we have not had easily accessible information on our rights and entitlements, especially financial issues. Later on in our recovery, many of us lack the energy or brain function to deal with employers and lack advocates who could negotiate on our behalf.

One of us has spent years trying to source entitlements and was told by a hospital social worker to contact the Citizen's Information Centre which, in turn, said to contact a social worker. Social work support is not available to someone who is not in hospital.

## **Our needs**

There is a general lack of awareness of the effects of Acquired Brain Injury and their severity.

A purely psychological or neuropsychological approach isn't always enough and some of us suffer from the lack of medical expertise which would complement these approaches. We need a balanced approach.

What information does exist about rights and entitlements is piecemeal and not collated in a manner useful to us. There is no widespread advocacy service for people with ABI to assist us in getting information about our entitlements and to assist us in getting our rights and entitlements addressed.

We believe that a lack of research contributes to the continuing lack of understanding of brain injury amongst the public and health professionals alike.

There is insufficient psychological support for people with ABI. We need more access to psychotherapy.

There is insufficient financial support for people with ABI.

Neurological and rehabilitation services are in very limited supply especially for those of us who have a high level of cognitive ability.

We need strategies to help us to deal with, or minimise the effects of, fatigue. We also see a need for more information on the medical causes of fatigue, e.g. abnormal glucose metabolism.

We need more training services and supports to help us get back into the workplace. We also need support in dealing with employers and educational institutions. We need opportunities to develop computer skills.

We need social workers who can deal with issues we experience.

## **Our recommendations**

Establish a Benefits Advocacy Service for people with Acquired Brain Injury. This confidential service could help us:

- Advocate for better neurological and rehabilitation services
- Understand and access rights and entitlements particularly in the early stages of recovery
- Improve general understanding of Acquired Brain Injury and the nature of our disabilities
- Negotiate the challenges we face in financial and employment issues
- Help us liaise with educational institutions

We would like to see this service available by telephone and email as well as by individual appointment. We would also like to see the involvement of people with Acquired Brain Injury in the running of the service.

Employ more medical professionals and people with academic expertise who have an acquired brain injury so that they can use their unique experience of having an ABI when working with us.

Improve the medical research on the causes and treatment of ABI

Include our group on mailing lists for notices about research seminars and developments that affect people with Acquired Brain Injury. We are the ones who most need to learn about our condition.

All seminars should create an opportunity for us as people with Acquired Brain Injury to present our opinions and afford a constructive critique of the seminar from an ABI perspective.

We need greater empathy and understanding from the specialist professionals that we encounter whether in the health system or in the civil service. Training which could involve Brain Injury advocacy groups could address this need.

We would like to see all information about rights and entitlements collated by one organisation and presented on a user-friendly website.

Every hospital should have a dedicated person to inform all patients with ABI of their rights and entitlements.

We want a full inventory and assessment of the allocation of state resources for Acquired Brain Injury so that people with ABI and a high level of cognitive ability be included and catered for.

The Harbour Group, June 2007