

# A head injury is for life



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What is the long term outcome after traumatic brain injury? How long do patients continue to improve? Once they have stopped making further improvements are patients then likely to slip back over the long term? How should services be set up to help minimise the disability? Over the last few years there have been several studies that have looked at these interesting questions.

We know that traumatic brain injury (TBI) is the leading cause of disability in those under 40 years such that about 150-200 people a year from every million of the population are left severely disabled. Patients who have suffered a traumatic brain injury often suffer with difficulties with memory, attention, executive function (ie organising, prioritising and monitoring ones thinking and problem solving), behavioural control particularly in terms of aggression and irritability, and regulation of mood. They may be unhappy and difficult to live with. Such neuropsychiatric sequelae are usually more troublesome than physical symptoms like ataxia or incontinence or slurring of speech.

The vast majority of recovery after traumatic brain injury takes place in the first two years after injury. In some patients further improvement in handicap is seen even as late as 5-10 years after injury. Thus some long term studies suggest surprisingly good outcomes. For example one study of war veterans who had suffered a head injury in the second world war showed no evidence of deterioration many years after injury. The psychologist who published this study suggested the good long term outcome might have been due to the expert and systematic care they received from very soon after the injury. But others have found that a proportion of patients are found to have deteriorated when assessed 10-20 years later. For example in Glasgow they assessed over 400 patients, most of whom had severe injury, 6 months after the injury. They



then followed them up 18 years later and found that twice as many (30%) had deteriorated as had improved (14%).

Because head injuries are most common in people aged 15-24 years, important developmental tasks, such as attaining independence from parental support, completing study and establishing a vocation, and forming social networks, are often disrupted. As a result, patients lose self esteem and become socially isolated and are a burden for their families. Regardless of the age of the patient, after a traumatic brain injury it is the changes in behaviour that represent the greatest source of burden to families. Patients may get into trouble with the law. Or the patient may avoid social contact because they find it difficult keeping up with conversations as a result of slowed information processing. This will contribute to their becoming anxious in social situations, quite a common symptom after brain injury. If the patient is self conscious for example because of facial scars or slurring of speech, then this will aggravate their social anxiety. Patients also report that they have a persisting sense of loss, due to failure to fulfil their dreams, and some patients describe how they feel that people in society make negative comments about them, perhaps because those people lack understanding of the consequences of head injury.

There is also a growing awareness of the high

incidence of long term psychiatric disorders following traumatic brain injury. Psychiatric disorders persist at 30 year follow up, with patients appearing to be particularly susceptible to depressive episodes, delusional disorder, and persistent changes in personality often with anxiety and substance misuse. It is not easy to predict who is going to run into psychiatric problems after a brain injury. It may be partly related to coping style; higher levels of symptoms are found in those who for example blame themselves, or try to ignore their problems, rather than actively deal with them.

The problems are often invisible; the patient may show little if any sign of injury. So people need to be taught about the consequences of brain injury and this is of course particularly important for families and carers. The brain injured person will then need easy timely access to a variety of services. In the UK there is a recent "National Service Framework for long term conditions" which specifies how services should be set up for people long term neurological disorders; it is particularly relevant for patients who have suffered traumatic brain injury. There is still considerable unmet need particularly for cognitive and psychosocial rehabilitation. In the end, it is the injured person, who must negotiate a lifelong journey with a brain injury.



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# Insight



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**Welcome** to this, our first edition of Insight specifically for the brain injury rehabilitation and neurodisability services of The Huntercombe Group. We are delighted to include articles which reflect the practical experiences within our centres. We hope to build upon these in future editions. Please contact us for further information on any of our services or if you wish to have more information about any of the articles in this edition.

## The management of spasticity

Spasticity is a common and disabling problem, particularly after stroke or traumatic brain injury but also in the context of other neurodegenerative diseases, such as multiple sclerosis. How should this troublesome problem be managed? The treatment should always be multi-disciplinary. The neurologist or rehabilitation physician should work closely with the neurological physiotherapist and usually with other relevant disciplines, such as an orthotist, nurse, occupational therapist and neurosurgeon. First, assessment is vital. Spasticity is a dynamic phenomenon that will vary according to medication, time of day, seating, positioning, etc. Thus, a prolonged period of observation is often required to determine trigger factors that worsen the spasticity. After a period of observation sometimes it is clear that very simple measures will help the problem. A key factor is often the position of the individual. A chair, for example, that is slightly reclined can often exacerbate extensor spasticity and the simple provision of a chair that keeps the individual upright will help the problem. The same principle often applies to wheelchairs with a reclining back. Proper attention to seating and positioning is vital and at this early stage a physiotherapist should be involved in providing such advice and helping with provision of suitable equipment. Often removal of other unnecessary exacerbating factors can also relieve the situation. These factors classically include tight clothing, catheter leg bags, skin infections or ingrowing toenails. In other words any unnecessary additional sensory input can worsen the underlying spasticity.

It is also important to note that spasticity does not always need treatment. Some individuals require the pseudo-strength of a spastic limb in order to support themselves whilst walking or to assist with self-care tasks, such as dressing. Spasticity can sometimes be useful to aid in transferring. If the stiffness of the spastic limb is removed then sometimes the individual is actually more disabled.

If simple measures are insufficient and spasticity still needs treatment, then the next decision is whether such treatment should be with oral medication or whether local treatment to a specific group of muscles is required. If spasticity is fairly mild and generalised then probably oral medication is the next best step. There is now a reasonable range of quite safe antispastic drugs that can be used. The commonest is Baclofen. It is certainly a safe and usually an effective agent. The dose required to relieve spasticity can vary considerably from individual to individual but is usually in the order of 40-60mg daily. The disadvantage of Baclofen is the induction of weakness and tiredness and these are often the main dose limiting features. Other drugs that can be used include Tizanidine and Dantrium. These agents, whilst usually effective, are also limited by tiredness and drowsiness and regrettably they need regular monitoring of liver function. Tizanidine probably induces less muscle weakness and fatigability but it is considerably more expensive than Baclofen. Diazepam is also quite a useful antispastic agent but induces significant drowsiness and is probably no longer appropriate for use in clinical practice. Two newer drugs are worthy of mention. Gabapentin has been available for a number of



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years and is mainly used as an anti-epileptic drug. However, it has antispastic properties as well as analgesic properties and it is useful for spasticity, particularly spasticity that is characterised by marked muscle pain. It is usually a safe and well tolerated drug which needs to be slowly increased to a maintenance level of around 1800-2400mg although the dose can go as high as 3600mg. Another effective antispastic drug that should be more widely available on prescription in 2007 is cannabis. This is likely to be marketed as Sativex.

Continued on page 2...



INSIDE: Traumatic brain injury by **Dr T Stephan**. Early management of spasticity by **Dr A Weir**

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This is a 'purified' form of cannabis that contains the two main cannabinoids (THC and cannabidiol) which have antispastic and analgesic properties. It is currently available on a named-patient basis and we are awaiting its full UK licence. It is available as an oro-mucosal spray and individuals can titrate their dose against the efficacy. Usually around 10-12 sprays per day are required.

Thus, there is a reasonable range of anti-spastic medication but all the drugs are often limited by unacceptable weakness and/or fatigue.

Often spasticity is focal rather than generalised. In other words it just affects a few muscle groups in one or two limbs. In such circumstances oral medication is less useful and targeted treatment to the affected muscles will have a better effect. The focal treatment of choice is now botulinum toxin. It is a very effective and safe antispastic agent which is easy to administer and virtually free of side effects. The technique simply involves intramuscular injection of botulinum toxin into the affected muscles. Whilst it is simple, some experience of the dosage and muscles to be injected is required and unfortunately availability is quite variable across the country. It does have some disadvantages. First, it is expensive and second, the treatment wears off after around

three months and thus for ongoing spasticity the individual will need regular re-injection. However, many would now consider botulinum toxin the first line treatment for the management of more severe spasticity.

An alternative focal treatment is the use of phenol



nerve blocks, which are slightly more difficult to administer but nevertheless the treatment is much cheaper and can be longer lasting. However, there are now few centres in the UK that undertake such injections.

What other treatments are possible? Many spinal cord injury and rehabilitation centres use Intrathecal Baclofen. This can be a useful and effective technique but obviously requires surgical

intervention and there are risks of both operative and post-operative complications. We now make a referral for implantation of an Intrathecal Baclofen pump around once a year from our centre in Newcastle-upon-Tyne for the few individuals who are not responsive to either oral medication or botulinum toxin. The technique requires the implantation of a pump under the skin with tubing leading into the intrathecal space. The pump delivers a variable amount of Baclofen to the spine and the dose can be adjusted externally by computer.

Untreated or poorly treated spasticity often eventually leads to muscle contracture. At that point the only method of treatment is surgical correction. Unfortunately many people who develop such contractures are not the best candidates for surgery and thus there are many people who remain severely disabled, and often in pain, because of badly treated spasticity. Overall there are now a number of modern techniques to alleviate the troublesome and often painful symptom of spasticity. The assessment and treatment should always remain multi-disciplinary and with such an approach the great majority of people with spasticity can be effectively treated.

Barnes MP, Johnson GR. (Eds). Upper motor neurone syndrome & spasticity – clinical management and neurophysiology. Cambridge University Press, Cambridge 2001 (2<sup>nd</sup> Ed due 2007).

## Traumatic brain injury (TBI) represents a heavy burden in terms of human and economic costs

Head injuries requiring hospitalisation occur in the UK at the rate of about 275/100,000 population annually. Within this overall figure there is considerable variation in different parts of the country between urban and rural communities and between age groups, with peaks at 15-24 and > 75 years. Moderate to severe brain injury is estimated to occur in 25/100,000 people per year of which: 2-4 (10-20%) patients are likely to have severe disability or prolonged coma. 18-22 (65-85%) will have had a good physical (but not necessarily cognitive or psychological) recovery.

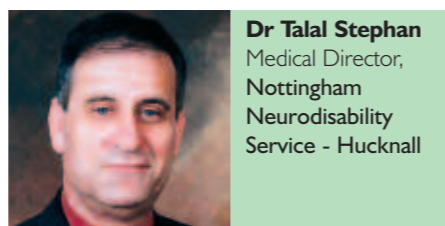
As a consequence the issues concerning rehabilitation management of brain injured patients are gaining more and more attention. Attention is required to the physical, psychological and social consequences.

The psychological consequences are very common and may be more problematic in the longer term than physical disability. They can be categorised as cognitive, emotional and behavioural problems but quite frequently coexist and can be difficult to disentangle from one another. The nature of any cognitive deficit depends to some extent on the severity and location of injury and may include difficulties with memory, concentration, initiation, planning, problems solving etc. Limitations of patients' insight and communication may affect their ability to engage effectively in rehabilitation.

Working with family members of those patients is important and it is essential to understand their feelings and the pressure they are under. Many of them have the sense of not doing all that they can for their relative. It requires much time and effort

meeting them, listening to their concerns and questions and explaining in simple medical language what is wrong, what treatment is needed and what are the latest developments in their condition. One Centre within The Huntercombe Group is the Nottingham Neurodisability Service - Hucknall, caring for adults from 18 to 65 years. There are 3 units: Fernwood Unit is a 20 bed high dependency nursing unit for patients who sustained severe brain damage as a result of an accident or of neurological diseases. Many patients are in a low awareness or persistent vegetative state. The unit has recently accepted their first ventilated patient and is soon to admit a second. Highly skilled staff provide a therapeutic and rich environment in a homely setting, which is very different to the usual NHS intensive care facilities for people needing this specialist type of care. Rosewood Unit is a 32 bed unit providing care for residents with complex neurodisabilities, and presently has a waiting list. As with all of the units, Rosewood provides holistic care focusing on social activities, living skills and life long learning. Millwood Unit is another 20 bed brain injury unit within the centre caring for patients with challenging behaviour resulting from brain damage. Referral to the centre comes from the main hospitals in the region, as well as from hospitals around the country and from Social Services.

An excellent multi-disciplinary team, including rehabilitation specialist nurses, physiotherapists, speech therapists, psychologists and doctors and managers, is essential for working with this very challenging group of patients. Many times working



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in these units feels like working in an intensive care unit where patients can deteriorate very quickly as a result of oxygen saturation drops or cardio-respiratory arrest.

Over the years, wide experience has been gained in managing complex and severe challenging behaviour. The service has gained an excellent reputation both regionally and nationally for caring for severe brain injured young patients requiring short, continuing care or slow stream rehabilitation. Outcomes for seating, pain control, stimulation, quality of life and social activities are excellent. Patients' and families' satisfaction are high.



## Early management of spasticity in brain injury



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The management of skeletal muscle spasticity and its sequelae following brain injury of any type, prior to transfer to a rehabilitation unit, is variable in quantity and quality. Most brain injured patients are initially found in acute medical, neurosurgical or neurological units for the early management of their condition. Unfortunately, at times, limb spasticity is either not noted (possibly because of extreme severity of the patient's brain injury) or is found to be present but is not managed appropriately. The end result of this management failure is, at worst, the development of joint contractures requiring lengthy therapy input, also requiring medical, orthotic and possibly surgical input. Overall this tends to delay discharge and complicate the rehabilitative progress regarding such matters as mobility, seating, pressure care, positioning, hygiene, pain and levels of care.

It is central to the efficient and successful rehabilitation of such patients that they are monitored for the development of spasticity in the early stages of their recovery, if possible. Skeletal muscle spasticity may not present immediately following brain injury and can take time to become apparent. At risk patients will require correct positioning in bed on a surface appropriate to their pressure needs. Correct seating in an adjustable wheelchair/seating system which may be adjusted as the patient's condition changes. Joints should be passively stretched, where indicated and where feasible if the patient is unable to actively co-operate. This should be carried out under the care of physiotherapy staff.

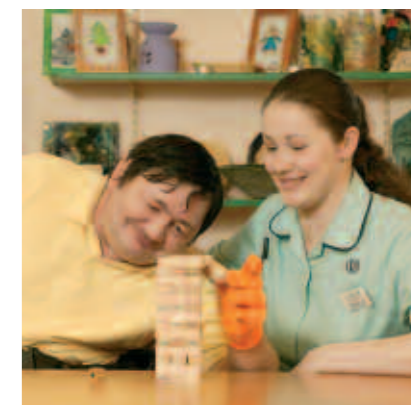
Medical treatment should involve the prevention or relief of conditions likely to increase tone such as urinary tract infection, ingrowing toenails, pressure area breakdown etc. Maintenance of good nutrition is often overlooked in the early stages of recovery from brain injury. The patients are generally in a catabolic state and thus their nutritional status is frequently compromised. Under nutrition may well compromise recovery and impair healing.

Medication may be required in order to reduce tone and the standard range of these medications employed appropriately. Skeletal muscle relaxants such as Baclofen, Tizanidine, Dantrolene or Diazepam may be used. Anti-epileptics such as Gabapentin may be used, generally as an adjunct to one of the skeletal muscle relaxants. The use of botulinum toxin injection and phenol nerve blocks may need to be considered.

The effects of neither of these are likely to be permanent and thus allow reassessment as the effects wear off. All of these medical treatments should be used in conjunction with and consultation with the physiotherapy, occupational therapy and nursing staff involved in the patients care. Orthotic techniques such as the use of Prafo's or fabrication of splints or plaster casts may be required.

Surgical techniques such as joint release and tendon lengthening procedures are unlikely to be required at this stage.

Thus involvement of multi-disciplinary neuro-rehabilitative staff at the earliest stages possible following brain injury, with co-operative management including the use of medication with feedback on its effectiveness in changing the degree of spasticity during the early stages of management is essential to effective and successful rehabilitation and in order to maximise the patient's recovery potential. Unfortunately the early assessment and management of skeletal muscle spasticity following brain injury appears often not to occur.



Failure to manage spasticity in these early stages may result in lengthy, complex requirements as regards the management of both the spasticity and its sequelae. This may result in delayed discharge and impair the ability of the patient to realise their maximum potential. The introduction of guidelines into acute units backed up by education of the staff involved and availability of the multi-disciplinary neuro-rehabilitation team for consultation may well be central to a successful, early commencement of neuro-rehabilitation.

