Adjustment after Brain Injury – how?

The process of adjustment is a journey unique to each person affected by brain injury yet when sharing experiences key stages do emerge corresponding to those shown in the diagram above. Naturally the journey and the length of the journey in terms of the person's adjustment is related to severity of impairment. However other factors are also important which will be discussed here. I will concentrate first on the first few stages, to the lowest point in the curve above and on discussing why the process typically happens this way.
If the accident or incident was severe enough to be perceived as life-threatening it is common for the person to experience a stage where the feeling of relief at having survived and even a sense of elation is dominant. However when the brain injury is severe the person may for a stage be too confused and cognitively affected to experience this. It may however come later when awareness and cognitive function improve enough for them to process information, e.g. realise they are in hospital, and remember that they have had a brain injury. It is not at all unusual in the stages before this for the person to be unaware that they have had a brain injury or even be aware of their surroundings. Thus especially in head injury some patients have quite elaborate explanations for their surroundings, i.e. that they are working in the hospital, and many others will attempt to leave or declare their intention to. Where brain injury is accompanied by significant physical problems, either as a direct result of the brain damage sustained, or due to other injuries sustained at the same time, e.g. in a car accident; it is common for people to focus on these rather than the neuropsychological consequences of the brain injury. A person may therefore be aware of physical problems but unaware of changes in behaviour, cognitive functions and social functioning. In part this is because these changes are much more dramatic and obvious. Thus being unable to walk or use one side of your body, is apparent in a way that loss of memory or inability to problem-solve easily are not. The focus of rehabilitation for patient, family, and therapists and doctors is equally usually upon any significant physical problems in the early stages. It is these problems which are going to limit the person's ability to leave hospital safely, perform activities related to self-care, and perform activities of daily living. Thus often physiotherapy and occupational therapy will dominate the person's rehabilitation programme, unless their brain injury is such that it interferes with progress in these areas, e.g. severe disinhibition or challenging behaviour, or emotional reactions. As time goes on however it usually becomes apparent that cognitive problems are also interfering with activities of daily
living. Thus the person may well be unable to remember the names of therapists, or find their way around the hospital.

It is usual now for some cognitive screening to be carried out in hospital. This may for some people be the first realisation that they are unable to think and remember things as they did before. Other people however may perform well below expected ability and still lack insight into any change. There are other problems that people typically do not associate with brain injury and require education about brain injury to help explain. These include vulnerability to fatigue, irritability, lability in mood, i.e. quick changes in mood for little reason, and personality changes. Equally families often do not expect or understand these changes.

Those people who spend a significant amount of time in hospital may show a particular difficulty in accepting cognitive changes due to what appears to be a kind of 'magical thinking'. This is characterised by those patients who may say that some or sometimes all cognitive or psychological changes are a result of being in hospital and will disappear when they return home. The main goal is usually discharge in any case, but such patients need careful follow-up, because on returning home it is extremely rare for problems to disappear.

Outside the protected environment of a hospital it gradually becomes apparent that certain difficulties are more persistent. In the first few weeks and months after brain injury patients tend to make quite rapid progress which then slows down. By the six month stage it is much easier to evaluate which problems are likely to be the main ones which will limit return to the life lived before the brain injury. Full neuropsychological assessment is therefore usually carried out between four and
six months, often later for medico-legal purposes. It is often thought that brain injury affects all cognitive functions equally. However certain functions are more likely to be impaired than others, and dependent upon the type of injury it is more usual to see a pattern of strengths, or relatively intact functions, and weaknesses signifying particular deficits.

For those patients who spend only weeks in hospital, or are not kept in more than a night or two, changes in functioning can be particularly dramatic on return home. Families often assume discharge a marker of expected return to normality and it may be shocking for all to realise the opposite is more likely. In the home environment both the person with brain injury and their family expect them often to carry out the same role as before, or to do the same things and adopt the same lifestyle as before. Instead what they often find is a person either avoidant of social contact or who behaves in a different way in social situations, ranging from ready irritability to frank inappropriate behaviour. Relatives may find the person very egocentric, focused mainly on their own needs, lacking in empathy towards others, and lacking in insight of this.

Without education, advice, and intervention, the complex myriad of changes in ability, behaviour, role, and personality can become overwhelming for all concerned and out of control. Children are particularly vulnerable in terms of having their own needs which demand to be met, which they cannot meet themselves, and in terms of not being equipped to understand what has happened. Thus unless it is explained carefully why dad is getting angry all the time, becomes short-tempered every time they bring friends round to the point of embarrassment, or now withdraws to another room at every opportunity, such behaviour will be scary, cause resentment and withdrawal in turn, and be profoundly upsetting for the
child. For the uninjured parent there is the burden of suffering the changes directly, and trying to perform a double role or shield the children from hurt or upset.

Thus the main role of rehabilitation at this stage is to provide education and information, warn of the possibility of certain changes, so that those with the brain injury and those around them can see the changes as symptoms of brain injury, in the same way sneezing is a symptom of cold. This is not to minimise the significance of such changes but to encourage the family to see them as difficulties to be managed or where different strategies should be adopted to minimise difficulty or work round things. A good example is fatigue. If not addressed and allowed for it will result in irritability and reduced ability to function cognitively and physically. A gradual process of increasing activity, a regular pattern of activity and relaxation, and giving the person permission and somewhere safe to go when they feel like 'opting out' is vital.

Many difficulties early on can be managed but not prevented entirely by timely intervention and advice. This will in turn prevent or minimise secondary difficulties, which occur as a reaction to the primary ones, such as relationship breakdowns.

Many people who suffer head injury or brain injury receive no psychological advice or help at all and neuropsychology is a scarce resource. But helping the person and those significant to them to understand and discuss how they feel is essential in reducing risk of severe depression and anxiety and in paving the way towards as good an outcome as possible.
To understand loss and adjustment it will be useful to return to the analogy of life before brain injury as a journey in a safe boat, with others to help, with an imagined or known destination, and the resources to look after those on board. There will be tools to fix problems, maps to navigate by, and steady progress to feel good about.

After a brain injury, when the knowledge and elation of the storm having passed without loss to life has dimmed, comes the gradual realisation that this is a very different journey. Things on the boat which kept it going smoothly, without even realising they were important, are gone or in short supply. Things like energy, motivation, confidence, are almost gone. When the storm passes and the sea calms, the person begins to realise they are actually not moving much anymore, the momentum of the waves has gone. Gradually can come the thoughts that this is either not their boat, or not a boat they can sail anymore and that they have no idea where its heading, or if this journey is even worth making. The person becomes aware of what the storm threw overboard, now miles behind and
irretrievable. It is not uncommon to wonder if a boat this empty is worth keeping afloat when so much has been jettisoned. Sometimes people only reach this conclusion after trying desperately to resume their normal life, i.e. by returning to work, etc. It may take several failed attempts with increasing loss each time before they collapse exhausted on the deck.

People typically report changes or loss in the following areas

**Relationships**
Change in balance or role in relationships, e.g. less control, dependence
Reduction in number of significant relationships
Difficulty in forming new relationships
Loss of interest in relationships
Estrangement, the sense of being behind a wall or separated

**Activities**
Reduction in number of activities carried out in various areas of life e.g. both at home and outside, hobbies and interests
Loss of interest in activities, reduced motivation to complete, seeing no point
**Mood**

Low mood, lability, hopelessness, or 'numbness', wish to feel strongly but somehow cannot, may express desire to cry but unable

**Anxiety**

Fear of situations where difficulty or deficits may be exposed

Associated avoidance of activities or situations which trigger negative feelings and thoughts or those which remind person of losses

**Anger**

May be inward, focused on self, or outward, focused on others

May be presented as having reduced 'setting' before anger switches on

Reduced tolerance for frustration, queues, road rage, disagreements

**Others**

Loss of identity and reduced self-esteem, not sure who one is and failure to value self

Sense of foreshortened future, sense of heightened vulnerability to future events
More Concrete Changes

- financial
- mobility or function, e.g. speech
- role, e.g. inability to provide for family
- loss of occupation, job
- not being able or allowed to drive
- not being advised to drink alcohol, difficult in social situations

For the next day or two I shall leave the boat as it is, imagining it safely moored, with access to advice and help and return to discuss how rehabilitation and normal emotional healing can help the person move forward again.

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Thanks to my car accident the boat was moored rather longer than expected.

The question now is ?
What moves the boat forward again from being stuck? What factors are important in guiding the person with brain injury forward? What tools do they need?

I remember a realisation in my time as a therapist which I wish had come earlier. It was that sometimes a person is not moving
forward because it is not time yet for them, they are not ready to. As therapists we naturally want to set goals and see progress. But this is our need sometimes, not the need of the person we are treating. It is essential first of all before a person begins to move forward that they feel safe to. This will only happen if those important to them, including therapists, are able to honour the magnitude of their losses and the strength it has already taken them to get this far. If the reality of what they are experiencing is not just understood but honoured, it helps make therapy a safe place, by giving the person permission to mourn when they need to, rage when they need to, despair when they need to, and finally move on when *they* need to.

I forgot a whole step in the diagram heading this page. Its called 'uneasy acceptance'.

To return to the analogy of the boat. Uneasy acceptance happens when the person gets up from their collapse on the deck and begins to look around their mooring point and see it for what it is. Thus those storms on the horizon, they aren't going to disappear, they will have to be fought and weathered. The person then reaches a fork in the journey; either they stay moored forever where they are, or they begin to accept unwillingly the reality that somehow the boat will not turn around to the journey or life they had before, neither can they reinvent the boat or deny the damage. But they still have choices. Either they try to move forward and accept that life will be a different journey, the route and destination unknown for a while, or they are stuck. This is where rehabilitation is so important.

Remember crucially that if as we hope, the person is not alone on the boat, then those sharing the journey have their own
adjustment to make and it will happen for different people in
different ways and at different times. Thus rehabilitation should
involve family and their loss is to be honoured too, as is their
strength.

By beginning to take small short turns at steering the boat the
person with brain injury begins to recognise their limitations and
where their safe waters are, and where there lie undercurrents
or rocks, in the form of barriers to moving forward, such as
changes in ability which don't improve. But learning this can
take some time and is not a comfortable process. When the
person accepts that they are not going to recover the life they
had before, which is often the case, and realises the true effect
of their brain injury, or makes big steps in doing so, and
accepts also the need or desire to move forward then this is
'uneasy acceptance'. But it should not be mistaken for
adjustment, or happiness, or the end point. It is instead a
beginning.

People who have suffered brain injury describe it sometimes as
a process of re-creating the self or identity. Actually all of us do
this at major transitions in our lives, in smaller ways perhaps. A
woman or a man becomes a parent, a person who loses a
loved one is forced to re-create a life without that person.
Hence the person after brain injury is forced to re-create a life
without the 'old' self, or with the knowledge that it can only
partly be retrieved. Crucially what begins to happen, in the right
circumstances, is that the person begins in small, baby steps,
to re-invest in living again. This means acknowledging at some
level that there may be a purpose in carrying on. Also crucially
it includes the idea that the purpose is for them, not just for
others. It means beginning to imagine a different journey, plot a
course, or possible various courses, decide what tools are
needed to move on, and try to keep hope shining like a
lighthouse in the distance. Sometimes there will be clouds and the light will be gone. They may for a bit feel fear and hopelessness. The goal of a therapist is to find them concrete things or meaningful ways of thinking about the changes to hold onto when they can't see the lighthouse.

Concrete factors which are correlated with adjustment include good social support, particularly from family, activities which are meaningful or valued by the person, including activities outside the home and family, such as work, be it voluntary, or paid. A new hobby or interest is a good thing. Crucially research has found that people with brain injury themselves consider adjustment as linked to achieving these things. They also describe changes in what they value about activities like work, such as having a structure to their time, and giving opportunities for social interaction. Change may be seen in that after brain injury people value work because for them it equals a 'normal' activity, symbolising recovery. rather than being focused as before on achievements or status at work. Threats in the workplace have been identified as lack of feedback about performance and lack of structured support. Challenges to rehabilitation services are to be able to link the person with work opportunities which are attractive and meaningful to them, offering a range of choices, with support tailored as needed. This is vital when considering that many people will not be able to return to their previous job, or may not have had one.

A 'toolkit' for this stage of the journey includes strategies for managing depression, anxiety, and social situations. To many others by this stage the brain injury will be 'hidden'. The person may need space in therapy to practice or even role-play different ways of explaining to different people. This
usually means being able to do so without becoming upset or angry.

Gradually one achievement leads to another, the person grows in confidence and takes longer trips in the boat without having to stop so frequently. People say long afterward that they began to see compensations, or 'silver-linings' to their injury. This means they begin to create a new identity, based on what they have gained, not just focused on loss. Thus a person may reflect that their job before is no longer meaningful and retrain in an area of work they now value. This often involves helping others. Others may say that they learned to live in the present, to enjoy and value each day, not always focused on either past or future. Many say they valued the increased opportunity for spending time with children, or in leisure. As therapists its vital to remember that it is their journey and their course to navigate. It is also vital to remember that the losses will be felt and mourned repeatedly despite the boat having moved on. Even when it has gone a good distance every so often the person will still occasionally be overcome for a little while by the memory of what life was like before. Triggers for this can be things such as trying something new, e.g. a new career, and finding it too effortful, too far out of the safe zone. Accepting limitations and internalising them but not seeing them as unbearable any longer is a marker of change. A balance has to be found in steering the boat which accepts the differences in abilities or direction but no longer sees these as damaging or alien to their own self and identity, or demeaning when compared to others. But this is a long process.

Sadly there are still too many people after brain injury left to make their adjustment without the safety net of rehabilitation or even advice. Others are given a limited amount of help which crucially is often discontinued after a time-limited period, which
does not reflect the actual time needed for a meaningful adjustment process. Short-term rehabilitation where inappropriate is like taking someone into deep water and leaving them there before they learn to swim, especially if it opens them to discussing how they feel, but then leaves them without the tools to deal with those feelings. People also need to have services where they can return to when they reach another step upwards, or encounter change, such as moving away from family, becoming a parent, etc.

The good news is that it is never too late for rehabilitation or therapy to result in meaningful benefits, if it is provided by therapists who are expert enough to pick someone up along their journey and trace the complicated paths they will have taken since their brain injury occurred.